My Estrogen Breast Cancer Treatment Diary: Improving Estrogen Health

By T.J. Hills

Breast Cancer Risk Factors: My Overall Estrogen Exposure

[Diagram showing various risk factors and their associations with estrogen exposure, including:
- Being a Woman
- Age
- Family History
- Genetics
- Personal History of Breast Cancer
- Radiation to Chest or Face Before Age 30
- Certain Breast Changes
- Race/Ethnicity
- Smoking
- Low Vitamin D Levels
- Light Exposure at Night
- DES (Diethylstilbestrol) Exposure
- Eating Unhealthy Food
- Exposure to Chemicals in Cosmetics
- Exposure to Chemicals in Food
- Using HRT (Hormone Replacement Therapy)
- Drinking Alcohol
- Dense Breasts
- Lack of Exercise
- Exposure to Chemicals for Lawns and Gardens
- Exposure to Chemicals in Plastic
- Exposure to Chemicals in Sunscreen
- Exposure to Chemicals in Water
- Exposure to Chemicals When Food Is Grilled/Prepared

- Old BCP, IVF, DHEA
- Urban Female in the United States]
Notice:
The information contained in this book is based solely upon the personal experiences and research of the author. The author is a patient advocate and has no medical background or training. It is not intended as a substitute for consulting with your physician or other healthcare providers. Any attempt to diagnose and treat an illness should be done under the direction of a healthcare professional.

Mention of specific companies, organizations, or authorities in this book does not imply endorsement by the author nor do they endorse the author.
To My Husband who should be Sainted
INTRODUCTION

2019 Introduction

FERTILITY TREATMENTS

January 18, 2005: I Meet With A 2nd Fertility Doctor and enter A Study For Women Of Advanced Age

January 18, 2005: The 2nd Fertility Doctor’s Notes

February 16, 2005: They Begin Search For Egg Donor

February 16, 2005: The 2nd Fertility Doctor’s Notes


April 2005: The 3rd Fertility Cycle Yields 2 Good Eggs

April 2006: Our twins are born

May 19, 2010: The Fertility Curve Drops By 5 Years

THE BEGINNING: DIAGNOSIS & SURGERIES

Early February 2009: I Find A Lump In My Left Breast In The Shower

February 12, 2009: I Don’t Tell My Best Friend About The Lump

February 24, 2009: My Mammogram Is Abnormal And The Radiologist Recommends An Immediate Biopsy

February 25, 2009: I Visit My 1st Breast Surgeon – He Tells Me Not To Worry As It Is ‘Palpable And Hurts’.

February 28, 2009: I Prepare For The Excise Biopsy And Wonder Why I Am Doing That At A Small Community Hospital

March 2, 2009: Surgery #1 - The Doctor Cuts The Middle Out Of My Tumor And Leaves The Rest

March 3, 2009: I Have The Most Aggressive Form Of Breast Cancer


March 5, 2009: I Visit With Surgeon #2 - I Have Breast Cancer?

March 6, 2009: I Take Valium And Have My Breast MrI, Upside Down In A Small Tube

March 9, 2009: I Visit With Surgeon #3 – St. Lukes Roosevelt & Find Out That Surgeon #1 Didn’t Leave ‘Markers’ In My Breast

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2019 INTRODUCTION

2019: 10-YEARS LATER
Category: Diagnosis, Estrogen Health, Friends and Family

On March 3, 2009, at 44 years old, I was diagnosed with an “extremely aggressive, fast growing, garden variety breast cancer” Garden Variety cancer is shorthand for Estrogen Receptor Positive. While every cancer diagnosis is different in its own horrific way, I was told that I had a “70% chance of death within 5 years without treatment and 30% change of death within 5 years with treatment”. Like over 80% of those of us with breast cancer, genetic testing in 2009 and subsequently show no hereditary genes whatsoever. There was so little cancer in my family that I wasn’t even afraid of it.

My diagnosis seemed like it didn’t belong to me. It seemed like a mistake. My children were 9, 4 and 4 years old. I was determined to not leave them motherless. My decision to pursue a lifetime of improving estrogen health was my adjunct to traditional cancer treatment.

While I am passionately committed to my path and to sharing what I have learned to prevent more diagnosis like my own, I am keenly aware that cancer is a wily enemy. While 10 years ago, I was the first person in my far extended family to ever have been diagnosed with any sort of cancer, tragically, I was not to remain alone in my cancer status.

In 2015 and 2016 about a year apart, my parents were diagnosed with estrogen dependent cancers. My father was diagnosed with pancreatic cancer and lived exactly 18 months after his diagnosis. His death was exactly at the time that the statistical tables predicted.

My mother was diagnosed with a rare endometrial metastasized, estrogen positive cancer. Due to the rarity of her cancer there were no exact tables to predict her death. She exhausted treatment after treatment and surgery after surgery and tolerated off-label use of immunotherapy until she didn’t. Her death was surprisingly rapid.

I am now afraid of cancer.

While I had no cancer history, it turns out that I did have a long extensive history of estrogen metabolism dysfunction. Prior to my diagnosis I was suffering from severe irregular bleeding and exhaustion, my sister around the time of her first period had severe endometriosis and ovarian cysts, my other sister has since been diagnosed with severe endometriosis and ovarian cysts, my aunt had to have a hysterectomy at a young age, my other aunt was infertile and my great aunt as well.

I had a long history of excessive estrogen exposure; 18 years on and off the old, high estrogen dose, old birth control pill, 3 rounds of high dose IVF, participation in a super high dose DHEA (DHEA converts to estrogen) study and of course my initial excuse for my breast cancer; 40 years of copious consumption of unwashed grapes and cherries (presumably covered with DDT or some other noxious pest protector.

By the time I reached a doctor that began to help me improve my estrogen function, it was too late. I was diagnosed with an aggressive breast cancer several weeks later.

Of all the known risk factors for non-hereditary breast cancer, the common denominator for almost all of them is lifetime estrogen exposure. Using HRT and other estrogenic medications such as fertility
medications, exposure to chemicals in food, cosmetics, lawns, plastic and exhaust fumes (phytoestrogens) are examples of estrogen. For those of us unable to efficiently process excess estrogens, the consequences can be devastating.

Happily, unlike cancer, estrogen health dysfunction is easy to diagnose and relatively easy to treat. For me, remission maintenance required traditional treatment, 10 years of Tamoxifen followed by a lifetime of and improving my estrogen health with simple and lifelong steps like taking Bio-Response DIM, arming yourself with strong antioxidants like Vitamin C or Resveratrol and other steps discussed at http://myestrogenbreastcancer.com/better-estrogen-health/#estrogen

Certain groups of women are immediate candidates for estrogen metabolism function genetic screening such as: women taking hormone replacement therapy, fertility medications, or those with a family history of endometriosis, polycystic ovarian syndrome, infertility, irregular bleeding and of course estrogen receptor positive breast cancer.

Genetic screening allows you to learn your underlying condition. Estrogen metabolism urine testing should ideally be used to assess if the interventions are working. It may be difficult to obtain the genetic test but it is worth contacting the testing companies and seeing if a physician near you offers it. Years ago, I became so frustrated about the difficulty women were having obtaining the test that I worked with a lab to offer the test directly, but legislation quickly changed that option and the test is only available through physicians.

As I re-read my diary from 2009, I see the common thread running through all my entries is fear.

Fear of losing control over my body, fear of ingesting cancer-causing substances, fear of recurrence and fear of death. I have learned from my parents the great uncertainty inherent in a cancer diagnosis. Although both of them were given a terminal diagnosis from the onset, their outcomes for the time they lived couldn’t have been more different. My father followed a statistical script almost to the day and my mother puzzled the world renown oncologists with her continued health and vibrancy for years after her expected death.

Improving my estrogen health has allowed me to the opportunity to actively leave no stone unturned in my quest for continued health. It does not negate traditional treatment or the imperative of keeping up with new cancer treatments for the rest of my life, but I believe that it is a piece of the puzzle that keeps me cancer free.

Talk to your physician, get the test if you belong to one of the groups outlined and improve your estrogen health.

I wish you the very best of health.

T.J. Hills
Fertility Treatments
JANUARY 18, 2005: I MEET WITH A 2nd FERTILITY DOCTOR AND ENTER A STUDY FOR WOMEN OF ADVANCED AGE

After spending December trying to recover from my failed November attempt to create embryos, I went to see a doctor in Chicago who was famous for being one of the early pioneers of fertility treatments. He also had one of the largest egg donor databanks outside of a university. In order to discuss egg donors, you must meet the doctor. After hearing my story, he told me that all hope was not entirely lost although the chances of success were miniscule. He recommended I enter his DHEA study for several weeks before trying again. That meant I would almost be 41 before trying the 2nd time. I clung to the hope that the DHEA would work and agreed to try before the next retrieval. The DHEA at such high levels was like the fountain of youth. My hair and skin became excessively oily again and my sex drive was astonishing.

JANUARY 18, 2005: THE 2nd FERTILITY DOCTOR’S NOTES

### SUMMARY:
- ADVANCED FEMALE AGE: 40+++  
- SEVERE SPINAL INJURY  
- OVARIAN RESISTANCE  
- R/O SUBCLINICAL (AUTO) IMMUNE DISEASE/RAFS  
- MALE FACTOR  
- ON MULTIPLE MEDS/SUPPLEMENTS  

**PLAN:**
- MAMMOGRAM ASAP  
- INCREASE DHEA to 75 mg  
- DISCUSSED FACT THAT PREGNANCY CHANCES LIMITED  
- DISCUSSED FACT THAT, IF AGAIN PRODUSES ONLY ANEUPLOIDIC EMBRYOS, SHOULD PROBABLY GO TO EGG DONATION. IS AGREEABLE  
- DISCUSSED FACT THAT, SHOULD SHE HAVE NORMAL EMBRYOS FOR FREEZING, WE THEN CAN CALCULATE HOW MANY SHE NEEDS AND THEREFORE HOW MANY IVF CYCLES SHE HAS TO DO.  
- REQUESTED THAT DC CHINESE HERBS  
- IVF: FOR ALL-FREEZE  
  - MICRODOSE LUPRON  
  - 8 AMPS (6+2)  
  - bASA  
  - PREDNISONE 20/6020  
  - ICSI YES  
  - PGD FOR ANEUPLOIDY  

Self-referred  

January 18, 2005: The 2nd Fertility Doctor’s Notes
FEBRUARY 16, 2005: THEY BEGIN SEARCH FOR EGG DONOR

The doctor suggests that we begin searching for an egg donor in the event that my next egg retrieval is a failure. I try to look at the pictures in the database, but every time I do I become nauseous and can’t believe I am picking out a woman for my husband to have a baby with. I decide that I want the doctor to pick out the egg donor, but my husband wants to see the pictures.

We discuss asking my sister to provide eggs, but he explains how that is a bad idea in his experience.

FEBRUARY 16, 2005: THE 2nd FERTILITY DOCTOR’S NOTES

```plaintext
>>> BROUGHT IN WISH LIST AND PHOTOS
>>> WISH LIST:
    >>>> CAUCASIAN but not English or Irish, preferred Polish
    >>>> height >5'7
    >>>> slim
    >>>> coloring: light brown hair
        eyes hazel/green
        skin light olive
    >>>> College ++++
    >>>> doesn’t want a “girly” girl
    >>>> athletic
    >>>> HUSBAND WANTS TO SEE PHOTO; F DOES NOT !!!!

PLAN:
    >>>> PROCEED WITH HER OWN CYCLE
    >>>> ALL-FREEZE
    >>>> THEN DECIDE WHETHER TO DO MATCH OR NOT
    >>>> GIVE DHEA PAPERS AND LIST HER IN DHEA LISTING
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MARCH 28, 2005: MY SECOND IVF CYCLE YIELDS ONLY 2 LOW QUALITY EGGS.

My second egg retrieval fails to yield eggs good enough to create embryos.

I simply can not believe that I am failing to do something I want and when the 2nd IVF cycle fails I return to my original doctor.

APRIL 2005: THE 3rd FERTILITY CYCLE YIELDS 2 GOOD EGGS

The DHeA from the trial is finally kicking in and I make 6 embryos; 2 of them good enough to give it a try. It does not work and I am devastated.

I ask yet another doctor to pursue the egg donor.

APRIL 2006: OUR TWINS ARE BORN
MAY 19, 2010: THE FERTILITY CURVE DROPS BY 5 YEARS

I saw a snippet on ABC News a few months ago. Robin Roberts, ABC Morning News anchor interviewed a gynecologist who was discussing how the fertility curve that we were familiar with, the one in which women’s fertility radically drops off at 35 years of age, had just been revised.

The new fertility curve shows women’s fertility radically dropping off by the age of 30. According to the new study, published by PLOS One, women, on average, only have 12% of their ovarian reserve left by the age of 30.

When I heard this news I was shocked. As time went on, I could not find the study or any mention of it in the press. I couldn’t believe that the entire world wasn’t talking about this news as it changes the paradigm of having a family radically. And yet I could not find this article until I saw it in the reference section of another article. Children should be taught this in sexual education class.

![Graph showing percentage of ovarian reserve related to increasing age.](image_url)

The Beginning: Diagnosis & Surgeries
EARLY FEBRUARY 2009: I FIND A LUMP IN MY LEFT BREAST IN THE SHOWER

Category: Diagnosis

Found lump at 6 o’clock in my left breast while showering. It was big and protruding a little bit. Once I found it, I couldn’t believe I hadn’t found it earlier.

Immediately went to see my midwife.

She examined me and then assured me that it was almost certainly benign as it was palpable and “hurt”.

She explained I should not have my Mammogram until the correct time in my cycle, so I scheduled for a few weeks later.

I said, I don’t care what it is, I need to get it out. She said I should worry about that later and I shouldn’t worry about it.

FEBRUARY 12, 2009: I DON’T TELL MY BEST FRIEND ABOUT THE LUMP

Category: Diagnosis, Family & Friends

My best friend visits from Chicago. I don’t tell her about the lump. I was a little nervous about it but given the fact that there was no history whatsoever in my family and what the midwife had said I was not worried about it. And so, begins the ruse, even with those I am closest, that all is well.

Before the mammogram, the lump began to annoy me as it was pushing against my bra.
FEBRUARY 24, 2009: MY MAMMOGRAM IS ABNORMAL AND THE RADIOLOGIST RECOMMENDS AN IMMEDIATE BIOPSY

Category: Diagnosis, 2019 Advice

FINALLY had Mammogram. The technician was very nice.

Sonogram took FOREVER. A Brazilian technician gave me the sonogram. After about 45 minutes on my right breast I lost my temper… and asked her to hurry up as I was really worried about my left breast.

She explained, in very good temper, that I had so many cysts and abnormalities in the right breast that it was taking her a long time as she had to measure them exactly. Then I became alarmed and began to watch her. From all the experience with fertility treatments, I can sort of spot things on an ultrasound and started to see all the black cysts….

She finally finished and they asked me to wait for the radiologist. The radiologist was a very nice older man. He examined me and explained that the right breast had a lot of fibroid adenomas and cysts. He told me that he wanted me to have a needle biopsy of the tumor as soon as possible. He said that he was pretty sure that it was benign as it was ‘palpable and it hurt’ but the shape was not strictly ‘textbook’ and any suspicion had to be ruled out. He explained that a needle biopsy was exactly that; an extremely long needle that they stuck into the suspect area and cut out a piece. There was no anesthesia just a long needle.

Scheduling the needle biopsy was difficult as our insurance was changing in a few days. The radiologist was very kind. He heard me talking about delaying the biopsy and so he asked me to come back into a private room.

He said, “If you were my wife, or my sister, I would insist that you go to a breast surgeon.” That was the first time I heard that clause, “If you were my wife or my sister”…. I was to hear it many many many times from every male doctor I met.

I immediately called my midwife. The midwife recommended two different surgeons; Dr. W and Dr. Sahgal. She worked mostly with Sahgal and highly recommended her.

It was difficult to schedule with Sahgal and she didn’t take my insurance. Scheduling with Dr. W was a breeze and they accepted our insurance, so I went to him. He fit me in right away.
FEBRUARY 25, 2009: I VISIT MY 1st BREAST SURGEON –
HE TELLS ME NOT TO WORRY AS IT IS ‘PALPABLE AND HURTS’.

Category: Diagnosis, Surgery

Dr. W explained I could have a needle biopsy right that second or do an excise biopsy in the hospital under sedation. I opted for the biopsy because I wanted it out anyway. He never explained to me that should the tumor be found to be malignant that it was better to open me up with a game plan. At no time did he suggest that I have only the needle biopsy because that was the more conservative thing to do. He did not seem concerned that should it be malignant, it would result in an unnecessary surgery.

He assured me that it was probably benign as it was ‘palpable and it hurt’.

FEBRUARY 28, 2009: I PREPARE FOR THE EXCISE BIOPSY AND WONDER WHY I AM DOING THAT AT A SMALL COMMUNITY HOSPITAL

Category: Diagnosis, Surgery

Went for Bloodwork at the tiny community hospital on the river. I thought it was a very stupid place to do a surgical procedure but then out of laziness thought that speed was better than worrying about a biopsy. I told myself that if anything was wrong I would do major research on the doctors in New York.

I was nervous but not that worried about it.

MARCH 2, 2009: SURGERY #1 - THE DOCTOR CUTS THE MIDDLE OUT OF MY TUMOR AND LEAVES THE REST

Category: Diagnosis, Surgery

Major blizzard. My husband, My Husband and I drive through blizzard to the empty hospital. Surgery proceeds on time but I didn’t understand that it was a surgery as Dr. W improperly explained the anesthesia. I thought I would be drowsy and awake. No, not at all. It was full anesthesia but without the ‘tube down the throat’.

I wake up trashed. I was brought to the room and was very nauseous because the anesthesiologists don’t give migraine patients the necessary ingredient in anesthesia to subdue the nausea. The nurse was very nice. View great. The doctor did not come to check on me.

I went home and slept until 5 pm. I was shocked that the anesthesia was not explained properly but relieved to have the whole thing over.
MARCH 3, 2009: I HAVE THE MOST AGGRESSIVE FORM OF BREAST CANCER

Category: Diagnosis

I break into hives under the steri-strips that were used to bandage the incision on my breast. I call Dr. W to inform him I must take them off. He calls me back at 1 pm while I am taking my eldest son, My Eldest Son to the dentist. Dr. W tells me he has bad news. It is malignant. It is an “AGGRESSIVE FORM OF BREAST CANCER.” He keeps talking but I don’t hear anything. I ask him if I can talk to him later.

We speak again at 5pm. He explains it is malignant. He says I must immediately have another surgery to take the ‘margins’ out which he left in. He will see me tomorrow night. I only hear “AGGRESSIVE FORM OF BREAST CANCER.”

My Husband and I apologize profusely to each other for wasting much of the past 8 years arguing. Since our eldest son was born 8 years ago but particularly the past few years since our 3 year old twins were born, we have bowed to the multiple pressures of having children and argued mostly about them daily. We have wasted precious time arguing, being mean to each other and spending our time feeling hurt and bitter instead of loving.

We have been told that it is not clear how much time we have together that a normal lifespan is currently in question.
MARCH 4, 2009: THE SURGEON EXPLAINS MY DIAGNOSIS –
“THE MOST AGGRESSIVE BREAST CANCER. BAD BUT TREATABLE.”

Category: Diagnosis

I have the results of the biopsy faxed to me before the late-night meeting with Dr. W. I try to understand the report but can not. I look up every single item in the report, but it doesn’t make any sense. I do however understand that it is BAD.

I spend 4-5 hours calling every major hospital in New York City trying to get an appointment with doctors after getting referrals from other doctors, friends and research.

Wednesday night… W takes an ultra-sound needle biopsy of my left lymph node which is 2.2 cm large and one of the suspect sites.

If the cancer has spread to my lymph nodes already, I would be “Stage II”. From there it may have gone to other parts of my body.

I apparently have become my pathology report. Dr. W takes My Husband and I through the report item by item. He begins by calling my cancer, “GARDEN VARIETY”. It is the first time that we here this phrase, but we will hear it repeatedly and from every single oncologist we meet. My Husband arrives after he does the biopsy and Dr. W spends two hours taking us through every single item on the pathology report and what is means.

Dr. W explains…that treatment for my MOST AGGRESSIVE GARDEN VARIETY BREAST CANCER is:

Must have MRI but it often has false positives
Must have MRI biopsies…he wants to consider the right breast
Must have lymph nodes ‘sentinel biopsy’ and during surgery it is determined if basically all the lymph nodes in my entire left armpit must come out
The tumor is Growth phase 3; the most aggressive of all cancers of the breast.
It has penetrated my lymph vascular system.

The minimum I will need is:
A lumpectomy
The lymph nodes surgery during same time possibly resulting in all of them removed
Daily radiation for 6 weeks
Chemotherapy for at least 4-6 months to be determined post-surgery

Dr. W says “Some of the results are not in yet… we don’t know if it is hormone receptor positive which means it would be more treatable and I could take Tamoxifen for the next 5 years. Hormone receptor positive means that the cancer grows off hormones

If the lymph nodes are malignant…it is NOT GOOD. The test results will be back by Friday.

My Husband and I leave Dr. W’s office reeling at 9pm. We go home separately and pray. For some reason, I have an Aerosmith’s Greatest Hits CD in the car. I blast away my thoughts and try to relive the Aerosmith
rock concert I ever went to 30 some years ago.

Dr. W just spent almost 2 hours explaining that my inevitable death had just been moved up. He does not have enough information to give a full prognosis but based on the limited information here. There is a high risk of recurrence.

A few days later, we receive the full pathology report. Dr. W completes his review of the phone.

“GARDEN VARIETY . . . AGGRESSIVE BUT TREATABLE”

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HER2: NEGATIVE
HER2 positive cancers are very difficult to treat and have a worse outcome. GOOD.

Invasive Ductal: Cancer has spread into and beyond the breast’s duct system. BAD

Tumor Size: 2 cm
2cm is often the dividing line between chemo vs. no chemotherapy BAD but COULD BE WORSE

Nottingham Score: Grade 3
On all counts, this tumor is growing at the fastest pace that cancer grows. VERY BAD

Hormone Receptor Study:
Estrogen 95% + Positive
Progesterone 95% + Positive
GOOD: ‘THIS MAKES THE CANCER MORE ‘TREATABLE’ IN THAT I WILL BE GIVEN THE MEDICATION TAMOXIFEN FOR 5 YEARS BEGINNING AFTER RADIATION.

Lymphovascular Invasion: Present
The cancer has spread into the lymphatic system of the breast. No way to know yet, if the lymph nodes are malignant. VERY BAD
MARCH 5, 2009: I VISIT WITH SURGEON #2 - I HAVE BREAST CANCER?

I spend all morning calling every major hospital in New York City trying to get an appointment with doctors after getting referrals from other doctors, friends and research.

I set up 4 appointments for the following week.

At 1:45 I see Dr. Sahgal the surgeon that the midwife recommended. She provides a much better explanation of the possibilities and risks to come. She says she wants to biopsy much of the right breast to be sure. She says there are at least 3-4 places in the right breast that she would like to biopsy regardless of the MRI results. She explains that the most important thing to figure out is the status of my lymph nodes. That is the first place that the cancer spreads and will determine my ‘stage’. She thinks that the lymph node test may be negative. (Retrospectively, I have absolutely no idea why a surgeon would take a guess at such a serious matter.)

She recommends that I read “The Breast Book” by Dr. Susan Love. http://www.dslrf.org/

She is far away in Mt. Kisco which is a ½ hour drive and without traffic almost equi-distant to the city. She works in White Plains so that would be good.

Reeling with all this information, I go home to prepare for an extremely important dinner meeting of all of my twins’ therapists at my house. There is a team of 5 therapists who work with the twins on improving their many developmental delays. This team of therapists is new to the twins and has only been working with them for the past month. My Husband and I had been working with the government agencies for the past 3 months to get the twin’s better therapists as the therapies from the prior year had not resulted in developmental gains for the twins. The dinner tonight represented months of hard work for My Husband and me and represented a huge step forward in helping our twins.

Prior to 2 days ago, working with the multiple NY State government service agencies, the children’s existing and new therapist and yet trying to keep my business alive was one of the more stressful times of my life. As I sat through the dinner, I was so grateful that we had succeeded in finally assembling a team to help our children and knowing at the same time that it would be impossible for me to continue to manage the process given the diagnosis.

As each therapist reviews the twins’ needs, I realized that the first casualty of the cancer will be the children’s development.

I feel nauseous through much of the meal.

That night, my eight-year-old son, My Eldest Son spends the night vomiting and having horrific nightmares. I spend the whole night up with him. I have decided not to tell him until I know exactly what is wrong with me. I have no idea at this stage how sick I am, how far the cancer has spread and what the treatment will be so keeping him informed along the way is something I am not considering. Clearly, however, he already knows something is horribly wrong.
MARCH 6, 2009: I TAKE VALIUM AND HAVE MY BREAST MRI, UPSIDE DOWN IN A SMALL TUBE

Category: Diagnosis

Take a valium at 7:45 and have the Breast MRI at 8:15. Face down in a small tube...I could have cared less. I LOVE valium. The nurse messes up my IV filled with dye and I have a huge bruise at my elbow.

Both Dr. W and Dr. Sahgal tell me to call them at 11am for the results of the MRI. The MRI has a tendency to show false positives hence Sahgal’s desire to biopsy much of the cysts in the right breast.

Friday afternoon there are no results from either the MRI or the lymph node.

Dr. W calls to tell me the Hormone Receptor test is strongly positive. That is the first bit of good news as now I am more ‘AGGRESSIVE BUT TREATABLE’. I can take Tamoxifen for the next 5 years. This drug will push me into menopause (and the chemo) everyone keeps mentioning it...as if menopause were a bad thing......

The weekend...without the test results it was very tense. My Husband takes care of everything and the children insisting that I rest at every possible turn. I am in a state of shock at both all the news and how well I am being treated.
MARCH 9, 2009: I VISIT WITH SURGEON #3 – St. LUKES ROOSEVELT & FIND OUT THAT SURGEON #1 DIDN’T LEAVE ‘MARKERS’ IN MY BREAST

Category: Diagnosis, Surgery, Doctor Shopping,

Dr. Estabrook is referred by a friend and my midwife.

Dr. W informs me that the lymph node results are negative. (not conclusive for the rest of the lymph nodes but a good sign.) AND the MRI only shows cancer at the margins left where he took the tumor out. I begin to cry hysterically for the first time since I heard the news. These results dramatically reduce the risk of double mastectomy.

And the game begins…. My husband and I are determined to do our research in advance so in case I have to have a double mastectomy we will be comfortable with the surgeon…

My Husband meets me at Estabrook’s office. It is almost 70 degrees outside and 110 inside. None of the windows are open. We wait for about 45 minutes and then go to meet a 20 something Physician’s Assistant. She explains to us that W’s surgery is not ‘marked’ as it should have been and therefore the margins are unclear and Estabrook will have to take more tissue than if the surgery had been performed properly.

We talk to the assistant for at least ½ hour. Estabrook gives us 10-15 minutes. During this time, she is clearer, answers more questions and gives me a greater sense of relief than anything all week. She is abrupt and seems annoyed (not at me) at finding a 44-year-old woman with aggressive cancer and at Dr. W’s bumbling.

We go to schedule surgery. The doctor tries to be accommodating and gets me on the schedule within a week, but I refuse the appointment because it is the same day as the twins’ government review, and I am still stuck on that and not the cancer yet. So, I walk out without a surgical date.
MARCH 10, 2009: I VISIT SURGEON # 4, LENOX HILL

Category: Diagnosis, Surgery, Doctor Shopping,

I don’t want to go to this appointment. I want a day off to sit at the computer, catch up, process, research alternatives, buy a book on breast cancer, but My Husband says no we must exhaust every alternative… this surgeon was referred by Dr. Fatteh my fertility doctor and the best in New York City. His wife has breast cancer, and this is his wife’s surgeon.

We arrive at Dr. S’s chichi Upper East Side office EXCEPT the secretary and assistant’s desk is out in the middle of the waiting room. Dr. S gives instructions in public, diagnosis and names out in front of everyone. The assistants’ book all the appointment with all the gory details with everyone to hear… in fact it is impossible to hear anything else.

I want to leave but we stay. We wait almost 2 hours to see the DEEPLY TANNED cancer surgeon. What kind of cancer doctor allows themselves, no goes out of their way to acquire a deep tan? She is all about medical liability. She immediately begins discussing mastectomy and double mastectomy.

She is very messy. She has bad energy; I finally get out of there after 3 hours……

I accidentally leave my films in the bathroom at the Metropolitan Museum of Art where I parked.

MARCH 11, 2009: VISIT WITH SURGEON #5 SLOAN KETTERING

Category: Diagnosis, Surgery, Doctor Shopping,

First available breast surgeon able to see me at the cancer-dedicated hospital

I had been really looking forward to going to Sloan as I was hoping they had more of a system than the others. What they have is good marketing. The hallways are very beautiful and plush. There is coffee, ambient music and crackers for those nauseous patients. We are seen exactly on time and shown to a horrible, hospital like room with one immovable chair and nowhere for My Husband to sit. Did I mention that the breast center is in the basement? We are left there for an hour.

The doctor is okay, but we don’t have any films to show her and she refuses to speculate.

She answers questions but again explains ‘if she can’t clear the margins, a mastectomy will be necessary’.
MARCH 13, 2009: I TELL MY FAMILY

Category: Family & Friends

My father lives overseas. The rest of my family is in Chicago. I buy a telephone conference call-in number and somehow manage to get everyone on the phone without advance notice this morning. I read from the script below as I am too nervous to ad lib. Also, without the script I have no idea what I am talking about. I then send them the letter below.

Dear My Family

I have breast cancer.
I found out Tuesday, March 3rd.
INITIAL PROGNOSIS
It is the most aggressive type. Type 3 growth.
It is uncertain if I am Stage 1 or 2. This will be known about 10 days post surgery and possible later.
INITIAL TREATMENT
Surgery on xxx
Radiation daily for 6 weeks
I will need chemotherapy for at least 6 months
I must take a drug called Tamoxifen for the next 5 years.
FURTHER PROGNOSIS
After surgery, my condition and options will be clearer.
The pathology reports from surgery should be back by xxx and then I will move on to visit oncologists or discuss double mastectomy with the surgeon.
SURGERY
I had a lump, but it was excised. Now the remaining cancer must be removed. It is called a lumpectomy or in my case ‘clearing the margins’
I must have a ‘sentinel node biopsy’ which may result, at the same time, in an axillary dissection’ (essentially taking all my lymph nodes under my armpit out.)
TREATMENT
After surgery, I move on to the oncologist who will oversee the radiation and chemotherapy treatments

I have seen 6 surgeons at 2 hospitals in Westchester and the 4 major hospitals in New York City. My Husband and I have researched all the surgical options and chosen this one.
WHAT I NEED FROM YOU

There is a lot of information to take in and unfortunately, I will not be able to completely keep you up to speed as I must manage the cancer, my treatment and my life.

I don’t want to talk about the cancer unless I bring it up. I will keep everyone appraised about my condition anytime something significant changes via e-mails and phone calls.

I have not told my children as I want to know what my real prognosis is before telling them/My Eldest Son. Please make sure that my condition is not discussed ever in front of the children regardless of the language both now and later.

Please be patient if I don’t answer telephone calls, e-mails etc in a timely fashion or at all. I am very busy re-arranging my life. Please ask each other for news not me or My Husband.

If you don’t hear anything it is because there is no change in status.

My Husband needs support from all of you but also can not discuss the cancer at work or at home. Please offer him support but don’t expect him to keep you up to date.

My life must be stripped to the essentials. Given that I have 3 children and the medical care will be time-intensive, I will still be extremely busy.

WHAT I NEED FROM YOU DURING CHEMOTHERAPY

I will need a lot of support during chemotherapy. But I do not know how sick I will be. Once a treatment date is decided, I think I will need a lot of support initially until I know how my body reacts to the medications.

Please consider how you might be able to spend time here taking care of our children. (This statement is addressed to the 4 grandparents.)

SOME SUPPORT OPTIONS FOR YOURSELVES

Be very careful about the information you obtain on the internet. Restrict your research to well-known sites such as www.webmd.com

www.cancer.org

www.gildasclub.com
MARCH 15, 2009: (WRITTEN JAN 22, 2010) - I VISIT WITH MY CHINESE DOCTOR

I go to visit my old Chinese Doctor who I have not seen since I was taking the fertility drugs 4 years ago. She is saddened by my condition and tells me that the only thing she can recommend the regimen administered by the Gerson Institute in Mexico. Cancer patients go there for complete detoxification and live on the recommended juices for several weeks. She tells me she could help me do this at home, but I basically must be resting which I can not do because I am still going to visit doctors, recovering from surgery and preparing for chemotherapy. She recommends I study up.

I am beginning to learn that there are different ways to treat cancer but none of them are applicable to me since my case is “so bad.”

http://www.gerson.org/
MARCH 17, 2009: SCHEDULE FOR FAMILY

Category: Family & Friends

SCHEDULE PAST AND AS FAR KNOWN – STATUS AS OF 17 MARCH 09

Mid-Feb  Found lump in the shower
28 Feb 09  Mammogram and Sonogram
2 March 09  Excised Biopsy
(Results: Malignant – tumor 2.2cm – lymph node status unknown)
3 March 09  Lymph Node Needle Biopsy
(Results: No Malignancy – not conclusive)
5 March 09  MRI
(Only Malignancy at tumor site – not conclusive for lymph nodes)
16 March 09  BRAC (Genetic mutation) testing Blood work
Results expected mid-April. If positive must have double mastectomy and hysterectomy
Based on family history there is a 20% chance of this outcome
24 March 09  Lumpectomy and Sentinel Node Biopsy (possible axillary dissection – dissection of lymph nodes in armpit)
1 April 09  Pathology Results from 24 March Surgery expected
1 April 09  If lymph nodes are not malignant, pathology slides from 2 March surgery
24 March surgery will go for ONCOTYPE Testing to further refine chemotherapy planning. ONCOtype is gene testing of the tumor.
14 April 09  ONCOTYPE testing results.
24 March -  Rest for 4 weeks to recover from surgery as Radiation and Chemo can not be started in a weakened state.
April ?  Begin Chemotherapy for 6 months
Then Radiation 6 weeks
MARCH 17, 2009: (Written Jan 14, 2010) —
MY PHONE CONSULT WITH DR. W IN CHICAGO

Category: Estrogen Health

Phone visit with Doctor W from Chicago. Usually it takes months and months to get an appointment to see her but somehow, she winds up fitting me in quickly within a few weeks of the request for the phone call. She tells me that my cancer feeds on sugar, alkaloids and stress. She tells me to eat neutral foods for the next year at least.

She refers me to a bio-chemist in New Mexico named Joe Veltmann. “He is very good at altering people’s bio-chemical pathways” She even gives me his phone number.

Phone number 1-505-986-8835

MARCH 18, 2009: (Written Feb 9, 2010) —
I TELL MY BEST FRIENDS I HAVE CANCER

Category: Family & Friends

I call My Best Friend to tell her about my diagnosis. I worry about telling her as it has only been two years since she lost her husband. Three years since she lost her mother. our other best friend was recently in the hospital with heart problems. I tell her much as I told my family. Then I say that I will call her two sisters and our other best friend.

I am numb as I make the phone calls. I try to sound upbeat.

We talk again later than night and I tell her what I have going round in my head all day long.

This song is sung to the tune of “a Tisket, a Tasket, a green and yellow basket”

A Tumor, a tumor, a quickly growing tumor

Kill it, kill it — Before it kills you!!!

I tell my best friend my theories about the cancer. Since no one knows what really causes breast cancer and often attribute it to chemicals I have no choice but to attribute my breast cancer to the 44 years of unwashed grapes. We laugh and I know that the laughter is all that matters.
MARCH 19, 2009: I HAVE A PHONE CONSULT WITH DR. VELTMANN AND LEARN ABOUT HIS ESTROGEN RECEPTOR POSITIVE BREAST CANCER STUDY: MY UNUSUAL BLEEDING & WHY I HAVE CANCER

Category: Estrogen Health

I call Dr. Veltmann as per Dr. W’s instructions. We play phone tag for the day and then I finally reach him as I am pulling out of the North of NYC YMCA’s parking lot. I had gone for my post excise biopsy swim. I go swimming every day as a form of tranquilizer. It is the only thing keeping my sanity going.

“Hi. Dr. Veltmann. Dr. W suggested I call you because I have just been diagnosed with an extremely aggressive form of breast cancer.”

“Did Dr. W tell you about my breast cancer study? I am conducting a breast cancer study that is funded by the National Institute of Health. I have approximately 60 women in the study. The study has been going for about 5 years” A breast cancer study that sounds promising, I thought.

“No. She just told me to call you because you alter people’s bio-chemistry.”

He laughs and then asks me the basic information about the cancer and myself. I tell him I am 44 years old and have GARDEN VARIETY MOST AGGRESSIVE BREAST CANCER, Grade 9, Invasive Ductal, etc, etc,

Once I finish with my pathology report, the first question he asks is, “Have you had any unusual bleeding?”

“Yes. I have had horrible problems with unusual bleeding. I had 3 rounds of fertility treatments in 2004/2005. I was trying to retrieve eggs to get a surrogate pregnant. Finally, I was unsuccessful, and I went the egg donor and surrogate route. A few months after I completed the fertility treatments I began to bleed irregularly. Sometimes I would bleed all the time and then sometimes I would stop and almost miss a period. My periods became extremely heavy. I went to a variety of different gynecologists and complained about the bleeding, but they all dismissed my complaints as part of ‘peri-menopause’.

After the irregular bleeding started, I then began to gain weight and no matter what I did it wouldn’t come off. This weight gain was after weighing the exact same weight (give or take 5 pounds since I was 17 years old.

I finally found a doctor who was willing to help me and was also concerned about the bleeding. She said that if I continued to bleed, I would be at risk for uterine cancer. She put me on bio-identical hormones. They did nothing except make me tired.

Then I went on the birth control pill and while that controlled the bleeding, I had horrific migraines, so I stopped that. We were just discussing next steps when I was diagnosed with the cancer.”

Dr. Veltmann said, “Yes, many of the women in my breast cancer study have similar stories.”
Me: “Do you think that I have cancer because of the fertility treatments? I have never been the same since I took those shots.”

Joe: “My thesis would be that you robustly have SNPs on your DNA that do not allow your body to methylate estrogen. The problem started and then was most likely kicked into even higher gear by the stimulation of the Hormone Replacement Therapy and the Birth Control Pill regardless of how small the dose. Fuel for the Fire.”

He explained how he worked. He would mail me a questionnaire, mail me tests and then we would proceed. He would alter the DNA through the use of nutrition, supplements and when required pharmaceuticals.

Me: “How many of the women in your study have had a reoccurrence?”

Joe: “Zero.”

Dr. Veltmann tells me he will be sending me blood test kits in the mail and a patient intake survey by e-mail. He tells me how he works with people in the study…on a cost basis and I hang up after telling him my joke about the unwashed grapes.

I began to cry. Finally, someone who knew why I had been bleeding these years after so much mystery. At the beginning of the year, my New Year’s Resolution had been to get to the bottom of the bleeding and now I knew. I was bleeding because the estrogen in my body couldn’t exit. This toxicity developed into cancer.

An answer. What a relief!! Someone knows why I have been bleeding all these years AND they know why I have cancer. The unwashed grapes theory is no longer necessary.

Sitting in that parking lot, I had absolutely no idea how much of a relief meeting him would be. Knowing exactly why I had cancer would be such a different way to live through the disease…but all of that fear was yet to come. At this point I was still in shock.
MARCH 19, 2009: DR. VELTMANN’S STRESS TEST

Category: Estrogen Health

I receive the patient intake and some information from Dr. Joe Veltmann. One of the items in the patient intake is a questionnaire regarding stressful events that have happened in your life in the past 3 years. I tick off almost every one of them; a move (in the same neighborhood), house reconstruction (almost every single molecule), financial difficulties (Husband laid off), starting a new business (I closed my successful one and opened a much more difficult one for less money), the death of two close friends (the assassination and My Best Friend’s husband’s diabetic death), the impending death of a good friend (MY NOT DEAD YET FRIEND’s kidnapping in Asia), the birth of children (the twins), major medical procedures (fertility treatments), marital problems and a variety of other high stressors. I hope that cancer is not caused by stress, but I already know that just as with other major illnesses it plays a big part.

Veltmann also sends me an abstract about the Breast Cancer Study that is totally unintelligible to me. I understand that the study proceeds as follows:

1) Genomic Testing
2) Estrogen Testing - Urine
3) Estrogen Testing – Saliva

The SNPs that all the women in his breast cancer study group have are on CYP1B1, COMT, and GST. He suspects that I have them too.

MARCH 20, 2009: I VISIT WITH GENETIC COUNSELOR FOR BRAC TESTING

Category: Diagnosis

Dr. Estabrook has a genetic counselor who asks me to put a family cancer tree together going back 3 generations. This requires extensive research by my mother and father. I learn that I have 2 great aunts on my grandmother’s side who died of cancers. I also have a great uncle who died of lung cancer. Dr. Ott tells me that lung cancer doesn’t count as a risk factor in the tree if the person smoked. I have a low risk of being BRAC 1 and 2 positive, but the process is nerve –wracking. The idea that I would have to have a double mastectomy and a hysterectomy if the test is positive is anxiety provoking.

I tell myself all of it doesn’t matter. I must do whatever I have to do in order to live to take care of my children and not orphan them.

The cancer still doesn’t feel as if it has anything to do with me.
Hi Everyone:

Asma is in New York and while I haven’t been able to see her, we have talked on the phone.

I would prefer that you hear my news from me and not through the grapevine.

I learned on March 3rd that I have an aggressive type of breast cancer. I should know by the middle of April what my true status is (what Stage IIA...IIB or some other Roman numeral?) and what the full treatment will be.

What I know now is that I am having surgery Tuesday March 24 (lumpectomy and lymph nodes) and then chemo for at least 6 months followed by radiation.

I am not telling the children until I know the exact treatment plan, when chemo will start, if I require further surgeries and etc so I will not talk about it unless they are all at school if you call me please forgive me for refusing to discuss anything. It means the children are in the house or near me.

Asma asked how I am doing psychologically. I am doing okay with all this due to my advanced skills in disassociation, denial and shock.

I am not so okay with anything beyond the above but am trying to be patient until the middle of April (one of my not so developed skills.) I don’t know how sick I will be from the chemotherapy so mostly what I am concerned about is the impact on the children....

I had planned, reserved tickets to The Old Country for end July, but that is impossible now. I hope to see you all next year.

I will be closing my business down next week and will have a lot more free time than I have had in at least 15 years...so what you can do to cheer me up is send me your news and/or pictures of your children.

I hope everyone is well and I miss you all very much. I am sorry we are not living nearer to each other but years and distance have not lessened my affection.

Love, TJ
MARCH 23, 2009: E-MAIL SENT TO FRIENDS AND FAMILY GROUP:
SURGERY #2 — TAKING OUT THE REST OF THE TUMOR AND
TAKING APART THE LYMPH NODES IN MY ARM PIT AND THE VERY
VERY BAD NEWS OF BEING LYMPH NODE POSITIVE

Category: Diagnosis, Surgery

Hello. Well the good news is that although much more painful, this surgery went far better than the last
one on March 2nd as the anesthesiologist concocted a great mix which did not leave me sick for 24 hours.

The surgeon did the ‘sentinel lymph node biopsy’ which unfortunately was malignant. It means that the
cancer has spread beyond my breast and into my lymph nodes.

She then immediately performed an ‘axillary dissection’ which is the removal of much of the lymph nodes
in the armpit and then finished the lumpectomy.

We will have the pathology results in 10 days and then will know if more surgery is required or I go
immediately to chemotherapy. I will be report back after seeing the surgeon on April 6th. I will tell the
children after that meeting.

In the meanwhile, I have started seeing oncologists and will be having full body scans and etc.

I can really feel your good thoughts and prayers and love so don’t think it is in vain and keep them
coming.

What you can do for me is send me news about your life and what is going on with you. The more detail
the better.

Love, TJ
MARCH 24, 2009: I DO NOT HAVE THE BREAST CANCER ‘INHERITED GENE’ OR I AM NOT BRAC 1 AND 2 POSITIVE

Category: Diagnosis, Surgery

Receiving the news that I am not BRAC positive and do not have to have a double mastectomy and a hysterectomy was a huge relief.

![Patient Copy of Comprehensive BRAC Analysis](image-url)
MARCH 27, 2009: E-MAIL SENT TO GROUP: I FIND OUT THAT THE
SURGEON DID NOT GET ALL OF THE TUMOR AND MUST GO BACK
IN TO CLEAR THE REST OF IT.

Hello.

The surgeon’s office called with the pathology results today. Unfortunately, the ‘margins were not clear’
from the removal of the tumor. I am having surgery again on Tuesday March 31 to Hopefully clear the rest
of the tumor.

I had 4 sentinel lymph nodes (I did not know there was more than 1). Of the 4, 3 were malignant with the
most aggressive type of cancer.

4 regular lymph nodes were removed. There were clear. The plan so far is to treat the lymph nodes with
radiation . . . (after the chemotherapy).

I am having body scans, surgery and oncology appointments next week so will be out of touch.

Thank you for sending your news. Keep it coming. It is the best medicine to be in touch.

Love, TJ
MARCH 27, 2009: SUPPLEMENT LIST SENT TO JOE VELTMANN

Category: Diagnosis, Surgery

TJ Supplements as of 3/26/2009

Nightly

GABA 3000mg (in lieu of Klonopin since 2000)
Magnesium 400mg (for PVC’s)
Adrenal Support (contains DHEA to help sleep)
Relafen (4 herniated discs)

Daily –

Multivitamin

Indole Carbinole (300mg) (to regulate menstrual bleeding)

COQ10 (200mg)

EPA-DHA (3600mg fish oil)

Vitamin D (4000mg) (found to be deficient in blood work)

Vitamin A (25,000IU)

DHEA (5-15 mg) when remembered

Flaxseed oil (1000MG)
MARCH 30, 2009: E-MAIL SENT TO GROUP: BRAC 1 AND 2 TEST RESULTS: NEGATIVE

Category: Diagnosis, Family & Friends

Hello.

I have just learned that my BRAC 1 and 2 testing is completely negative. I realize that for most of you this doesn’t mean anything because I didn’t really dwell on it.

For my sisters and female cousins, it means you may breathe easier as well although you must continue to be monitored more closely than others.

For me, I can not overstate my relief. Treatment for BRAC 1 and 2 positive women (those with genetic mutations) is double mastectomy and hysterectomy; of which I was terrified.

While I realize, future developments over the next few months...years could be bleak, I am deeply relieved about this. I can face the few days, weeks, months and etc while further results, prognosis and treatments are acquired with a lighter heart.

I can breathe again.

Hopefully, tomorrow will clear me surgically for the time-being.

Love, TJ

MARCH 24, 2009: APRIL 15, 2009: MY HUSBAND AND I VISIT 6 DIFFERENT ONCOLOGISTS

Category: Chemotherapy, Surgery, Doctor Shopping

I go to Dr. Estabrook’s office every two days to have my armpit drained. Dr. Estabrook continues to ask me if I have chosen an oncologist and that I must start chemotherapy soon. I am trying to find one but it is really difficult. My Husband and I visit 6 different oncologists. 4 in Westchester and 2 in the city.

They all say exactly the same thing, so it becomes a process of evaluating their style, their office, their chemo room, their back up and hospital rights.

I find the group chemo rooms extremely depressing. I don’t want to do forced group therapy while I am being poisoned. Some of the rooms don’t even have room for family. The group rooms seem designed to maximize stress and I can’t picture doing this.
**APRIL 4, 2009: E-MAIL SENT TO GROUP**

Category: Family & Friends

Hello. Thank you sending me news about yourselves. I love catching up and it makes me feel close to you.

I received the results from last week’s surgery. The pathology report was completely clean…so the 3rd time it seems is good….so good the surgery was unnecessary but there is no way to know that until they took a few more inches…

I am having complications from the 3.24 surgery which require me to go to the surgeon’s office every 2 days, so we are behind schedule on choosing an oncologist as all the appointments have had to be re-arranged and they are very difficult to set up.

If the body scans, I am having are clean, I will begin chemo…. (somewhere…) on April 27th for approximately 5 months or so…. then a break and then 6 weeks of daily radiation….

So, I am thinking about a really wild and crazy Christmas somewhere….

I will be telling the children next week so feel free to call anytime after April 19th and I should be able to talk.

Love, TJ

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**APRIL 5, 2009: THE ENTIRE FAMILY GOES TO THE HEALTH FOOD FAIR (WRITTEN JAN 22, 2010):**

Category: Family & Friends

Mom, My Husband, I and the children go to an alternative health conference in mid-town Manhattan. We go through the booths with a very different eye than the last time we attended several years ago out of curiosity. We find lots of references to cancer and we find information about Alkaline Diets.

We learn that in 1931, Dr. Otto Warburg received a Nobel Prize for proving that cancer cells can not live in an alkaline environment. http://en.wikipedia.org/wiki/Warburg_hypothesis

I buy an alkaline food card and put it on the refrigerator. I wonder why no one pays any attention to Dr. Warburg’s work. I go out and buy a tube of oxygen from the sports drink store down the street and never use it.

At the fair, I learn that I should be drinking wheatgrass daily. I see a juicer that is cool. I learn that different foods have anti-cancer properties. I see tea from the American Indians that is supposed to keep cancer at bay

Everywhere around me every reference is to cancer and yet I have been to this fair before and never once even noticed the word ‘cancer’. It is surprising to me how preoccupied everyone is with cancer.
APRIL 7, 2009: I HAVE A FASTING PET SCAN FOR BREAST CANCER STAGING (WRITTEN APRIL 27, 2010)

Category: Diagnosis

The PET Scan requires fasting and the technicians were running very late. I had arranged for My Friend’s to pick me up which turned out to be a very good thing as I was exhausted by the test.

In addition to the fasting, it is surreal to be taking tests to find out if the cancer has spread throughout your entire body. The technicians were extremely kind to me, but it was really stupid of me to go alone. No one explained that I would have to wait 2 MORE hours while the dye worked its way through my body, so I was completely unprepared. They gave me a room to lie down in because I was so tired, and no one told me I should have had a valium because the machine is almost as bad as an MRI and I did not bring my two remaining valium pills.

APRIL 7, 2009: WE FINALLY FIND AN ONCOLOGIST WE LIKE

Category: Chemotherapy, Doctor Shopping

We finally meet Dr. Estabrook’s favorite oncologist. She is thorough, kind and has a 10-year plan. She is the first one to discuss the long-term plan and explain what my new medical life will look like. She is also the only one to fully explain the forced menopause that will happen immediately upon starting chemo.

AND she has private chemo rooms facing a rooftop garden. Both My Husband and I really like her but are concerned that the drive to the city will be too much especially if I get sick. We ask her to refer us to someone in Westchester and she remembers her old friend Dr. Hollister.
## DR. MOORE’S NOTES ON CHEMOTHERAPY REGIME

<table>
<thead>
<tr>
<th>Provider: Anne Moore</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address: 425 E 61ST ST, 8TH FLOOR New York, New York 10065</td>
</tr>
<tr>
<td>Phone: 212-821-0550 Fax: 212-821-0796</td>
</tr>
<tr>
<td>Email: <a href="mailto:almoore@med.cornell.edu">almoore@med.cornell.edu</a></td>
</tr>
</tbody>
</table>

### Patient Instruction

**Anne Moore**

**Attending**

**Tue Apr 7, 2009 9:41 AM Signed**

I recommend:

- Adjuvant chemotherapy
  - Dose dense chemotherapy is a good choice:
    - Dose dense ACT:
      - Adriamycin and Cytoxan every 2 weeks 4 times - about 1-1 1/2 hours
      - Taxol every 2 weeks 4 times-4-5 hours each time
      - Neulasta shot the day after each treatment for the white blood cell count
  - Radiation therapy after chemotherapy-about 6 weeks, 5 days a week. Before chemotherapy-MUGA scan or ECHOCardiogram-for Adriamycin
- Other options: avastin protocol, TAC are probably equivalent.
- PET scan alone and Bone scan--will be done
- After chemotherapy—Tamoxifen to begin and later anrimex—one dose a day.
- Ovarian suppression with lupron if you don’t go into menopause is a good idea—for 2 years.
- Bisphosphonate trial--

| RA | 60 | 111.9 |
| 1.87 | C | 600 | 112.2 |
| T | 135 | 327 |

Dr. Moore’s notes on chemotherapy regime
APRIL 9, 2009: TEST RESULTS FROM VELTMANN: SNPs on GENES
RESULTS IN ESTROGEN METABOLISM IMPAIRMENT: IMPAIRED
ESTROGEN METABOLISM PLUS FERTILITY MEDICATIONS RESULT IN BREAST CANCER

Category: Estrogen Health

I receive test results from Dr. Veltmann. I open the documents and try to read through them. They may as well be written in Mandarin and I have absolutely no idea what they mean. We schedule a time to review and after he spends nearly 2 hours explaining my test results to My Husband and I, I still have no idea what he is talking about. I only hear one thing.

Dr. Veltmann starts out, “As I suspected you have SNPs on your CYP 1B1 gene, your COMT and your GSTM genes. This means that you are indeed not methlyating estrogen.”

Dr. Veltmann explains the pathways of the estrogen and breast cancer. I don’t understand anything he says except that I have all of the ‘SNPs’ (Messed up DNA) that cause the estrogen not to be excreted in my urine. Instead the estrogen (the most recent excess estrogens being the high doses of fertility drugs and then birth control pills the gynecologist put me on to control the uncontrolled bleeding) stayed inside my body wreaking havoc.

I learn that the conversion of Estrone to 4 and 16 hydroxyestrone is cancerous. I have a SNP on CYP1B1, COMT and GST.

Now we must test my estrogen levels through a urine test.

I can not take in the information. I listen politely and ask him what to do.

He sends me a list of supplements to take and then sends me the supplements.
I finally prick my finger to find out what Blood Type I am. It is Blood Type B. I have learned about alkaline diets preventing cancer from a variety of sources including Dr. Veltmann. I have not made much of an attempt to follow it except I stopped drinking coffee the day of the 2nd surgery and I stopped drinking Diet Coke the day of the 3rd surgery.

I prepare in my head for a combination of the Alkaline Diet and Blood Type B Diet.

Joe Veltmann sends me information about BLOOD TYPE B Diet. It is not too arduous but it does mean stopping many of my most frequently eaten foods like chicken, avocado, crab, corn, soy and others.
### April 11, 2009: Summary of Joe Veltmann Supplement

**Schedule to Repair DNA**

<table>
<thead>
<tr>
<th><strong>Date</strong></th>
<th><strong>Event</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>4.11.2009</strong></td>
<td><strong>Supplement and Prescription Medicine Schedule for Veltmann - NIH Breast Cancer + Estrogen Research Study</strong></td>
</tr>
</tbody>
</table>

#### Possible Test Results:

- **SNP** = Single Nucleotide Polymorphism
- **1 SNP**
- **2 SNPs** (You inherit one chromosome from each parent)
- **ABSENT** Absent is not Good

<table>
<thead>
<tr>
<th><strong>Test Results</strong></th>
<th><strong>GENOTIC TEST: PHASE I DETOXIFICATION - CYTOCHROME P-450 ENZYME SYSTEM</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>SNP ON GENE RESULTS</td>
<td>SUPPLEMENT ACTION</td>
</tr>
</tbody>
</table>

#### Genomic Test: Phase I Detoxification - Cytochrome P-450 Enzyme System

- Cytochrome P450 1B1 converts estrogen to 4-hydroxy estrogen. **A SNP on CYP1B1 increases risk of estrogen sensitive cancer.** Hyper induction can generate oxidative stress and the 4-hydroxyestrogens may convert to quinone compounds that can cause DNA damage in breast tissue.

<table>
<thead>
<tr>
<th><strong>SNPs</strong></th>
<th><strong>Enzyme</strong></th>
<th><strong>Action</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>2 SNPs</td>
<td>CYP1B1</td>
<td>Down regulates CYP1B1</td>
</tr>
<tr>
<td>No SNP</td>
<td>CYP1A1</td>
<td>Upregulates CYP1A1</td>
</tr>
</tbody>
</table>

#### Genomic Test: Phase II Detoxification - Conjugation of Toxins and Elimination

In Phase II detoxification the body modifies reactions formed by Phase I Detox. Transformed toxins are eliminated in urine of feces.

*(In my case, since CYP1B1 is impaired as are COMT and GSTMs, the fertility drugs were not transformed and eliminated through urine.)*

#### Methylaion

- **COMT** enzyme breaks down neurotransmitters dopamine, epinephrine and norepinephrine. **SNPs on COMT are associated with increased breast cancer risk and lymph node metastasis.** This risk increases 4-5 times with 2 bad COMT genes or in combination with SNPs on CYP1B1, GSTM1, GSTP1.

<table>
<thead>
<tr>
<th><strong>SNPs</strong></th>
<th><strong>Enzyme</strong></th>
<th><strong>Action</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>2 SNPs</td>
<td>COMT</td>
<td>SAM-E, COMT catalyst, decreases fight/fight response</td>
</tr>
</tbody>
</table>

#### Glutathione Conjugation

- The GST isoforms catalyze the conjugation of electrophilic compounds with glutathione. **Defects in GST activity can contribute to fatigue syndromes and to various cancers.**

<table>
<thead>
<tr>
<th><strong>SNPs</strong></th>
<th><strong>Enzyme</strong></th>
<th><strong>Action</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSENT</td>
<td>GSTM1, GSTP1</td>
<td>NAC, GSTM1, GSTP1, SOD2</td>
</tr>
<tr>
<td>1 SNP</td>
<td>GSTP1</td>
<td>NAC, GSTM1, GSTP1, SOD2</td>
</tr>
</tbody>
</table>

#### Oxidative Protection

- **SOD2** is an enzyme that protects cells from increased oxidative stress and free radical damage to cell structures like membranes, DNA and proteins.

<table>
<thead>
<tr>
<th><strong>SNPs</strong></th>
<th><strong>Vitamin</strong></th>
<th><strong>Enzyme</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>2 SNPs</td>
<td>Vitamin E</td>
<td>GSTM1, GSTP1, SOD2</td>
</tr>
</tbody>
</table>

#### Acetylation - Fast & Slow Metabolizer Polymorphism

- **SNPs on NAT are at increased risk for lung, colon, bladder & head or neck cancer.**

<table>
<thead>
<tr>
<th><strong>SNPs</strong></th>
<th><strong>Action</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>2 SNPs</td>
<td>Quercetin, Modulates IL-13, NAT2</td>
</tr>
</tbody>
</table>

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*www.myestrogenbreastcancer.com*
It takes me almost a full year to vaguely understand the chart above.
APRIL 11, 2009: THE SUPPLEMENT SCHEDULE DR. VELTMANN SENDS TO ME

<table>
<thead>
<tr>
<th>Supplement</th>
<th>Amt/day</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPA/DHA</td>
<td>3</td>
<td>Suppresses IL-1B, Modulates IL-13, SOD2</td>
</tr>
<tr>
<td>Milk Thistle</td>
<td>2</td>
<td>Suppress IL-1B, SOD2, GSTP1, GSTM1</td>
</tr>
<tr>
<td>Sterol 117</td>
<td>1</td>
<td>Suppresses IL-6</td>
</tr>
<tr>
<td>Curcumin</td>
<td>2</td>
<td>Suppresses IL-1B, Modulates IL-10, SOD2</td>
</tr>
<tr>
<td><strong>Nutri E</strong></td>
<td>1</td>
<td>GSTM1, GSTP1, SOD2</td>
</tr>
<tr>
<td><strong>Ester C</strong></td>
<td>3</td>
<td>Modulates IL-13, IL-10, GSTM1, GSTP1, SOD2</td>
</tr>
<tr>
<td>Quercetin</td>
<td>2</td>
<td>Modulates IL-13, NAT2</td>
</tr>
<tr>
<td>SamE</td>
<td>2</td>
<td>COMT catalyst; decreases fight/flight response</td>
</tr>
<tr>
<td><strong>N-acetyl-cysteine</strong></td>
<td>2</td>
<td>GSTM1, GSTP1, SOD2</td>
</tr>
<tr>
<td>DIM Pro</td>
<td>2</td>
<td>Upregulates CYP1A1</td>
</tr>
<tr>
<td><strong>DHEA</strong></td>
<td>1</td>
<td>Down regulates CYP1B1</td>
</tr>
</tbody>
</table>

APRIL 13, 2009: I HAVE A TOTAL BODY BONE SCAN WITH RADIOACTIVE DYE

Category: Diagnosis

More fasting in order to be shot up with radioactive dye in order to find out if the cancer has spread.

Again, completely and totally surreal. This time I was more prepared, and it was less stressful. There is no way to tell which will be more stressful in advance, the hospital environment or the private clinic environment. Each one of these offices that makes prognoses about death have their own little environment where they can add or relieve stress.
APRIL 13, 2009: E-MAIL SENT TO GROUP: WHY MUST I HAVE CHEMOTHERAPY?

Category: Chemotherapy, Family & Friends

Hello. A belated Happy Easter and Passover to all.

Here is an update on my status.

First, regarding my stress level, I am very happy to announce to all of you that my friend, Jack, has miraculously been released from captivity in Asia.

If evidence is required of the ability of people to overcome bad things, I can’t think of a better story.

After 2 ½ weeks of complications, I was released from the care of my surgeon today and scheduled to see her 6 months from now . . . that is very good news.

I have completed my scans today also which allow the oncologist to conclusively ‘stage’ me. The scans show my body to be free of cancer and only a few things which must be monitored.

People have asked if the scans show me ‘clean of cancer’ why must I have chemotherapy and radiation?

I must have chemotherapy because of the following strong reasons

1) My tumor was over 2 cm.
2) My cancer is the most aggressive there is
3) It has already spread beyond the initial tumor to the lymph nodes and there is . . .
4) Extensive Lymphatic Invasion (meaning it spread to my lymph nodes)
5) Women with my type of cancer and profile respond well to chemotherapy

There is a high probability that a cancer such as mine has spread microscopically throughout my body all of which would be undetected by any tests available. Therefore, I must have chemotherapy to decrease the probability of recurrence.

I must have radiation because it is the standard protocol to the tumor sites after surgery.

I still have not chosen an oncologist that I feel happy about but have more appointments to go to. There has been significant delay to my ability to see doctors because of the surgical complications. Chemotherapy will start no later than April 27th with one of the doctors . . .

I still have not told My Eldest Son because I am a coward but will do so this week. Please feel free to call whenever you like although I may not be able or willing to discuss my medical situation but would be very happy to hear from you.

Thank you for your e-mails, cards and prayers.

Love,

TJ
APRIL 15, 2009: I FINALLY CHOOSE MY ONCOLOGIST
(WRITTEN JAN 18, 2010)

Category: Chemotherapy, Doctor Shopping

Dr. Hollister’s waiting room is the first breast surgery/oncology waiting room that is not unbelievably unpleasant and the first one that is well run. Dr. Hollister is a kind man with a good sense of humor and a complete willingness to discuss statistics honestly with us. He urges me to begin chemo right away, but I stall. I tell him I want to wait to see my cardiologist before beginning.

Category: Family & Friends

I have been thinking about how to tell My Eldest Son about the cancer since the first minute I heard it when he was in the car with me. I have read about how to do it, I have worried about it and have decided to talk to him in the car as per expert advice.

We were driving to his final first communion practice and I told him, “My Eldest Son, I went for a check up and the doctor found a lump in my breast. They had to take it off and now that it is gone, I have to take some really strong medicine that is going to make my hair fall out. So, before my hair starts to fall out, I am going to shave my head. The medicine is going to make me sick and tired a lot and I might be really crabby.”

“Oh, that’s going to be weird. How long will you not have hair for?”

“It should start to come back around Christmas time.”

“That’s a long time.”

“Yes. But I will wear wigs and it shouldn’t look too bad.”

“Okay.”

“My Eldest Son, I want you to know that the name of what I have is called Breast Cancer.”

“CANCER!!! CANCER!!” He is shouting at the top of his voice. “You have CANCER!!!!!”

Yes, My Eldest Son I have Cancer. Where did you hear that word before?”

“I can’t tell you.”

“What do you mean you can’t tell me. You must tell me. That is how you get stomach aches.”

“Cancer is what Uncle M has and Uncle M is dying.”

“Oh, My Eldest Son. I am sorry. I don’t have what Uncle M has. Cancer is a word that means many things. It is a word like infection. There are hundreds of different types of cancer just like there are hundreds of different infections. I don’t have what Uncle M has and I am not going to die.”

He calmed down just a little bit. I had completely forgotten about Uncle M. My brother-in-law the perpetually inappropriate and never-ending talker had just spent Easter with us talking about Uncle M’s impending death in great detail.
Uncle M was his uncle but essentially filled the role of father for my brother-in-law and faithful companion to my mother. He was an ever-present component of their house in ways that neither of his parents or my father were a big presence in our lives. My brother-in-law, My Sister’s Husband, was distraught about his impending death and spent all of Easter vacation talking about it. I had completely and totally forgotten about it as I did not associate myself at all with him…but My Eldest Son immediately made the connection.

I tell him that I will keep him up to date on every part of my treatment. He asks if he will get it because I have it. I say, “No. It is something that only women can get so you won’t ever have to worry about it.”

He knows all about genetic inheritance because he knows his asthma, sinus disease and reflux all come from his father. He knows all about medications because he takes so many and he knows about their side effects.

Well, at least it was out in the open. My Eldest Son went into the church while I parked the car. That was the most difficult thing I have ever done in my life and I find even writing about it to be quite painful.

I worry about being around for my children. I am so old in having them I really wonder if it was a mistake but to even think such a thing is to negate their existence. I worry about whether or not I will be able to stick around for another 30-40 years to take care of them and be a part of their lives.

I consider my body not my own but something that must be dedicated to being around to being part of their lives. Every doctor’s appointment, every surgery, every IV, doesn’t matter because it brings me one step closer to my goal of being part of their lives.

It was wrong to keep My Eldest Son in the dark these past several weeks. Of course, he wasn’t in the dark but was rather manifesting my own anxiety through his nightly attacks but I couldn’t see how to tell him until I knew what was wrong and it took so long for the plan to be clear and all the tests to come back. But it was wrong, and I still have not figured out how to protect them from my own feelings on the matter.
APRIL 16, 2009: E-MAIL SENT TO ‘BREAST CANCER’ ONCOLOGIST DOCTOR MOORE

Category: Chemotherapy, Doctor Shopping

Dear Dr. M,

My husband and I saw you several days ago. I was considering if there was a doctor located closer to my home where I could have chemotherapy and you referred me to Dickerman Hollister.

I met Dr. Hollister yesterday and was very relieved to meet him and enjoy his well-run practice. I have decided to work with Dr. Hollister and keep in touch with you every few months.

Gratefully yours,

TJ

APRIL 16, 2009: E-MAIL RESPONSE FROM DR MOORE

Category: Chemotherapy, Doctor Shopping

TJ-you are in such good hands...let me know if I can help. Dr. M
APRIL 20, 2009: EMAILS FROM ME TO DR. VELTMANN AND BACK ABOUT IF

I CAN TAKE THE CHEMOTHERAPY MEDICINES SUGGESTED

Dr. Veltmann sends me the result of his analysis of my ability to process the chemotherapy medications based on my DNA. As I have no SNPs associated on the enzymes involved in the processing of ‘DOSE DENSE’ ACT Treatment, he clears me to proceed.

TJ:

My pharmacogenomic analysis of the drugs (see attached) that you will be taking indicate that your SNP associated with CYP1B1 (see genomic results, Phase 1 DetoxGenomic) will not be a factor in your treatment.

Since you have a functional CYP3A4, the primary cytochrome P450 enzyme in the detoxification of these chemotherapeutic agent, I am enclosing a list of drugs and/or botanicals that are known to inhibit this pathway (something we do not want while on the chemo drugs). Please see the column listed as inhibitors and refrain from taking any of these while on chemo. Because your adrenal support contains naringenin I would suggest not taking this product during chemo since it has the potential to impede the removal of these chemo drugs from your system.

If you need to discuss this, you can reach me on my cell phone (505.986.8835).

Joe

APRIL 21, 2009: DR. VELTMANN AND I DISCUSS MY CARDIOGENOMIC PROFILE

During surgical prep on March 24th, I took blood for the Cardio-Genomic profile. The results came back today which I reviewed with Joe Veltmann.

Joe adjusts my supplement schedule to account for the results.

There are a variety of SNPs but the ones which draw my eye are those which suggest reduced inability to methylate.
Category: Chemotherapy, Family & Friends

Hello.

Thank you for your e-mails and calls. I am saving responding to your e-mails for when I am at home more in the weeks to come. I am very happy to hear your news and updates about the slightest things in your lives. It allows me to feel close and connected to you until we can catch up on the phone.

As of today, I am FINALLY finished with all tests, exams and extra doctor visits. My Breast Cancer Stage is II. I am ready to start chemotherapy every 2 weeks on April 27th which will continue until the fall. Then there will be a break and then radiation starts. I am doing the “Dose-Dense…AC followed by T” treatment for those of you who know chemotherapy protocols.

After exhaustive research and exhausting doctor visits, I have chosen my oncologist. My surgeon’s favorite oncologist is Anne Moore at Weill-Cornell. I met with Dr. Moore and said that I would prefer if humanly possible to stay our in the suburbs for treatment given that visits to the doctor’s office are very frequent in between every 2-week chemotherapy. She recommended Dr. Hollister at Greenwich Hospital. Greenwich, CT is about 15-20 minutes from my home. Dr. Hollister is a very good fit and that is where I will be treated. It is far easier for me than Manhattan to go to Greenwich especially since driving will often be forbidden. Greenwich allows friends to help and is a short taxi or train ride away. Greenwich Hospital has the added perk of looking like it is in the United States as opposed to a deeply poor and unhygienic country which is what all the other NY offices look like…. On top of all that, the chemo is administered in relative privacy instead of the forced group circles that most places offer.

On Saturday, I told My Eldest Son about the cancer and chemotherapy. That was the most difficult thing I have ever done in my life. I will be doing the best I can to minimize the damage to him and the twins as much as possible. I hope I can succeed in this and be able to take care of them during the treatment. I have already ordered one custom-made wig and am in the process of ordering several others as I hope that will ease the situation for the 3 of them as much as possible. My Little Sister is doing research on make-up and hats etc., so I am in good hands.

I am in the process of joining Gilda’s Club (Gilda Radner which died of ovarian cancer in 1989…Gene Wilder, her widower, organized a nation-wide cancer support club in her honor).

I will also try to find a yoga class when I have time for ‘stress management’…in the meanwhile I rely of the good people in the pharmaceutical industry.

I don’t think there will be anything significant to report for quite a while. I will be in touch in a group e-mail when I am halfway through treatment in a few months.

In them meanwhile, please feel free to call or text as I can speak freely now….if I don’t respond it is because the international texting with Sprint rarely works so if you send me a text and I don’t respond within a day send me an e-mail and let me know you texted….I really want to work out the American phone system…..so we can text...if it doesn’t work I will get another GSM Blackberry as My Husband took mine…

Please keep your notes coming, too. They are a source of great comfort.

Signing off for now…. Love, TJ
APRIL 25, 2009: UNCLE M DIES FROM CANCER

Category: Family & Friends

My brother-in-law's uncle, who has been like a father to him, dies after a 20-year struggle with cancer. I don’t tell My Eldest Son as I try to shield him from the cancer and death association. It is no use as my nephew tells him while they are talking about Pokemon.

APRIL 27, 2009: (WRITTEN JAN 18, 2010): MY FIRST CHEMOTHERAPY

Category: Chemotherapy

Chemotherapy. At least the suspense is over…My Husband and I go together. We take a video machine and an old video, but we don’t have 2 of the right headphones so we listen to it very quietly.

My Husband orders sweet potato fries from the deli I love down the street. The volunteers come by and offer us drinks and sweetness.

MAY 1, 2009: MY IN-LAWS ARRIVE FOR THEIR ANNUAL NY TOURIST VISIT

Category: Family & Friends

All my in-laws have descended upon North of NYC. I still do not understand how they could possibly all get together for the first week of my chemotherapy.

I look at them and wonder how you can get to be that old and have nothing in life have touched you…is it the ultimate form of detachment…where there is no loss, no pain, no death, no emotional anxiety, where everything is always going to be okay??

My Husband had not told them anything at all about my treatment, my condition, my experience or more importantly his experience. I sit over an hour bring them up to speed. They were mostly concerned with the impact on the children. I give My Father-In-Law a lot of credit for this. He insisted that I get help for My Eldest Son now not later and he is right. I think it was the first time in the past 12 years where I learned something from him and appreciated his point of view.

He was very clear about it. “My Eldest Son has made the association between cancer and death due to Uncle M. It is up to a psychotherapist to break the connection and offer him some support.”
MAY 3, 2009: THE TWINS 3rd BIRTHDAY PARTY

Category: Family & Friends, Exhaustion

The babies’ birthday party was today. As usual, I did not spend anytime having fun with the children but was running around hostessing.…

By the time the party was over, I was not seeing straight. I had always thought that that was an expression but over the last few days I have realized that it is true…. if you are really really really tired, your vision becomes blurry…. not great for driving.

I was glad to be able to pull off the babies’ party although at the end of the day it was too much for them and they would have been equally as happy with a playdate and cake.

After the party, my in-laws tried to give presents to the exhausted twins and I went ballistic; screaming at them to stop, to get out of their bedroom, to put the fucking trucks out of the house… I was very upset that I lost my temper…. 
MAY 5, 2009: MY BLOOD COUNT PLUMMETS TO DANGEROUS LEVELS: 1st IV ANTIBIOTICS

Category: Chemotherapy

Today was the scariest day yet. I started to get a sore throat over the weekend. By Monday, I had the chills, a bit of a fever and could not get warm and could barely swallow…it didn’t help that I had been stressed out of my brain by my in-laws visit…

So, the numbers are as follows…

My white blood cell count on April 27…4000
My white blood cell count today, May 5, 400

My expected white blood cell count  1250
My required white blood cell count to resume chemotherapy 2500

So much for a sore throat.

My Best Local Friend brought me and stayed with me while they pricked and poked me. The first nurse hurt me very badly with the IV needle and I swore at her. She took great offense but I explained that I swear a lot and it wasn’t directed at her or personal…

So today alone they pricked me 3 times. The doctor wanted me to keep the IV in overnight so didn’t have to prick me again. I am like…are you out of your mind? I am allergic to tape and I have 3 kids…plus it hurts very badly…

I DONT WANT A PORT!!!! Don’t ruin my veins.

Even after my bad behavior, they were very nice to me. I saw Nurse Joy passing by and I made her help me. They took 4 buckets of blood to test for bacteria running around me blood (just in case) but they explained that the treatment is just the same regardless…antibiotics more Neulasta like bumpers for the white blood cell count and etc…
MAY 9, 2009 (WRITTEN MARCH 1, 2010): MY HAIR COMES OUT IN CLUMPS

Category: Chemotherapy

My hair begins to come out in clumps 2 days early. Everyone had told me that by the end of the day of my 2\textsuperscript{nd} chemo treatment, the hair would fall out in clumps, but it is starting now. I comb my hair and it comes out in clumps. My pubic hair is coming out on the washrag.

Monday is a day off and my wig maker is closed. Where will I get this taken care of…

MAY 11, 2009: CHEMO \#2: I SHAVE MY HEAD WHILE MY HUSBAND FILMS AND MY FATHER WAITS IN THE SALON

Category: Chemotherapy

Not sure that I wrote about the head shaving that My Husband and my father attended. The good thing about it was that it was over. The anticipation of the head shaving was worse than the actual head shaving. My Husband held my hand and took videos. My father was banished to go look for an espresso on the streets of Greenwich…which he found at the Lebanese restaurant for $10 for a few sips.

My wigmaker was closed on Mondays, so I went to the wigmaker next to Greenwich Hospital where a nice and incompetent Iranian woman shaved my head and then took and hour to fix the hair with hat that I had bought.

The next day My Best Local Friend and I went to my wigmaker where he fixed my wig and shaved my head closer.

My pubic hair had been coming out quite heavily but seems to have slowed down.

I have a killer yeast infection from the IV antibiotics from last week and think that I will never have sex again.
TJ asked me to come along with her and her dad to the wig place to help her figure out what was wrong with her new wig. She was having issues with it because as she put it, “it was too puffy “, and her real hair was not puffy. She wanted her wig to look as natural as possible. When we get to the wig store, the staff there couldn’t be any nicer or more accommodating. I guess they deal with women going through the same problems as TJ and it was second nature to them. I was very nervous. I was thinking to myself how can she be so cool about this, but than again, look who we are talking about. I knew I had to hold it together for her. Her dad went to find some espresso across the street and she and I went in this tiny room with the wig stylist. She was very calm, but frustrated because she wanted this wig to be perfect. I was explaining to her that the wig was too long and needed to be shortened, and angled around her face. The wig also needs to be thinned out a bit. She sat in the chair facing this huge wall size mirror. The stylist came in, and TJ took off her scarf, and proceeded to tell the short little man that she had just shaved her hair, and that she was not happy with the result. She showed him that it was not even, and if he could fix it. As I stood there, my heart was breaking. Tears were welling up in my eyes, and I was really trying to hold it together for my good friend who was so brave. I kept thinking of her men at home, and how she is the driving force in that household. I also thought of how she was managing all she had to do, and a horrific illness, and able to plan birthday parties, and making sure her Eldest Son was never missing an event at school, and on and on. The wig went on and she and I were trying to explain what we thought he had to do to make it right. Finally, after a half hour of what it seemed like a scene in Edward Sissorhand, the wig looked great. She put it on and seemed content with it. When we left the tiny room, her father appeared, and the look on his face when he saw his daughter was priceless. He said, “ Oh darling, your look beautiful”. Again, like a blubbering idiot the tears that never really went away, came back again. Needless to say, when I got home, I was exhausted, emotionally that is from the day’s events. TJ, like the energizer bunny kept going and going.
MAY 16, 2009: (WRITTEN JAN 18, 2010) I FIND OUT WHY I HAVE CANCER: I HAVE AN IMPARIED ESTROGEN METABOLISM WHICH COMBINED WITH MY HISTORIC ESTROGEN EXPOSURE INCLUDING FERTILITY MEDICATIONS RESULTED IN MY BREAST CANCER

Category: Estrogen Health

Results for the 24-Hour Estrogen Test which I took on March 26th have finally come in.

The summary of the test is that as Dr. Veltmann suspected, my body is not ‘methlyating’ estrogen. The commentary from Genova Diagnostics is as follows.

My methylation results are ZERO. See Below.
Contd. I find out why I have cancer...

Estrone (E1) is the second most potent estrogen next to estradiol, and is derived from either estradiol (reversible reaction) or adrenal androstenedione via aromatization in peripheral tissues such as adipose. In turn, E1 is converted to 2-, 4-, or 16α-hydroxyestrone. E1 is the predominant estrogen in a post-menopausal woman, being formed primarily from androstenedione.

Estradiol (E2) is the most potent estrogen and is the major estrogen secreted by the ovaries in a premenopausal woman. In the postmenopausal woman, E2 derives from estrone (reversible reaction) or from testosterone via aromatization in peripheral tissues such as adipose.

The least potent of the estrogens, estriol (E3) levels are traditionally used clinically to gauge the viability of pregnancies. E3 has generally been viewed as a "protective" estrogen because of its low relative potency and has been found at higher levels (compared to E1 and E2) in the urine of women with a lower incidence of breast cancer. E3 is a metabolite of 16α-hydroxyestrone.

Low levels of 2-methoxyestrone (2-MeOE1) indicate impaired methylation of 2-hydroxyestrone (2-OHE1) or simply reflect low levels of 2-OHE1. Methylation may be improved via methyl donors such trimethylglycine as well as cofactors such as folate, B6 and B12, and magnesium. 2-MeOE1 has potent antioxidant and anticancer properties.

Low levels of 4-methoxyestrone (4-MeOE1) suggest impaired COMT-mediated methylation of 4-hydroxyestrone (4-OHE1). Because 4-OHE1 is procarcinogenic and free radical inducing, 4-MeOE1 production is considered protective. Methylation may be improved via methyl donors such trimethylglycine as well as cofactors such as folate, B6, B12, and magnesium.

The ratio of 2-methoxyestrone to 2-hydroxyestrone (2-MeOE1:2-OHE1) provides a gauge of methylation efficiency in the body. The 2-hydroxyestrone metabolites are generally considered protective against breast (and possibly prostate) cancer; however, they are only protective when converted to their methylated forms. Lower ratios suggest inadequate methylation of estrogen. Rule out excess stress, as catecholamines compete for the same COMT methylation enzyme. Ensure adequate nutritional support for methylation, e.g., methionine, Mg, B vitamins, and betaine (TMG).

The ratio of 4-methoxyestrone to 4-hydroxyestrone (4-MeOE1:4-OHE1) provides a gauge (along with 2-MeOE1:2-OHE1) of methylation efficiency in the body. If not adequately methylated to 4-MeOE1 by catechol-O-methyltransferase (COMT), 4-OHE1 can more easily convert to compounds that damage DNA and increase risk of breast and prostate cancer. A lower 4-MeOE1:4-OHE1 ratio thus suggests inadequate methylation of estrogen. Rule out excess stress, as catecholamines compete for the same COMT methylation enzyme. Ensure adequate nutritional support for methylation, e.g., methionine, Mg, B vitamins, and betaine (TMG).

I am unable to understand anything on this page except the last paragraph and the sentence, "If not adequately methylate to 4-MeOE1 by COMT, 4-OHE1 can more easily convert to compounds that damage DNA and increase risk of breast and prostate cancer."

May 16, 2009 - I find out why I have cancer: I have an impaired estrogen metabolism which combined with fertility medications resulted in my breast cancer
So, the Estrogen in my body goes from Estrone to 4-OH E1 to Quinones to Mercapturate instead of to 4-Methyl-OH E1.

“Dr. Veltmann, how are we going to get the estrogen out of my body?”

“That is what the supplement schedule is for.” He answers.

I must trust him. Without these answers there is nothing except the intense fear that I see in the faces of everywoman around me worrying about chemicals and food and Airplane travel etc.

If it weren’t for Dr. Veltmann, I would have to revert to my theory about the 44 years of unwashed grapes giving me cancer.
MAY 17, 2009: MY ELDEST SON’S FIRST COMMUNION PARTY; MY HAIR LOOKS GREAT & MY FATHER CRASHES MY CAR

Category: Chemotherapy, Family & Friends

My mother, father, sister and nephew have traveled to be in town for My Eldest Son’s first communion. They arrive on Friday and I give them the instructions for the party. They take care of everything. Our theme is Hawaiian but, on the day, it is pretty cold and no one winds up going outside.

My Husband spent much of the First Communion ceremony crying in the back of the church because the pastor was being such a jerk yelling at everyone to be quiet and saying that he would stop the ceremony if anyone spoke or took pictures. He gave us dirty looks because the twins were peeping a little. He was the most inhospitable priest I have ever encountered, and it was unfortunate that My Husband had to experience that. It was simply too much for all of us, but My Eldest Son had a good experience.

My Eldest Son’s Communion party was very nice although half the people did not show up.

I was tired but regained some energy somehow. It was the first day I had worn my wig for most of the day and I got a LOT of complements about how nice my hair looked. Finally, one of My Eldest Son’s friend’s mom said that my hair looked great. I burst into hysterical laughter . . . she had no idea what was going on and I didn’t clarify. I just told her it was a wig.

That night my father crashed my car and wasn’t even aware of the fact that he had had an accident. My Husband went ballistic.
MAY 18, 2009: GILDA’S HOUSE FOR MAKEUP SESSION AND CANCER IN THE EYE

Category: Chemotherapy

Went to Dr. Hollister in the morning. My blood count is where it was supposed to be…at 2700. Came home to do paperwork and then went to Gilda’s Club for the Look Good Feel Better session that I was really looking forward to

It was run by two older ladies who were both hard of hearing. They refused to start the session because 1-2 was supposed to be for people who want wigs….I was really tired and that was my nap time… I sat in my chair and demanded to know what the makeup session would be comprised of…they told me it was just a general makeup session with a huge gift bag…

The two women next to me had breast cancer…one it was her second time in chemotherapy. The other was in a wheelchair and she had among other things CANCER IN HER EYE…they were discussing the black marks that radiation was leaving on their skin and they were obvious. The black woman with the cancer in her eye was quite dark and yet had a BLACK mark around her eye from radiation apparently. They talked about cancer in the eye for awhile.

I got up from the table to make sure my mother who was sitting in a chair behind all of us couldn’t hear them. I asked some questions about eyeliner and then took off for my nap.

Scary time at Gilda’s House…. I understand that this is bad, but I prefer my denial to sharing feelings with anyone. I don’t think I will go there again except for the lectures.
JUNE 2, 2009: I GET SICK AND “YOU HAVE A NICELY SHAPED HEAD”

Category: Chemotherapy

Today was the first day I succumbed and spent most of the entire day in bed. I got up to have a 2-hour acupuncture session and have my nails done.

The day in bed adventure was made easier because USA TV Station had a day long special and they were broadcasting the TV show “Burn Notice” all day. My 3 papers lay unread by my side.

The migraines are coming on almost like clockwork a 5 days post treatment. They start out slow and then gather steam until a feather dropping the wrong way will set them off.

I am sure it is all chemical as my doctor assures.

So, the compliment of the week has been “You have a nicely shaped head”. Surely chemotherapy inspires the most bizarre behavior from friends, acquaintances and loved ones. So far that is the best yet…You have a beautifully shaped head…is even more the bizarre than the “you look good’ exclamations from friends in genuine surprise.

I am very bummed out because just like in my only pregnancy I had begun to calculate the days to go completely wrong and in earnest…no small feat for someone who just spent the last 3 years buried in spreadsheets…

The last day of my treatment is August 17th, god willing, if everything goes to plan…NOT August 3rd as I had made plans around…

Fucked up.
JUNE 7, 2009: I GET SICKER WITH ANAL INFECTION, BLEEDING, MIGRAINES, HOT FLASHES

Category: Chemotherapy

Had a bad week. Tuesday was the first day I spent the entire day in bed. The migraines are getting worse. They seem to start on Day 7 and last until the next session.

On Wednesday, my count was low again; only 700. On Wednesday night, I began bleeding from my anus. During the hour it took for the answering service to reach a doctor (they finally woke up my own who was #3 on the list), we imagined that I was bleeding internally. I was never so relieved in my life to be told by the doctor that it was a burst hemorrhoid and that I must come in to the office the next morning.

On Thursday, he told me that it wasn’t just hemorrhoids but that due to my low blood count, I had developed an anal infection. He explained that that was the first part of the body to go since it had the most bacteria.

On Friday, my count was back up.

The migraines persist. I am living on Imitrex and Treximet and worried that I may give myself a heart attack.

On Saturday night, I found a lump in my right breast. I have had every cancer test that exists, and nothing showed up in the last 3 months, but stranger things have happened; right? I fear I am about to go on another round of testing. I assume and hope that it is one of the many fibroid adenomas that they found in my right breast but since the biopsy of my lymph nodes was negative and in fact, they were malignant, I don’t have a lot of trust in the tests anymore.

This is the first week, I have also started to feel sorry for myself. I am being beaten down by the migraines; they are truly debilitating.

The isoflavones seem to be helping with the hot flashes.

Tomorrow is #4. let’s hope I can keep the white blood count up.
JUNE 11, 2009: CHEMO #4: I FIND ANOTHER LUMP

Category: Diagnosis, Chemotherapy, Exhaustion

Had my #4th AC treatment and mercifully immediately had an ultrasound where the radiologist informed me that she thought the lump in my breast on the right side was a cyst. Saw My Cancer Friend in the waiting room. She has developed lymphedema and her breast is fucked up from radiation.

Feel better these past 2 days without the migraines. I think the migraines are more debilitating than all the rest. Hopefully I can get through this and the next drugs will not be as bad?

Everyone is annoying me. I think it is time for me to go to bed.
Hello. I am sending some news but would prefer to hear yours.

In 10 days, I will be at the halfway mark for chemotherapy. In 10 days, I switch chemotherapy medications and can expect things to be different, but I do not know if they will be better or worse.

I have proved ‘sensitive’ to chemo according to my doctor, which means that my white blood cell count has been going down more than most people. What is happening to me is not unusual, but it is also a little worse than the norm, so I have been monitored extremely rigorously oftentimes having to go to the doctor’s office daily. Because my white blood cell count is plummeting and also not responding to the bone marrow enhancing medications that they are giving me daily, I have had a host of infections, maladies, scares and fatigue. All of this doesn’t matter, it is just important to get through the chemo and I am 10 days away from halfway.

Regarding my morale, being me oftentimes doesn’t seem like being me without lots of energy, but as long as I am not in the hospital and able to spend a little bit of quality time daily with the children, I am good.

Highlights of treatments were

1st treatment - The twins’ 3rd birthday party and a visit by the My Husband’s entire family was distracting.

2nd treatment - Shaved my head, My Eldest Son’s First Communion and my father’s visit

3rd treatment - Dad’s return visit

4th treatment - My Husband and I were alone. Nothing eventful but My Eldest Son’s baseball and then baseball playoffs have kept the weekends very busy

My Mom spent several weeks with me. Now, My Best Friend is coming to visit for a week, then My Little Sister and then my mother will stay for at least a month through July and possibly August depending on how I react to the second set of medications.

Because of the doctor’s visits, my daily naps, a flimsy attempt to keep up with our household paperwork, the family visits and the above special events I have been very busy and have not yet even gotten to the list of things to do I comprised 3 1/2 months ago upon learning about the cancer.

I love hearing your news, consider mine to be very boring and look forward to hearing from you. I will write more often and promise to respond to e-mails in a more timely manner now…I hope.

Love, TJ
JUNE 17, 2009: OUTPATIENT HOSPITAL NOTES FROM HOLLISTER – THROAT IS CLOSED

Category: Chemotherapy

This 45-year-old woman, on adjuvant treatment for her breast cancer, was admitted for fever and chills. She is profoundly neutropenic despite being on b.i.d. Neupogen.

The patient complains of some soreness in her throat and some perianal tenderness. She had both of these symptoms at her previous neutropenic episode as noted in the record.

She also notes some dyspnea on activity including going upstairs and a rapid pulse.

On exam, the patient is pale in mild distress. She is afebrile now, but did describe fever and chills earlier. Chest is clear. Heart sound is tachycardia at 110. Abdomen without tenderness. Extremities negative. Perianal area mildly tender. Rectal was not performed.

The patient will continue on her twice-daily Neupogen 480 mcg, which she self administers. She received Rocephin 2 g intravenously for 2 day. On June 18, 2009, she was feeling better. She still had some fatigue, but no further fever and chills. Her ANC had risen to a 1400.

The patient will continue her b.i.d. Neupogen and her Cipro. Rocephin will be discontinued. She will return for account again in the morning.

Job#: 4798856

** Information in this report should not be considered FINAL until authenticated by the author and should not be re-disclosed.**

Rep#:0618-0098 D:06/18/09 1047 T:06/18/09 2215 U:CRU

June 17, 2009: Outpatient hospital notes from Hollister - throat is closed
JUNE 19, 2010: Email from TJ’s Mother

Category: Family & Friends

Thank you for phoning me today.

Hearing your voice sounding strong encourages me.

Your sisters and I are having many sleepless nights over your news.

There is nothing any of us can do, and the worry comes naturally because we love and care for you.

We will reply on Dr. Hollister’s judgment.

You have almost reached the half way point, the other half and then the strength will return by its own volition. red and white cells and energy etc.

We are all praying and thinking positive thoughts.

I meet people, complete strangers, they want to know only your 1st name to include you in their daily prayers.

Can you feel how powerful that is?

I am shocked by these strangers’ interest and prayers...and grateful at the same time.

I spoke to Your Eldest Son about his League and the garden.

Both he and your sister’s son spoke for quite a while on the phone about their webkinz and connecting in the playrooms It was funny to hear them talking about the computers and what buttons to push to connect with each other when they are only 7 and 8.

Love Mom

JULY 19, 2009 EMAIL TO SMALL GROUP

Category: Family & Friends

I am doing better today. My white blood cell count is back up but my red blood cell count is not.

My Best Friend is going to the Airport shortly.

Dr. Hollister thinks I will have to take a week off and forego chemotherapy next week. Red blood cells take longer to go down and longer to go back up. He will decide on Monday what the course of treatment will be.

I will be in touch as I am able...
Hello My Family,

Let’s all stop for a moment to consider ME and sentence number 3 of Mom’s e-mail below.

I have cancer. It has been scalped out of me. I am undergoing chemotherapy treatment based on statistical probabilities. I am having a reaction that is more severe than most. It is difficult for me. I am doing the best I can for myself, my children and my husband. There is no cancer inside me at the moment. That is the best it will ever be. I repeat. I am the healthiest I will ever be right now. Today. Undergoing chemotherapy is an intellectual exercise that is necessary for my children and the side effects are difficult. But I repeat. I am the healthiest I will ever be right now.

Chemotherapy is difficult for me but as long as I am able to stay out of the hospital, I am okay mentally.

What is extremely unhelpful if to hear all of your anxiety in your phone calls to me, to each other, to My Husband and in your e-mails. I repeat it is UNHELPFUL to me… the one undergoing all of this. I know we have a dysfunctional family, but I hardly think this is the time for me to be trying to support you.

So, I humbly request that since you are unable to shield me from your own anxiety you get rid of it. I simply can not bear to support your anxiety in my frail state, and I see no reason for you to be more anxious about me than I am. If you can not control your own anxiety through whatever means necessary; drugs, therapy, speaking to other people besides each other or to each other THAN DO NOT CONTACT ME.

This is about me at the end of the day not you so why not follow my lead and be uplifted by all the people, even strangers that are praying for me. Cancer is for life. I will not be better at the end of this. I am better now.

I have many many more months of treatment ahead of me and I need your support not to support you.

So, do what you need to do to take care of me and be a source of uplifting to me not another burden for me to bear. Be a source of uplifting for yourselves because at the end of the day there is only God and his energy manifested through these prayers and support and love. Anxiety is the anti-God for it implies a lack of trust in God.

Please help me by getting rid of the anxiety through whatever means necessary and not involving me in it even peripherally. Support me. I really need it.

Love TJ
JUNE 21, 2009: LESSON LEARNED - COMPLETELY OVERWHELMED BY ILLNESS

Category: Family & Friends, Exhaustion

The sicker I become, the less able I am to cope with any thing, any demands, any emotional needs of anyone else. Everything bothers me, everything irritates me, I must lie in bed and watch TV as I am too weak to read for the first time in my life deprived of the comfort of books.

I have heard stories about people becoming really mean when they are dying. I have heard all kinds of theories about why people become mean when they are dying, and I believe they are all untrue. Total and complete exhaustion with not one molecule to spare for anything except the physical task of staying alive. That is why people become mean when they are dying.
JUNE 28, 2009: EVEN SICKER: HOSPITALIZED

Category: Chemotherapy

On Tuesday, I was slow to get out of bed, but I went out for breakfast with My Best Local Friend and then got my nails done. I was happy and surprised to feel the humidity and smell of a hot June day with laziness. It has been so many years since I felt that feeling sometime in my distant childhood.

At 1pm I took the boys to go to the pool for an hour before my OB/GYN appointment. The pool read 79 degrees. If it wasn’t that cold at 75 two days earlier when I last went swimming than how come I couldn’t get warm today? I kept swimming trying to warm up, but I couldn’t. The hot shower at the side of the pool didn’t help.

I then yelled and screamed at My Little Sister about how she wasn’t being helpful because she would rather stay with My Nephew than with me. I told her that I couldn’t compete with My Nephew’s 99-degree fever and little virus. I changed my clothes but was freezing. My Little Sister got in the driver’s seat and I didn’t say anything. We dropped off My Eldest Son’s friend and the boys and I began shaking. By the time we got to the OB/GYN’s office, two blocks from Greenwich Hospital, I was shaking uncontrollably. I went to the office and asked for a blanket and then another one. They put me in an office, brought in a space heater and a heating pad. I still couldn’t warm up. With a little tea and the heating pad cranked up all the way I stopped shaking for a few moments.

The new OB/GYN sent me to Hollister’s office. I walked into the office wrapped in the bright pink blanket the OB/GYN had given me and said, “Help Me.”

They brought me into a room. I lie down and started to cry. Nurse Joy took my temperature and it was 103.3. She said, “Of course you have the chills, look at this. Hollister came in. They gave me Tylenol. I said, with my teeth chattering uncontrollably, “I have the chills and they won’t do away.” He asked for my sister and I said, “I don’t want to do to the hospital.” He said, “Its 3 o’clock. It is too late for me to take care of you here and I can’t leave you like this. You must go to the hospital. My Little Sister came in to the room and he gave her instructions and I waited for her to drive me a ½ block across the street. They took me by wheelchair from the car straight into a room. I was still shaking. IN the hospital I was confronted by bureaucracy and an incompetent IV nurse. Hollister was extremely nice to me and got the mean doctor and the nurse off my back. It is 4 hours before they have antibiotics hooked into my IV. Despite the pleasant lies from Hollister about being out in the morning, I know that I am going nowhere.

My Husband came, My Little Sister stayed and the following day my mother arrived. I slept with help from Ambien. I stay for 72 hours before they let me go never being able to say what exactly happened.

It is generally agreed that that was a very severe reaction to Taxol or a continuation of the pattern that just continued. Either way, the idea of continuing or stopping is very frightening.
JUNE 30, 2009: HOSPITAL NOTES FROM THE INFECTIOUS DISEASE SPECIALIST

Category: Chemotherapy

The patient is a 45-year-old woman with a history of breast cancer diagnosed in March 2009. She is status post ACT therapy with Taxol given about 7 days ago. She has had neutropenia very frequently on and off since May 2009, and started to have Neupogen b.i.d. for many days of this period.

The patient received 2 courses of Rocephin each a couple days long followed by Cipro 1 starting on May 5, 2009 and one on June 18, 2009, for perianal tenderness without any obvious abscesses that had to be drained. That process resolved, and she has been off antibiotics for at least the week or 10 days. Dr. Hollister's note indicates she got Rocephin on June 18, 2009, so that she really should have finished her antibiotics about a week ago, the best that the patient remembers. The patient was seen yesterday with a white count over 14,000. She now comes in today with fever and chills for 1 day. No other localizing complaints including nausea, vomiting, diarrhea, constipation, abdominal pain, dysuria, or hematuria. She has children at home and her children also appear to have respiratory infection, but the patient herself has no respiratory symptoms. No one is around there have a new novel influenza A/H1N1. The patient's temperature at Dr. Hollister's office was 103.3, here it is 101.7. The patient's head, eyes, ears, nose, throat, heart, chest, abdomen, extremities, and perianal area are all fine. The patient's examination is remarkable only really for alopecia. Her white count is 10,900, hemoglobin is 6.9. It was over 8 yesterday, platelet counts 229,000. Her creatinine is pending as are chemistries. PT is 13.1, INR 1.3, and PTT 24.3.

This patient has fewer of uncertain cause. She is not neutropenic. The perianal area looks okay, although she could have seeded her bloodstream at some point when she was neutropenic. It is possible she has a delayed fever related to Taxol, but that would be unusual. Finally, I feel it is possible she may develop respiratory symptoms related to the apparent viral infection (respiratory) present in her household.

The patient is quite anemic and we are awaiting for her chemistries to make sure that she is not hemolyzing. Dr. Hollister is to address her low hemoglobin.

The patient is supposed to have blood cultures x2. I have just had a long discussion with the patient. She refused the second blood culture complaining about the phlebotomist who in my opinion is the best phlebotomist I have ever met in my career of over 31 years. The patient is limiting our knowledge with only one blood culture. I have informed her of this, but we will do the best we can with the second blood culture. The patient needs her chemistries done, UA/CS, and a chest x-ray. Pending all this, I have elected to cover her with Fortaz intravenously. She does have a history of hives to penicillin, but tolerates Rocephin well.

Also with respect to the antibiotics, she has not had any diarrhea. She has also had some Diflucan for a "vaginal infection" and has had some Famvir given for herpes labialis.

Greenwich Hospital PCI "LIVE" (PCI: CE Database GHD)

Run: 07/09/09-16:48 by BOSSON, ANGELA
JUNE 30, 2009: HOSPITAL NOTES FROM DR. HOLLISTER

Category: Chemotherapy

This 45-year-old woman with a high-risk breast cancer, 2.2 cm primary tumor with 3/4 positive lymph nodes, BRCA1 and BRCA2 negative, ER positive, HER-2-neu negative, is admitted for fever and chills.

The patient has completed her 4 cycles of dose-dense Adriamycin and Cytoscan. She had significant neutropenia with this requiring daily and for a period b.i.d. Neupogen injections. She had perianal infection which was clinically treated with Cipro. On occasion, she was also given Rocsohin as documented in the dictations.

The patient began her Taxol, receiving cycle 1 on June 23, 2009. This is a standard dose of 175 mg/m². The following day, she began Neupogen which she has been on b.i.d. for the last several days at 480 mcg.

The patient was seen by me on June 29, 2009, when she was doing fairly well. Her white count was 14,000. Her hemoglobin was 8.3. She was to continue her Neupogen. She stopped this morning; however, because she was having bone aches.

This afternoon, she developed shaking chills and fever. She presented at the office.

On exam, she is sick but not toxic. She is clearly febrile with temperature of 103, blood pressure 144/76. She is not icteric. There is some thrush on the tongue. Her chest is clear. Heart sound is tachycardia at 110. Abdomen is soft without tenderness. Extremities are unremarkable.

The patient gives no localizing signs.

The patient will be admitted for culturing and Infectious Disease consultation prior to institution of additional antibiotics. Her Neupogen will be continued pending her blood counts.

This is day 8 from her first Taxol treatment.

Job#:

<<SIGNATURE ON FILE>> 07/01/09 1222
Dickeman Hollister Jr MD

copies to: James R Sabetta MD
JULY 4, 2009: E-MAIL TO DR. ANNE MOORE ABOUT MY HOSPITALIZATION

Category: Chemotherapy

Dear Dr. Moore,

Unfortunately, I was unable to keep my July 1st appointment with you as I was in-patient at Greenwich Hospital under the care of Dr. Hollister. I would like to see you to discuss next steps.

My treatment has been roughly as follows.

1st A/C – Neulasta – Day 7/8 - White blood cell count fell to 500. Fever 102. Bad sore throat etc. 2 days IV antibiotics.

2nd A/C – daily Neupegen – Day 7/8 - White blood cell count 800? Various side effects (migraines, skin rashes requiring steroid shot) etc.


1st Taxol – twice daily Neupegen - Day 7/8 – Fever 103.5. Severe Chills. Checked into Greenwich Hospital for 50 hours during which constant IV Antibiotics. No known infections found. Blood, urine, chest X-ray and Chest CT scan all clear.

I do not want to continue treatment along this course (3 more full dose Taxol) and would like to consider other options.

I am meeting Dr. Hollister on Monday July 6 to discuss his proposed strategy. Would like your opinion as well if I am able to see you next week and if they can not fit me in perhaps, we might speak on the phone.

I remain yours gratefully,

JULY 5, 2009: E-MAIL FROM DR ANN MOORE

TJ--what a hard time you have had with this. I will be in the office all week-happy to speak with you after you meet with dr hollister-you can call me. am
JULY 6, 2009: MY CHEMOTHERAPY TREATMENT IS ABORTED

Category: Chemotherapy

After my stay in the hospital, 3 more days at home on bed rest with a low-grade fever, a declining white blood count and stable red, Dr. Hollister said, “I am disenchanted with your treatment”. It didn’t sound as harsh as that coming from my Norman Rockwell oncologist.

My Husband, my mother and I were discussing the future treatment options and that was the first thing he said. After much discourse during which it was abundantly clear that there are no numbers to be had for someone who drops out of treatment… we left it as follows….

I would wait another week and then meet to discuss whether I stopped or continued with 50% Taxol.

I called Dr. Anne Moore and she said Stop. She said that I had derived the biggest benefit from the A/C portion of the treatment at 80%. She said that my bone marrow is very sensitive, and we could consider that I had been given twice as much medicine as a ‘normal’ person. She said that I had probably derived 85% of the treatment and that she was extremely comfortable with me stopping.

My Husband, my mother and I will see her on Wednesday. We face a big decision, but it was at least comforting that her opinion was unequivocal as opposed to Hollister who was more leaving it up to me.
JULY 8, 2009: E-MAIL SENT TO GROUP ON TREATMENT ABORTED

Category: Chemotherapy, Family & Friends

My white blood cell count is back up today and my anemia improving today.

I will send details next week after I meet again with Hollister but want you to know that My Husband, Mom and I met with Dr. Anne Moore (top breast cancer oncologist in the NYC area) today at Weill-Cornell to discuss my status after my extremely frightening hospital stay last week. She and Dr. Hollister had spoken earlier that morning about my chemotherapy and the toxicity to my system.

She said that in the many thousands of breast cancer patients she has treated, she has had only one patient whose blood count had gotten as low as mine repeatedly. She said that she would not have had the stomach to treat me as aggressively as Dr. Hollister and watch me be hospitalized many times over. (I was only hospitalized once but should have been 3 times as typically if a chemotherapy patient requires IV antibiotics it is done in-patient not out). She also, incidentally, said that both she and Hollister had studied under someone who schooled them to only resort to blood transfusions under the most dire of circumstances which is why Hollister kept avoiding them.

She said that although I have only had 5 instead of 8 doses of chemotherapy, they could consider that I had had the equivalent of many times more that based on my white blood cells plummeting and that I certainly had had “ENOUGH” chemotherapy.

She said that chemotherapy was only 1 step of preventative therapy and that now it was time to move on to hormonal therapy and radiation therapy. She cautioned that my white blood cell count must be monitored closely during radiation based on my severe reaction to date.

I will be meeting Hollister on Monday to discuss next steps and will begin scheduling radiation doctors’ appointments tomorrow.

I will stay here to be monitored until my blood returns to normal, until my stamina returns, and I am no longer anemic....and assuming that happens within a few weeks plan to go to Chicago for a break before beginning radiation therapy for a well-deserved break.

I will update again next week.

I still need prayers to get my blood back to normal and be able to walk up a flight of stairs without my heart-pounding out of my chest so keep them coming. They have certainly helped.

Love,

TJ
JULY 9, 2009: WE VISIT WITH ONCOLOGIST MOORE FOR SECOND OPINION ON ABORTED TREATMENT

Category: Chemotherapy

Saw Dr. Ann Moore today with My Husband and Mom. I went in the appointment really nervous about stopping chemotherapy before 8 treatments and ruining my chances of risk reduction and left the appointment really annoyed with Dr. Hollister and myself for letting me live through the craziness of the last 11 weeks. After talking to Dr. Moore, I feel like Hollister is insane. She said that of the many 1000's of patients she has treated over the years she has only seen 1 repeat 1 with blood counts as bad as mine.

Why did he do it? I will ask Monday, but I know the answer because he could. We didn’t object and didn’t realize how out of the box the situation was.…

Now I am worried about side effects from the rigor of the treatment but at least I am not worried about risk reduction. According to Dr. Moore, I have had many times the normal dose of chemotherapy that other patients have.…

At my visit with Dr. Moore, the ‘breast cancer goddess’ she discussed the following.

1) My chemotherapy treatment was hard on my white blood count and therefore probably more effective.
   We could consider that I had had 100% of the dose considering the bad blood counts.

2) Since I am estrogen positive the A/C (Adriomycin/Cytoxin) part of the treatment was much more important than the Taxol and that the ratio of benefit should be considered 80% (A/C) to 20% (Taxol).
   In fact, according to Moore, there have even been some trials that state that Taxol doesn’t benefit estrogen positive cancers.

3) Chemotherapy was only one part of my preventative treatment. Taking Tamoxifen is and extremely important next step and should be started 4 weeks into radiation.

4) Ovarian suppression was very important as well should my period ever come back.

5) Radiation was next and I should be very careful about my blood count during radiation and be monitored closely.

Then she was done with me. She said in the 1000’s and 1000’s of patients that she has treated she has only had 1 with a blood count as ‘bad’/low as mine. That she would never have had the stomach to continue to treat me as Hollister had. She said that she would have lessened the dose and lengthened the time between treatments but none of that was any guarantee that I wouldn’t have had the same type of reaction to chemotherapy.
JULY 11, 2009: (Written Jan 18, 2010): ZOMETA TREATMENT AND MY BONES

Category: Chemotherapy, Zometa Study

So, if I am not to continue with chemotherapy, the new plan of action is;

1) Radiation
2) Tamoxifen
3) The IV Bisphosphonate Zometa taken once every 6 months for 3 years

When I first met Dr. Moore, she told me about the Bisphosphonates Trial and suggested that it was the only clinical trial currently ongoing that was worth pursuing. She spoke rather passionately about it and explained that IV Bisphosphonates would become standard protocol shortly.

Greenwich Hospital was also participating in the trial and I had spoken to the nurse in charge about it. Every time, I went to the office which was often everyday, I simply had no more left to give to go and find out about the next step. So, I kept putting it off, assuming that I had an indefinite period to sign up.

I had mentioned it to Hollister at the last appointment and I had told him I was too tired to cope with the trial. I asked him if he could just give me the drugs without being on the trial. He said, “Yes. It may not be covered by insurance, but I can treat you off-protocol. I have done so with many patients.”

Results of My Osteogenomic Profile.

I have SNPs on every Gene responsible for bone formation.

Since the Bone is the most common place of breast cancer metastasis, it is critically important to improve their conditions.

Results of my osteogenomic profile.
Contd. Zometa treatment…

I don’t know exactly why they are giving IV Bisphosphonates and according Dr. Moore, they do not know exactly what function it is performing. They only know that it is decreasing recurrence in the breast cancer population.

Breast Cancer Recurrence happens most frequently in the bone. Intuitively this makes sense to me as I could feel my bones being destroyed during the chemotherapy. I would sit in the shower and I could feel the destruction in my bone marrow (and bones) when I was taking the multiple shots of neupegen daily.

I am confused but mostly I am tired and will not think about this now.
JULY 27, 2009: E-MAIL SENT TO GROUP

Category: Radiation, Doctor Shopping, Family & Friends

Hello,

I saw the 3rd radiation oncologist today and after hearing her thoughts, I have made up my mind to go to the radiation oncologist who has a new machine called Tomo Therapy which allows the area to be more accurately targeted. I am pretty sure this decision is final, but I will discuss it with my oncologist, Dr. Hollister on August 10th when I return from Chicago.

I will be radiating both the breast and the lymph nodes.

In theory, I will begin daily radiation the week of August 17 for 7 weeks. I will provide a better update regarding all treatments after meeting with Hollister.

I am feeling much better enough so that I now realize that I have been in shock since March 2nd and am just beginning to understand what is happening and be able to read a little about it. I am grateful to be well enough to travel and look forward to seeing friends and family.

I am grateful for all your thoughts, prayers, calls and look forward to talking soon.

Love, TJ

AUGUST 4, 2009: I GROW HAIR FUZZ BUT MY EYELASHES ALL FALL OUT

Category: Chemotherapy

I lost my last eyelash yesterday. I have 3 eyebrow lashes on the right eye and 2 on the left. The hair on my head has started growing and I have some peachfuzz everywhere except on the side of my head. My Eyebrows are starting to grow back too.

I think I am okay now and must only now get the diet going.

August 10, 2009: I FINALLY CHOOSE A RADIATION DOCTOR
(Written Jan 12, 2010)

Category: Radiation, Doctor Shopping

I come back from Chicago to see Hollister and discuss Radiation. I still have not chosen my radiation doctor and tell his office not to send the paperwork anywhere.

I have my ‘fitting’.

I decide to go with Dr. Fass because it is more precise although it will take so much longer. Unfortunately, because I did not set up the schedule before going to Chicago, I have no time slot.
AUGUST 17, 2009: MY HAIR

Category: Chemotherapy

I was supposed to start radiation today, but they changed it to Wednesday at 6pm… can’t think of a worse time to start as I will miss dinner every day but there it is…

I am obsessed about my hair growth. First, I was obsessed about the loss but now I am obsessed about the growth. I have eyebrows for the first time in my life. Dark, very hairy eyebrows… the body sure is a mysterious thing.

I continue to get better and for the past week have barely been napping. Today I got back to spending a day at a desk doing admin for the first time since the hospital stay….

I am worried about radiation but will learn to meditate….
AUGUST 18, 2009: E-MAIL SENT

Category: Radiation, Doctor Shopping, Family & Friends

Hello. I hope everyone is enjoying the summer. I have certainly appreciated the break that Dr. Hollister gave me. I had a great vacation in Chicago where I went out almost EVERY NIGHT!!! A week later in North of NYC I am FINALLY feeling more like myself for the first time in many months. Instead of dreading radiation, on the contrary, I am ready to get going and put it behind me.

I begin radiation tomorrow at 6pm which will dramatically upset the house schedule. Hopefully the time will change within a few weeks to 9am. I will have radiation Monday through Friday daily for 7 weeks (assuming no complications). I am going to a center less than a ten-minute drive from the house that has a new radiation machine. Treatment with the new machine takes much longer. I will be in the machine for approximately 25 minutes daily instead of 5-7 with the old machine but it will target the precise areas more effectively. All in all, I should be in and out within an hour daily.

The radiation oncologist is Dr. Fass. He was the director of radiation at Greenwich Hospital for 16 years and knows Dr. Hollister well. Dr. Hollister remains ‘in charge’ of my treatment and any complications which may arise.

The link below explains how this treatment is different. From him, I understand that this is the machine of the future and that all hospitals will have this when their multi-year contracts expire. This treatment is not controversial and delivers the same amount of radiation as the old machines.

http://www.instituteigrt.com/

Other treatments

I have started Tamoxifen and will be on it for 3-5 years.

http://www.cancer.gov/cancertopics/factsheet/therapy/tamoxifen

When radiation is complete Dr. Hollister will begin treating me with bisphosphonates directly as I have decided not to participate in the Bisphosphonates trial but simply go to him directly.

http://www.cancer.gov/clinicaltrials/ft-SWOG-S0307

I continue to work with Dr. Veltmann in his research study on methlyating estrogen more efficiently and plan to visit him in New Mexico in October or November depending on how radiation goes. Pray for me that I do not have complications in radiation and that my blood and skin remain strong.

Love,

TJ
Radiation
AUGUST 18, 2009: MY RADIATION BEGINS – HEAD FIRST, FACE DOWN IN A TUBE LIKE AN MRI (Written Jan 11, 2010)

Category: Radiation

I begin radiation. The first time slot I am given in 5:30 so I can not eat dinner with the children. It is a really bad time for the whole family.

I had asked the head technician, if he could be there to give me my first treatment and he was. I lie face down on the slab with pillow/bolsters propping me up, so I am slanted to the left. My left breast hangs into a hole and my arms must hold onto the top of the slab, not the armrest because I am too tall. once I am positioned, the two technicians measure my body tattoos against laser lights that beam across the room.

Then they push and push the slab and the pillows around until I am in the exact same position as I was for the very first scan. Then they cover me up with blankets and the slab slides into the machine.

I go into the machine so they can make sure I am in the right place. This takes approximately 5 minutes according to them. In real people time it takes ten minutes. Once the images are gathered, the slab automatically slides back out of the tube.

I can not move a muscle or the whole thing will have to start again. They machine adjusts itself with very loud clicking to get ready to shoot the radiation beams. They come back in, remove the blanket and make sure the tattoos and lasers have in exact position. They say, “This time for treatment.” Then the slab goes back into the machine for treatment. Treatment is approximately 12 minutes.

If you move at all during this entire process, it must start over again. You must remain completely still. It is very noisy in the machine; similar to an MRI machine but not as loud or as frequent.

Every day, I try to meditate. I become better at it; especially if I have ridden my bicycle to treatment.

The staff is extremely nice and professional. The times I have been given are horrible but they make every effort to change the schedule around so I can come earlier in the day.

I am no longer lying to My Eldest Son. I tell him where I am going daily and the twins too.
AUGUST 19, 2009: MY RADIATION: BLOOD COUNT PLUMMETS EVEN THOUGH IT ISN’T SUPPOSED TO AT ALL & JELLYFISH ON MY LEFT BREAST (Written Jan 11, 2010)

Category: Radiation

We have been experimenting with the different private beaches in Greenwich since we don’t belong to the yacht club this year. That was definitely one of the bigger mistakes made this year based on completely faulty thinking. When we came back from Chicago I called and asked if we could join for only the month of August but were told that it was impossible. The owner extended two weekends worth of passes for us to go to the club before Labor Day. That was very nice of her, but she is very sympathetic because her father is going through cancer treatment too.

So today we go to a new beach in Greenwich which has a swimming pool next to the water. I go for my very first swim of the season following the radiation doctor’s instructions to cover myself completely with a heavy sunblock and to wear a sunshirt over my bathing suit.

I swim all the way out to the rope reveling in the silky feel of the Long Island Sound without jelly fish. I leave the nanny with all the children as usual to disappear for my swim as they shout at me to come back and stay with them. The sun in on my face and I thank God for the opportunity to swim in the ‘sea’ again. I begin swimming towards the other side of the beach and suddenly feel an intense stinging on my left breast, radiated for the very first-time last night. I swim back to shore and go to the bathroom. I rip off my bathing suit and begin soaping my breast in the little public washroom sink with the liquid soap in the metal soap dispenser thanking God that there was soap in it. I soap up, wash off, put more sunscreen on and change my shirt.

Then I call the radiation doctor. Dr. Fass and Dr. Beth are not in. I am transferred to the very young, Indian woman who sits in a windowless office immediately next to the radiation machine. It is wonderful that they have doctors instead of nurses on site. This doctor is helpful because she can write prescriptions but every single time, I speak to her she dispenses instructions that are then contradicted by Dr. Beth a few days later.

I tell Dr. I that my left breast is burning intensely after swimming in the sound. She says she has no idea what that could possibly be.

How can it be that I am stung by a jellyfish on my left nipple a few hours after my first dose of radiation?

The results of my blood test come back the next day.

My white blood count has immediately plummeted. Dr. Fass and his staff are a little unprepared for how sensitive my blood is to treatment. Dr. Beth is really the person who will be taking care of me, but it takes me a few days to figure that out since no one tells you that Dr. Fass does not really work. They leave you to figure that out by yourself.
AUGUST 20, 2009: NIGHTMARES ABOUT THE FIRST TIME I SHOULD HAVE DIED

Category: Friends & Family

Last night, I had the most vivid dream. I almost never remember my dreams and when I do, they are usually very powerful. This was exceptionally powerful as if I was reliving it…at first, I found it profoundly disturbing, but I am thinking about it differently now.

When I was 14 years old, I ran away from home with a new friend. We had perhaps a $100 dollars between us. We skipped school and went downtown to the Greyhound bus station. We bought a ticket to Atlanta because it was warm there. Our plan was to go to California because it was warm there and we could sleep outside in the street.

We took the bus to somewhere before Atlanta. I knew that my father would have had the mafia looking for us and that they would be much faster than the police in finding us, so we got off the bus in the middle of nowhere to avoid the Greyhound bus station in Atlanta. We found a very beat up old car outside a farm house as night time hit. I have no idea if there were people in the house, but the car was open, so we slept in the backseat huddled up together because it was freezing. Now that I am a middle-aged parent, that act alone amazes me with the ferocity of its danger and that was the good part of the trip.

In the morning, we went to the road to hitchhike. I only remember vast fields of wheat. We were picked up immediately by some men who were duck-hunting. We rode in the back of the truck with the gun rack and equipment. The next day the owner of the house overheard us talking about the mafia and he quickly ushered us into his truck and dropped us off scared out of his mind at the nearest truck stop.

From there, we caught a ride with some Mexican truck driver all the way to Arizona where he got caught in a snow storm by the side of the road and then we were all arrested. From there jail and home.

I am staggered by the stupidity and ferocity of the story but most of all by our incredible luck at not dying. I think my dream is about the near escapes from death that I am dreaming about. I should have died back then and perhaps I should die now… but I will not.

I think perhaps my dream is about my resiliency and having a different than expected end to a life path.
AUGUST 28, 2009: HAIR – MY EYEBROWS GROW BACK LIKE A BUSH

Category: Chemotherapy, Family & Friends

I am obsessed with watching my hair grow. I am growing hair where I have never had it… almost as if a life of damage has been reversed or as if the fast-growing cells are now growing at hyper speed. . . .

I have hair growing within the scar at the top of my forehead where I cracked my head open when I was five years old. I think that my entire hairline has changed.

My eyebrows have grown back bushier than they have ever been. Thick black hair where I have never had any has appeared. I looked like a nun within a week and it was so disturbing I mistakenly had them waxed on 5th Avenue last week but then stopped the lady before she could take everything off as I want to see the most famous brow specialist or one of her minions on 79th and Madison next week for a consultation.

I have begun cleaning the house and taking care of things that only I ever do… like cleaning out the children’s toys. My Eldest Son and I cleaned his room last Saturday and it broke my heart to see how neglected he has been. I only looked through his report card envelope 2 months after he got out of school. I threw out all his work from last year after reading several moving stories he had written.

My complete and total absence from this reality for the past 5 months became crystal as I reviewed his work and saw the thick dust on his upper bunk bed where clearly the cleaning lady had not ventured in many months. I was horrified to find my severely asthmatic son living in dust and filth.

The twins started up their special services again and I have had the profoundly disturbing experience of being told how much Tall Twin has regressed over the past few months. I am trying to clean up the playroom enough so that all the exercises that the therapists want us to do could be more easily administered.

My Husband is falling apart. I think that he too is suffering from PTSD relief.

I also downloaded pictures from the digital camera yesterday. The fear and sorrow on my face as I celebrated my birthday, the twin’s birthday was extraordinary. The look on my face as they shaved my head was also terrified with a deep sorrow.

So, I feel that I am coming back… trying to put my house/family back in order before starting on the next phase of my life.

Radiation is a pain. Everyone is very nice, but I feel like I am completely unmonitored. My blood levels dropped, no one cared. No one returns phone calls. No one apologizes about not returning phone calls. Hollister says I am fine.

I am scared about my CA-15-3 levels but now realize I must know what the earlier levels were . . . .
AUGUST 31, 2009: FOLLOW UP APPOINTMENT WITH SURGEON ESTABROOK (Written January 12, 2010)

Category: On-Going Treatment, Lymphedema, Chemotherapy, Family & Friends

I have my first regular follow up appointment with Dr. Estabrook today.

I meet my NOT DEAD YET FRIEND for lunch on 79th and Madison. We sit upstairs because it is too windy and a little chilly to sit outside. He is a bit taken aback by my baldness but of course covers it up completely. He even manages to completely hide his moment of embarrassment because he is a good friend and loves me.

We have the same conversation that we have had for 25 years; about his antics with various women and how despite all the many women surrounding him he is lonely and has not found his love. It is a miracle to be sitting with him as I had given him up for dead when he was kidnapped in Pakistan. I really thought I would never see him again even though I tried to send him energy as much as possible as long as we knew he was alive. I am still in shock that he is alive and take it as another huge miracle and grace from God.

MY NOT DEAD YET FRIEND accompanies me to the ‘best eyebrow salon” in New York. He waits for me at an art exhibit while I get my ‘nunsy” eyebrows shaped and plucked for the second time. It takes about two seconds, but I stop her from doing what she wants to do as I realize that this is a total waste of time and money and I will have to pluck my eyebrows myself because I don’t want to look like a bland movie star.

We take a leisurely walk back to the Guggenheim where my car is parked and then I drop him off at the West Side Highway to run back to Dr. Estabrook’s office.

Dr. Estabrook doesn’t see me in her office. She comes into the examining room where I am waiting in the little robe and says okay let’s get this thing out.

The large cyst in my right breast which Dr. Hollister did not want touched while I was in chemotherapy is ready to be drained; except it is no longer there. She takes what is left out of the right breast and says “There, now you won’t have to worry about that.”

I show her my left breast and explain how the side and the breast swell up with the smallest amount of exercise and how I am not able to get back to any form of regular exercise. She looks quickly and tells me I do not have lymphedema that she doesn’t know why that is happening and tells me I will eventually get back to normal.

Can we quantify that? How? When? I am not wiped out for more physical therapy. I can’t incorporate another several hours of ‘doctors/therapist’ visits into my life.

I tell Dr. Estabrook about my horrific experience with chemotherapy.

She shakes her head and says. “They really don’t know what they are doing with chemotherapy.”

“Why haven’t you had another mammogram, yet? She asks.
Contd. Appointment with surgeon extrabooks

“Because no one told me too.”

“Well you should have had a new baseline mammogram already. You can have it now or after you finish radiation. It is up to you.”

She tells me she will see me in 6 months.

That is all.

Remember: Doctors visits that are a complete waste of time and money are the best kind. This was not but I hope it will soon be.
SEPTEMBER 10, 2009: SUSPECT MAMMOGRAM/SCAN TEST/ HOLLISTER

Category: Diagnosis, On-Going Treatment

I have a mammogram scheduled at Greenwich Hospital and then an appointment with Dr. Hollister. I keep forgetting to ask someone to keep me company on these visits because I can not seem to get it through my head how important they are. I keep approaching them as if they were just another errand, just another nuisance check-up. Then I am slammed with extremely stressful information and I am not prepared, and I am alone… and yet I keep doing it?

The mammogram is not clear. The radiologist wants to see an ultrasound of the right nipple. My heart seizes up.

I go from the squeeze the breast room and wait with the other women who have been left in their gowns just in case there is a problem. Some of the women come out of their rooms with their clothes on. Some of the women come back here to wait. Everyone avoids looking at me because I am their worst nightmare. I am bald and pacing and anxious. Glances are fast steadily avoided. I think of the scene in the movie with Jack Nicolson and Diane Keaton with the “Dancing Henrys” There really should be more humor in hospitals.

I go to the ultrasound room. The technician is having trouble with the machine and it will not set up to take images. I lay there for an eternity… at least 8-10 minutes thinking

“The aborted treatment didn’t work and now the cancer is back in the right breast.

They (the surgeons) all said that if you have cancer in more than 1 quadrant, the breast must come off. If it’s come back in my right breast, where else is it? These abnormalities are just part of having chemical menopause just like the other cyst, right? I text Al… ”Mammogram abnormal”.

BUT WHAT IF IT IS BACK!”

I can’t calm down. I get up from the table and walk into the hallway. At that just that moment, the radiologist, the one from last time who told me about the large cyst in my right breast that Dr. Estabrook had just drained was rob ably from chemical menopause, comes by and ask what is going on?

“The machine won’t record images so she can’t do the test.”

She seems annoyed and comes into the room and tells the woman that she will look at me without a recording. She takes the control stick away from her. I lie down again in relief and look at the screen and her face at the same time.

The radiologist explains that I now have several cysts under my right nipple as well as throughout my right breast. “But they are nothing to worry about. They are not remarkable in any way.”
Contd. Suspect mammogram…

“So, when do I follow up?”

“You follow up as regularly…6 months from now.”

“Thank you.”

I breathe a sigh of relief, but I am so worked up I can’t calm down immediately. So, I pass the first mammogram test but not with flying colors. I breathe and breathe.

“You have been given a reprieve. You are not dead. The death sentence is not changing. You must trust the tests…but how?”

I am in the uncomfortable position of having to trust the exact same profession that gave me cancer in the first place… the doctors. It is difficult to relax.
My Husband’s Birthday
Weekend Agenda

Friday 11 September 2009

12pm US Open

Afterward dinner with [male]

9pm Charles’ arrives LGA AA 1876

Depart to Thompson, CT straight from LGA

Saturday 12 September 2009

9am Nascar Racing, Thompson, CT

Lunch with Charles

Return Home to Nap

7pm Dinner at Copacabana with Friends

Sunday 13 September 2009

11:15 Boarder Surf School Lesson, Rockaway Beach
(Wife and children will be touring beach clubs)

1-718-496-3371 192 Beach (92nd Street) but lessons will take place at 67th Street

Evening Charles Departure
SEPTEMBER 14, 2009: MY ‘TUMOR MARKERS’ ARE FINE

Category: Diagnosis, On-Going Treatment

Messages on my home and cell phone that say…” You blood results came back and your TUMOR MARKERS are fine.” Mark a new stage in my life. I assume that if they call you and say please call us back or even worse, Dr. Hollister wants to see you…your tumor markers are NOT okay?

Tried to have My Husband’s birthday extravaganza this weekend.

The US Open was cancelled due to rain. The Nascar racing was cancelled due to rain and on Sunday when we were on our way to his surfing lesson, I felt like I was going to pass out. I told him I didn’t feel good and I thought I should stay home. Everyone was in the car and only waiting for me to enter.

He cancelled the trip and we went to his least favorite spot instead. North of NYC Beach.

SEPTEMBER 15, 2009: MY SUSPECT MAMMOGRAM
(Written January 12, 2010)

Category: Diagnosis, On-Going Treatment

A few days later I get a letter in the mail. “You have had an abnormal mammogram. You MOST PROBABLY do not have cancer, but we cannot be sure. Love, Greenwich Hospital.”

I send the letter to Dr. Estabrook’s office and ask them if they have looked at the mammogram films yet. Nicole, Dr. Estabrook’s, incredibly competent nurse assistant, who I dismissed because she was too beautiful and thin, tells me not to worry.

“Nicole, does everybody have cysts all over their mammograms?”

“No.”

“Then why am I not supposed to worry”

“Because short of biopsying every single cyst in your breasts, we must relay on the shape of them to decide what is potentially cancerous or not.”

They took biopsies of my lymph nodes from all over the place. The lymph node test, from multiple places, proved negative. That is why Dr. Estabrook was so surprised when she found the cancer had already spread to all 4 of my sentinel nodes. The biopsy was negative, but it was wrong.

So, I continue to worry, and I must learn to live with this cycle of testing, results and worrying. But I have not.
SEPTEMBER 24, 2009: HOLLISTER

Category: Radiation, On-Going Treatment

I see Hollister for radiation checkup because Dr. Fass calls Dr. Hollister too much. Every single time I have a question for Dr. Fass, he must call Hollister. The blood results which determine whether I am to abort treatment take too long at Westchester Medical and I have had to start going to Hollister's office to have blood drawn. I am on Zithromax for a closed throat still. Most of the month I have been on Zithromax.

I am starting to break into more severe hives and the itching is becoming unbearable. I use ice all the time, but I think I have passed the point of

Hollister tells me I am in fine shape.

I really would like to attend the In the Pink Support Group, but it doesn’t start until 7:30pm and is all the way in Valhalla (30 minutes away). I go to bed.

SEPTEMBER 28, 2009: HIVES & RADIATION
(Written Jan 11, 2010)

Category: Radiation

The hives on my breast are unbearable. When I get to the office, I ask to see Dr. Beth. I intend to tell her that I am aborting treatment and will not have my treatment today or tomorrow, but she is busy. I decide not to give up my time and wind up waiting there all morning, so I go to be radiated. It is my 27th day.

I show Dr. Beth the hives and she calls Dr. Hollister. They decide I will not have the 28th treatment and will try to stay off steroid shots. I am living on benedryl.
SEPTEMBER 29, 2009: RADIATION IS COMPLETE
(Written Jan 12, 2010)

Category: Radiation,

Hip Hip Hooray. Radiation is over and the ‘emergency’ part of the cancer treatment is concluded. I bring some cookies to the radiation technologists to wish them well. I write the head technician a little note because he is the most professional person, I have met in my cancer adventure. I am grateful to them for their kindness and I hope never to see them again for as long as I live.

My Husband has taken the day off to help me celebrate. We are biking down the Hudson River bringing our lunch from Amir’s at 114th and Broadway with us. Unfortunately, it is very cold and windy but most of the time not raining.

We go up to Harlem first to see the new (new to us) pathway. We eat our lunch up there and then bike down to around 50th street. There is a new café in the 60’s with a nice menu and a beautiful seating area but by the time we discover this I am already full and tired. I am too tired to go on and we turn around.

Dad calls when we hit the low 60s and thanks My Husband for taking care of me.

I am grateful to be able to go biking down the Hudson. I am so glad to be alive and using my legs.

SEPTEMBER 29, 2009: E-MAIL SENT TO LARGE GROUP

Category: Radiation, Family & Friends

Hip Hip Hooray!! Today was my last radiation treatment. I did not make it the full 28 treatments of radiation but today was released from treatment after 27 treatments due to some minor complications.

After the surgeries, chemo and radiation, the cancer is in remission. In theory, I have flipped my recurrence numbers from 70%/30% to 30%/70%.

Hopefully every test, exam and etc will always be negative from here on.

I get to rest for a month and then will start the bone treatments (which are supposed to make you sick for a week or so) and then will be monitored quarterly (with lots of tests) for the next 5 years.

After the 1st bone treatment, my intention is to put my life back together in an orderly fashion, go back to work, take some trips and enjoy my family and friends.

Thank you for sticking with me every step of the way with thoughts, prayers and news. Keep your news coming.

Love, TJ
OCTOBER 4, 2009: BLOCK PARTY – BREAST CANCER IS EVERYWHERE

Category: Family & Friends

Our block party is in the late afternoon. I meet one of my neighbors and she tells me about her mother’s breast cancer recurrence. Her mother is refusing treatment and relies only on alternative methods and diet.

Breast Cancer is everywhere I go now.

OCTOBER 5, 2009: E-MAIL SENT TO LOCAL FRIENDS

Dear Friends,

Please join us in celebrating the completion of my Chemotherapy and Radiation by joining us for a Potluck BBQ at home on Sunday, October 11, from 12 to 4.

If you have plans with other people, please bring them along. If you are busy but in the neighborhood, please stop by for a few moments.

Please contact Gretchen who is cc’ed on this e-mail to co-ordinate the Potluck items such as appetizers, fruit & deserts.

We look forward to seeing you. TJ, and Men.
OCTOBER 9, 2009: ONE WEEK POST RADIATION & IN THE PINK GALA

Category: Family & Friends

I finished radiation a week ago released one day early in the hope that the itching would subside, and I wouldn’t have to take steroids… but it is 10 days later and last night I had to take steroids again for the crazy itching. The burn on my skin and the pustules are turning into hives. Dr. Iacobellis doesn’t care if I must take steroids but my white blood count is still low, and I don’t want it to go way down again.

My Husband and I went to the In the Pink Gala last Friday. It was amazing. I only made it until 10pm but My Husband stayed until the end. He was very moved as was I. That was probably the most intimate conversations I have ever had with total strangers in such a short period of time.

My mother has been here for weeks. That has been a huge relief, but she is going stir crazy and it is time for her to go.

We are having a big party on Sunday to celebrate… once again I am having parties all the time but I don’t care if people reciprocate… I am happy just to be myself again which was totally confirmed today by being in Home Depot spending $500 dollars on stuff to fix up the house… nothing like a trip to Home Depot to commemorate a return to normalcy.

OCTOBER 12, 2009: POST-TREATMENT PARTY

Category: Family & Friends

Had a large BBQ party yesterday. It went very well although maybe 2/3 of the people invited did not show…. trying to celebrate with anyone at all that has expressed concern. Having cancer is like it being your wedding day everyday. You remember everyone who came, who didn’t show, what flimsy excuse they gave, who did what, who asked questions.

It is living in a heightened state. Not just for the party but all the time.

My Husband seemed to have a good time.
Long Term Treatment
OCTOBER 13, 2009: DR. WARSHOWSKY, INTEGRATIVE GYNECOLOGIST AND THE FIRST DOCTOR COMPLETELY FAMILIAR WITH GENETIC SNPS

I am SOO RELIEVED to have met a Dr. Allan Warshowsky who is an integrative gynecologist. He is very familiar with Dr. Veltmann’s type of work and perhaps even knows the field better?

I will see an integrative oncologist next week.

Dr. Warshowsky said that he will be monitoring the entire cancer project. I feel a huge burden lift off of me. He is very familiar with the genetic testing that Joe does (but not Joe himself) and promises to work closely with Joe.

He will be monitoring my vagina and uterus to make sure that the Tamoxifen does not wind up resulting in uterine cancer. We spend a long time talking about bone density and Zometa. He is, like Veltmann’s initial reaction, horrified that I would be taking Zometa. He explains that “ONJ is when your jaw bone disintegrates. There are quality of life issues to consider when approaching your next phase of cancer treatment. He is not trying to scare me but is clearly shocked at this use of Zometa. I explain the clinical trial and promise to send it to him.

He recommends his colleague, Dr. Mitch Gaynor, to discuss the Zometa.

I e-mail Drs Veltmann and Warshowsky to introduce them to each other and must make sure they are communicating.

I arrange to see Gaynor.

I send Dr. Warshowsky and Veltmann a briefing of my meeting with Dr. Warshowsky and the new supplements that he recommends for the cysts in my breast (Iodine) and a few others he likes in general like CoQ10 and Lipoic Acid.
OCTOBER 19, 2009: DR. HOLLISTER & ZOMETA: DECLINING TREATMENT

Category: On-Going Treatment, Zometa Study

My Husband and I go to see Hollister together.

I am scheduled to take my first dose of Zometa by IV today, but I have so many misgivings I ask to see Hollister instead of taking the treatment.

I see Hollister who says it is no problem to have only 27 treatments instead of 28.

I go through my list of minor grievances as usual including the letter from Greenwich Hospital telling me I MOST PROBABLY do not have cancer.

He says, “Can’t you tell a letter from a lawyer’s office by now. The hospital must cover their ass because you did not have a perfectly normal mammogram.” He is annoyed but with the state of modern medicine I believe not me.

I tell him we must have a long discussion about Zometa. He groans in mock despair.

“I am afraid to take Zometa based on my reaction to chemotherapy. But on the other hand, I am VERY uncomfortable refusing treatment. I have seen other people who refuse treatment and I think they are insane. But I am too afraid of possible ONJ and if regular people who sail through chemotherapy have a week worth of fever and a bad flu-like symptoms what could happen to me?”

Hollister says, “Just because you became ill from the AC/T treatment does not have any relation to whether or not you will have a bad reaction to the Zometa. This is still in clinical trial. I saw how sick you became, and I am not forcing you to take it. I think it is up to you as it is still not standard protocol.”

“Can’t I take something less strong? Can’t I take the other drugs?”

“Of course, you can.”

He calls in the clinical trial nurse from her office. She explains the dosing of the other 2 protocols.

He says.” I don’t feel comfortable giving you those. I am comfortable giving you Zometa ‘off-protocol’ because I give it to other people for bone cancer. It is, as far as I am concerned, a cancer drug. “The other drugs have not been shown to be effective whereas Zometa has provided interesting data in follow-up. I am willing to give you regular doses of Boniva.”

“But I don’t want to refuse what is best.”

“What is best is Zometa, but I will not insist you take it based on your history. Are you taking your Tamoxifen?”

“Yes.”
Contd. Dr. Holister & Zometa…

“Go see your dentist and see what they have to say about your taking Tamoxifen.”

Although Dr. Hollister is relaxed and comforting, I am very anxious about the fact that I am walking out of his office having not had my scheduled treatment even though I have his full approval.

I already missed the 3 Taxol’s and now I am missing what is ‘becoming standard protocol’ according to Moore and Hollister. I have met other women on the breast cancer walk and through the in the Pink Foundation and they are all taking Zometa or are in the trial. It feels very uncomfortable to be taking a different path and be ‘off the bell curve’.

I call my dentist, Dr. Minoli to discuss Zometa. He knows all about it and the Osteocronosis of the Jaw.

We schedule a cleaning.
OCTOBER 22, 2009: DR. GAYNOR, INTEGRATIVE ONCOLOGIST & ZOMETA: HAVE YOU CONSIDERED GETTING A HYSTERECTOMY?
THE SUPPLEMENTS DOUBLE

Category: On-Going Treatment, Hysterectomy, Zometa Study

My Husband and I meet with the integrative oncologist recommended by Dr. Warshowsky.

Dr. Gaynor’s office is the ground floor of a brown stone on the Upper East Side near the NY Hospital (Weill-Cornell) complex. His office has Indian meditation music piped through the entire area. There is information about the hospital in rural India (or Sri Lanka) where he works and a lot of information about Tibetan Singing Bowls. He runs a group of chanting meditation and there are pictures of the crystal made in water by the sounds of the bowls. The look like snowflakes.

It seems to me that he has incorporated vibrational medicine into his practice.

Dr. Gaynor has a very seductive southern accent. He exudes relaxation which is an odd trait from an oncologist.

He reviews my entire file and seems to know about the genetic work that Dr. Veltmann has done. I tell him I am there to receive guidance about the next stage of cancer treatment; particularly the use of Zometa for 3 years. I tell him about how Hollister wants me to stop taking the Calcitonin in order to take Zometa.

“Would you have stopped treatment after I was hospitalized?”

“I give Taxol in weekly increments over 12 weeks. That is how I would have proceeded. I would also have given you a bone marrow test to figure out why your white cell count was not recovering with each treatment.”

“How do you do that?”

“You biopsy the spine.”

“How could you have done that when I was as compromised as I was?”

“I like to obtain as much information as I possibly can while I am treating a patient. I don’t like working in the dark.”

We go to the examining room and he treats My Husband and I to a meditation tape and a vibrational machine which replicates the sound of the voice onto the heart as if the person who has it on him were chanting himself. It is a high-tech way of chanting without doing the chanting yourself.

On my way back to his office, I notice that everyone in his infusion room is either sleeping or in a state of deep meditation. Interesting.

The first thing he says is. “Has anyone talked to you about taking out your ovaries?”
“No. Everyone has said that if my menstrual cycle ever returns, we would look at ovarian suppression.”

“Okay. We’ll we can talk about it next time I see you. “

He reviews Dr. Veltmann’s supplements and proclaims, “This is a good list.”

I tell him about the study. He listens politely but doesn’t seem overly interested. He hands me a document several pages long which contains the supplements that he frequently prescribes. He has underlined at least a dozen MORE items that he wants me to take in addition to Joe’s regime.

He tells me we must rebuild my immune system and that he will see me in a month and that is enough time to take to make a decision about Zometa and that I must get moving. He asks me to see my dentist.

I ask him about the Calcitonin and he says, “The only person I know who can answer that question is Andrew Martorella, an endocrinologist who does bone work. Go see him.”

I am overwhelmed by the number of items he suggests I add to my regime.

Shitake Mushrooms
Rice Bran
Krill Oil
Betaglucan
Alpha GPC
NADH
Rhodiola
Royal Bee
Pro-Biotics
Pomegranate
A fiber,
A green formula,
A red formula,
Cacao and
Fermented Wheat germ.

His list essentially suggests that doubles the amount of stuff I am taking.
OCTOBER 23, 2009: DR. MINOLI – THE DENTIST & ZOMETA

Category: On-Going Treatment, Zometa Study

I go for my cleaning. As I was so very often not brushing my teeth during chemotherapy, I can’t believe I don’t have more cavities. Dr. Minoli and I discuss Zometa. He explains that the half life of the drug is at least 20 years and that it stays in your system for a very long time. He also explains that there is risk with all of the bisphosphonates although Zometa is the strongest and the one with the most side effects. He says that he only has experience with older patients taking Zometa and he recommends that I see his colleague Dr. Tunick the oral surgeon to discuss the root canals that I had the year prior.

He tells me that he doesn’t think I will have to take out my wisdom teeth as they are in perfect condition.

OCTOBER 23, 2009: I RECEIVE GUIDANCE FROM HEAVEN & ZOMETA

Category: On-Going Treatment, Zometa Study

Dear Cancer Diary,

I asked God for guidance and then I received it in the form on an e-mail from my former Uncle John about the Zolmerta treatment.

I met yesterday an integrative oncologist, Mitch Gaynor, who had me meditate in his office and suggested both a ton of supplements and very aggressive medical treatment.

I have also been talking to a My Cancer Friend, a new friend whom I met through a colleague of My Husband’s work. That is helpful as she is the only other person I know taking the same path as I.

And I face myself as they have been, I have been remote and absent like my father, remote and over-nurturing like my mother…

How to move beyond?

I don’t think I wrote about how incredibly relieved I was to meet Alan Warshowsky, an integrative gynecologist who took the time to read through Veltmann’s work, the cancer work, asked a lot of questions, referred me to Gaynor….

For the first time, I felt I would not have to oversee everything alone…in fact there is a great network of help all around me.
OCTOBER 26, 2009: DR. MARTORELLA – THE ENDOCRINOLOST & ZOMETA

Category: On-Going Treatment, Zometa Study, Side Effect: Hypothyroid,

I go to Dr. Hollister’s office for a Flu Shot.

Then I must go to Labcorp to have blood work for Dr. Gaynor.

I then to go to Manhattan see the endocrinologist. There is a sign on the gate of the building that this is a part of Memorial Sloan Kettering’s Long Term Care. That is comforting and bizarre all at the same time. My Husband is supposed to meet me there, but he does not. He does not call or text. He completely forgets the appointment. He has been so steadfast, so involved, so concerned about every single appointment; I think he must be completely falling apart.

Dr. Martorella is a young and gentlemanly man. I tell him my story, but I hesitate because I am not sure how much he needs to know in order to answer the question about Calcitonin and Zometa. I give him my list of supplements.

He explains the history of Zometa. “When we first started giving out Zometa, the recommended doses were too high so the proportion of people getting Osteocronosis of the Jaw was high over time. We then figured out that the dosing was too high and dramatically reduced the recommended dose. Furthermore, we monitor the recovery of bone building function before prescribing another dose. He tells me that I will take the “NTX” test today and then after Zometa is administered, I will take again 6 months later to see if my bone making function has recovered.

He explains that this is an old drug and that it is well known but only recently has been used for breast cancer. He also explains that the population that has been using it has tended to be older, so they don’t have great statistics on its use in a younger population.

He clearly knows more than anyone about this drug than anyone I will meet in this city and much more than the oncologists.

He is relaxed and friendly. Tells me not to worry about taking it as he will correspond with all the physicians regarding my bone function. He says that I can continue the use of Calcitonin, but it won’t make any difference because Zometa is so strong it will nullify any effect of Calcitonin, but it won’t add to toxicity.

We agree that he will write everyone and will continue to monitor me for the next few years.

I feel relieved to have met him.
OCTOBER 27, 2009: ZOMETA ANXIETY

Category: On-Going Treatment, Zometa Study

I talk to My Cancer Friend about Dr. Gaynor. I am so relieved to have met him and Dr. Martorella. I am relieved to talk to her because she is the only person, besides My Husband, who understands my treatment and state of my mind. I tell her how worried I was about ‘refusing treatment’ even though Hollister wanted me to visit the dentist and that he wasn’t worried about the Zometa in the least that I have been very anxious about being ‘behind schedule’ in my cancer treatment.

She is nervous because she isn’t doing any post-surgical treatment, except for working with Dr. Veltmann, either. I tell her how great Dr. Gaynor was, but she already knew about him. She is really on the ball and now my only form of cancer camaraderie.

NOVEMBER 2, 2009: Dr. TUNICK – ORAL SURGEON & ZOMETA

Category: On-Going Treatment, Zometa Study

I see Dr. Tunick, the oral surgeon, who is like a brother to my dentist, Dr. Minoli. A friend comes along to keep me company. The nurse takes a circular x-ray and then we go into a dental room. He is a very warm and friendly man. He seems a bit ill at ease initially but then warms up.

I tell him that Dr. Minoli was worried about one of the root canals that I had the prior year. He says, “That root canal is not a problem at all, but these wisdom teeth have to come out before you can have Zometa. The half life of Zometa in the body is at least 20 years. Each of your wisdom teeth already have deep cavities in them so if anything, else happens to them, even a filling needed to be replaced we would have to pull them at that time. The odds of your wisdom teeth being in fine shape for the next 20 years or so are not great, so they must come out.”

He is a surgeon at Memorial Sloan-Kettering, so he is dealing a lot with Zometa-induced ONJ. He says that the incidence is rob ably around 20% for Zometa users and no where near the 1% they mentioned in the breast cancer clinical trial. He says that there is absolutely no way to predict who will get it and that there are 3 different stages of ONJ all of which are currently lumped together.

Stage 1) the gum recedes, and the bone is exposed
Stage 2) More of the above but much more severe
Stage 3) the jaw ‘falls apart’ requiring it to be pieced back to together

He tells me that even though these are the risks there is no question that I should take Zometa if they have found that it acts like a chemotheraphy agent. I must follow the advice of my oncologist. He very politely and diplomatically says that Cancer trumps not having a jaw.

I feel nauseous and keep looking at my friend who seems completely calm and nonplussed. I am really taken aback that I must have all my wisdom teeth pulled and sink into the dental chair. I feel completely exhausted.
Dr. Tunick forces me to listen to the risks of having my wisdom teeth pulled. I don’t hear a word he says. His office is very uncomfortable. There is a construction crew on a dolly outside the window working on the building next door. The windows of his building are the very very old ones and don’t seem to close completely. I can’t concentrate and feel one of the now very infrequent migraines that I have coming on. The hot and cold flashes continue.

He tells me that if I wasn’t going to take Zometa it would be crazy to take out my wisdom teeth as they are in perfect condition.

I ask if I can go to a conference 4 days after the surgery. He says he thinks I should be fine by then. Only the first 2-3 days will be bad.

I finally get out of the chair and we schedule a surgical date for exactly a week later. I like to have surgery on Mondays so that I have the whole week to recover if I need it while the Nanny is there.

We go for lunch at the Time-Warner building. She tells me that, “Having your wisdom teeth out is absolutely no big deal at all.” I tell her that I don’t trust the opinion of someone who gave birth vaginally to twins at the age of 41. I am glad she is there. It really really helps to have someone else at these appointments.

The relief that I had told My Cancer Friend about only a few days earlier is gone.
NOVEMBER 3, 2009: Dr. FORCELLA, PERIODONTIST & ZOMETA

Category: On-Going Treatment, Zometa Study

My Uncle J told me to see both an oral surgeon and a periodontist in order to assess the state of my mouth before taking Zometa, so I go to Dr. Minoli’s favorite periodontist. I have learned the very hard way that a doctor’s visit that is a complete waste of time and money is the best kind of doctor’s visit to have.

Dr. Forcella examines me and says, “Are you here for a second opinion? Because if you are asking me if you should have your wisdom teeth extracted before taking Zometa the answer is yes. I have not had much experience with Zometa, but I just had a patient here with ONJ who was taking Zometa and is currently on Tamoxifen. It was not a good sight.”

He says that he thinks that compromised immune systems seem to have something to do with the onset of ONJ and that the administration of Zometa prophylactically to younger women is not something there is a lot of data on as most of the people taking it so far have been older.

He says that it is not just about Zometa but that all bisphosphonates are problematic from the dental perspective but that is irrelevant when considering a cancer diagnosis.

He tells me that if I wasn’t going to take Zometa it would be crazy to take out my wisdom teeth as they are in perfect condition.
NOVEMBER 9, 2009: MY WISDOM TEETH EXTRACTION FOR ZOMETA

Category: On-Going Treatment, Zometa Study

My Husband takes me to Dr. Tunick’s office. Beth is to meet us there and then she will drive me home while he goes back to work. Al comes into the room where the workers continue to work on scaffolding right outside and freaks out. He tries to get the nurse to close the 100-year-old window and starts telling her, “This place is dirty. What are you going to do about it?”

I am having a cold flash and ask her for blankets. I have more cold and hot flashes when I am tired and when I am nervous. I can almost use them as an indicator of whether I should be in bed. But I am not in bed; I am having another surgical procedure and extracting my perfectly good wisdom teeth to prepare for a cancer treatment that I have not completely decided to go ahead. I remind My Husband that we are in Manhattan and tell him next time I have a terminal illness we will have to move to a clean city.

Dr. Tunick administers the anesthesia IV himself. For the very first time in all these many treatments and blood tests, he gives me a tiny prick of anesthesia into my hand so that they place where he will put the IV is numb before he puts it in. I asked him about it, and he tells me he demanded it for his own recent surgery and his wife’s treatments. He says, “I can’t believe something so simple for helping people through what is an unpleasant process is never used. It just boggles my mind.” He then mercifully knocks me out.

When I awake, I am told the surgery is difficult for all 4 teeth because they were fused to my jaw bone. I don’t know what this means but he seems to think I will have more pain than I might have had. This is common for older people because wisdom teeth are usually removed in teenagers.

We walk to my friend’s car and she takes me home. I am bleeding and bleeding through the cotton ball bandages that they gave me. I try to talk. It is funny.

I go to bed for most of the rest of the day.

NOVEMBER 13, 2009: INTEGRATIVE ONCOLOGY CONFERENCE

Category: On-Going Treatment, Friends & Family

Today I go to my 2nd day of the Integrative Oncology Conference. Yesterday was profoundly moving due to the lunchtime speaker, the author of “AntiCancer”, David Servan-Schreiber, www.anticancerbook.com

Today I wear my breast cancer head scarf around my neck over my white t-shirt as I have always done…it is finally where it belongs.

For the past two days I have gotten up early to get ready for the conference and do chi-gung. I did not do chi-gung, but I met my children again for the first time since diagnosis like I used to…. It is also profoundly moving to see them when they get up.
Dear All,

Hello. So much has happened in the past week 10 days it is difficult to summarize but I will try.

I had my 4 wisdom teeth out last Monday. All 4 were fused to my jaw bone and the surgeon said it was a difficult surgery. I am feeling much better now after having some migraine days from the anesthesia and pain killers. There is some dispute among the various doctors about when it would be okay to administer the Zometa. The difference ranging from 3 weeks to 3 months so I am still unsure when/if I will receive the drug.

I received the results of several blood and urine tests today and reviewed with Dr. Warshowsky, the integrative gynecologist who is overseeing everything from now on.

My blood is still very compromised not only in white blood cell counts but in ‘lymphocytes’/natural killer cells, I have the worst kind of yeast and fungus (presumably from the months and months on oral and IV antibiotics and my blood continues in its DNA pathway destruction. I am also still not ‘methylating’estrogen properly.

Dr. Warshowsky and Veltmann reviewed the new plan together to address these deficits. I will see Dr. Veltmann in Miami on Nov 30th.

I briefly attended an integrative oncology conference last week which was fascinating, but I have so much information to integrate I don’t know when I will begin.

I am very pleased that I have found doctors who will oversee and monitor the cancer in a much more aggressive way than leaving me to fate. Hopefully, I can turn my immune system around and have my blood recover normal function asap.

Love, TJ
NOVEMBER 18, 2009: SUPPLEMENT SCHEDULE

Category: On-Going Treatment, Exhaustion, Estrogen Health

My supplement schedule seems is excessive administratively, financially and I am sure internally.

<table>
<thead>
<tr>
<th>Supplement</th>
<th>Quantity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPA/DHA (Omega3)</td>
<td>3 630mg</td>
<td>1890mg, Suppresses IL-1B, Modulates IL-13, SOD2</td>
</tr>
<tr>
<td>Milk Thistle</td>
<td>2 200mg</td>
<td>400mg, Suppresses IL-1B, SOD2, GSTP1, GSTM1</td>
</tr>
<tr>
<td>St John's Wort (Phytosterol)</td>
<td>1 300mg</td>
<td>300mg, Suppresses IL-6</td>
</tr>
<tr>
<td>Curcumin (Tumeric)</td>
<td>2 300mg</td>
<td>600mg, Suppresses IL-1B, Modulates IL-10, SOD2</td>
</tr>
<tr>
<td>Quercitin</td>
<td>2 333mg</td>
<td>666mg, Modulates IL-13, NAT2</td>
</tr>
<tr>
<td>N-acetyl-cysteine</td>
<td>2 600mg</td>
<td>1200mg, GSTM1, GSTP1, SOD2</td>
</tr>
<tr>
<td>DIM-Pro</td>
<td>2 75mg</td>
<td>150mg, Uregulates CYP1A1</td>
</tr>
<tr>
<td>DHEA</td>
<td>1 300mg</td>
<td>0, Down regulates CYP1B1</td>
</tr>
<tr>
<td>SAM-E</td>
<td>2 200mg</td>
<td>400mg, COMT catalyst, decreases flight/flight response</td>
</tr>
<tr>
<td>Methylecyclohexane</td>
<td></td>
<td>Homocysteine</td>
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<tr>
<td>Nattokinase</td>
<td>1 1000FU</td>
<td>50mg</td>
</tr>
<tr>
<td>B-Complex</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>B-12 (Folic Acid+B12)</td>
<td>1 400mg</td>
<td>FA 1000mg B12</td>
</tr>
<tr>
<td>Actifolate (FA +L-5methy)</td>
<td>2 800mg</td>
<td>1600mg, Bones</td>
</tr>
<tr>
<td>Cal-Apatite/MCHC (Vit D)</td>
<td>2 600IU</td>
<td>816mg Calcium 357mg Phosphorus 3036mg MCHC</td>
</tr>
<tr>
<td>Nutri E</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Ester C</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Resveratrol</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Iodine compound</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protein Shake</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>ADP (Garlic)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamin D</td>
<td>1 week</td>
<td>50.000mg, 2000mg daLow Levels of D</td>
</tr>
<tr>
<td>Vitamin K/D</td>
<td>2 drops</td>
<td>100/2000, Low Levels of D</td>
</tr>
<tr>
<td>Melatonin</td>
<td>1 3mg</td>
<td>as needed Sleep</td>
</tr>
<tr>
<td>UltraDophilus</td>
<td>2 1/2 tsp</td>
<td>30 billion Intestine</td>
</tr>
<tr>
<td>UltraBifidus</td>
<td>2 1/2 tsp</td>
<td>30 billion Intestine</td>
</tr>
<tr>
<td>Saccharomyces boulardi</td>
<td></td>
<td>Restore gut microflora</td>
</tr>
<tr>
<td>Isoflavones</td>
<td>2 as needed</td>
<td>Hot flashes</td>
</tr>
<tr>
<td>Tree Lignans</td>
<td>2 as needed</td>
<td>Hot flashes</td>
</tr>
<tr>
<td>Astralagus</td>
<td>2 as needed</td>
<td>1000mg Immune System</td>
</tr>
<tr>
<td>Echinacea</td>
<td>2 as needed</td>
<td>1600mg Immune System</td>
</tr>
<tr>
<td>Elderberry</td>
<td>2 as needed</td>
<td>350mg Immune System</td>
</tr>
<tr>
<td>Others Prescribed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GABA</td>
<td>4 3000mg</td>
<td>Klonopin replacement</td>
</tr>
<tr>
<td>Calcium/Mag</td>
<td>2</td>
<td>Bone Loss</td>
</tr>
<tr>
<td>Magnesium</td>
<td>4</td>
<td>Heart PVC's/Magnesium</td>
</tr>
<tr>
<td>Adrenal Support</td>
<td></td>
<td>See next Sheet for components</td>
</tr>
<tr>
<td>Ligaplex</td>
<td>as needed</td>
<td>Neuropathy in Legs from Back</td>
</tr>
<tr>
<td>Vitamin A</td>
<td>1 25000mg</td>
<td>Cancer</td>
</tr>
<tr>
<td>Selenium</td>
<td>1 200mg</td>
<td></td>
</tr>
</tbody>
</table>
When I complain about this list, I am told by all the various doctors that there is nothing that can be taken off. Either that or they tell me to stop taking Dr. Gaynor’s supplements because they are redundant to the others.

No one has a solution for this list, and I am too frightened to decide on my own which items are not important. It is clear that I must decide who I trust the most and that I must begin to do my own research.
NOVEMBER 22, 2009: SWOLLEN CHEEK, SOFT TISSUE INFECTION & TOO TIRED FOR FAMILY LIFE

Category: On-Going Treatment, Exhaustion, Zometa Study, Family & Friends

Every weekend, it is the same thing. I spend much of the weekend wondering how I can stand to spend another minute with my husband around the children.

I spend much of my weekend contemplating separation, but I see no way out.

I hope that my cancer doesn’t come back because of this horrible thinking.

I think I should go see a lawyer. It can’t be good for me to live like this and except for the period of chemotherapy it has been like this for years and years and years.

Every weekend, the behavior is erratic, sometimes violent, sometimes wonderful, changing from minute to minute, depending on the meal, the exercise, whether he has been eating crap all week or not…most of the time he considers the children a huge burden and then his mood changes and he is all loving and wonderful with them.

It is much worse than anyone in my extended family because their moods are stable for at least a whole day. My Husband changes from hour to hour mostly depending on I believe his blood sugar level.

Maybe it is more like living with my Uncle A…violent and loving.

Maybe he is a diabetic. He certainly behaves like one.

What should I do?

My cheek has started to swell up and it really hurts but I don’t page the doctor. I am tired of emergencies.
NOVEMBER 23, 2009: SOFT TISSUE INFECTION

Category: On-Going Treatment, Zometa Study

I call Dr. Tunick’s office first thing in the morning but he can not see me until tomorrow morning. They tell me to go see my dentist. I arrange to see Dr. Minoli’s colleague in the NYC office.

I meet his Indian colleague who also works at Memorial Sloan-Kettering. He has already been briefed on my story from Dr. Tunick’s office. He tells me I have a soft tissue infection and prescribes an antibiotic.

He tells me that in his experience ONJ amongst Zometa users is closer to 50% at Sloan. He says this is a bad sample because the patients at Sloan tend to be ‘sicker’ than at other institutions as it is kind of an ‘end of the road’ place but he says it is laughable to think that the risk is 1% as they say in the clinical trial information.
NOVEMBER 24, 2009: DR. TUNICK PUTS A DRAIN IN MY JAW

Category: On-Going Treatment, Zometa Study, Exhaustion

I go to see Dr. Tunick. I assume that this is a waste of time visit because I am already on antibiotics. I am tired and very annoyed that I must drive to Manhattan to see him when I should be in bed resting but I must, so I go. I park at a one-hour space several blocks away because I know this is going to be a quick visit.

Dr. Tunick looks at me and then says, “I must put a drain in your jaw. We are going into a holiday weekend and I don’t want you to have any emergencies. I am not certain that the pus in your jaw and cheek will clear enough on the antibiotic. What have you had to eat today? Where is your husband?” I tell him very little, but I have had too much for proper anesthesia. He tells me he will have to do the procedure with regular Novocain.

Dr. Tunick tells me he thinks I will be able to drive home.

I call My Husband and tell him what is going on and that I must have ‘surgery’ but that I should be able to drive home afterward.

It takes Dr. Tunick what seems like an hour to put shot after shot after shot of Novocain in my mouth. While he is doing this, he tells me stories about medical treatment about different members of his family and patients at Sloan. I am very lucky to have such great doctors around me but then again here I am having complications. He is in Sloan almost every day, so he reminds me that this is nothing. He then puts in a ‘drain’. He is very happy he did so because the pus is everywhere.

He says, “You don’t look so good. Can you call your husband and tell him to come here?” But as he asks the nurse comes in and tells him that My Husband is already in the waiting room. They make me rest for another half and hour. They give me serious pain-killer and insist that I take them. He tells me he expects the pain to be worse than the initial extraction.

The car is far away and has a big ticket on it as I have been gone for hours and hours.

My Husband drives me home and I go to bed. I continue to prepare for a treatment I have serious misgivings about.
NOVEMBER 26, 2009: THANKSGIVING

Category: On-Going Treatment, Zometa Study

Thanksgiving. We have Thanksgiving dinner at home. My Best Neighborhood Friend and her family join us. We toast each other, the adults implying the thanks to God for my continued life.

I try not to cry but am deeply grateful to have another Thanksgiving and to make my special stuffing, fight with my mother, toast my friends.

I can eat out of the side of my mouth and finally eat something besides Cream of Wheat for the first time all week.

NOVEMBER 30, 2009: DR. VELTMANN IN FORT LAUDERDALE

Category: Estrogen Health

Mom stays and My Husband and I fly to Fort Lauderdale to meet Joe Veltmann. He is staying in a hotel near the airport. He stays there to treat the Merchant Marines in Fort Lauderdale. We decided it was far easier to travel to Florida than go to New Mexico.

I was not surprised to see what he looks like because My Cancer Friend had already met him and described him. I have formed close relationships with people based solely of the telephone, so I did not feel very different meeting him but was grateful to do so.

We spent much of the time visiting and did not really review my latest test results at length. It was moving to meet him as I consider his work to be saving my life.

DECEMBER 1, 2009: MIAMI SWIMMING FOR THE FIRST TIME ALL YEAR

Category: Family & Friends, Side Effects: Breast Lymphedema/Frozen Shoulder

My Husband and I go for a short bike ride on the beach. I am wearing 50 sunscreen, my bathing suit, a sports bra on top of it and then a shirt. Then I go for my first swim of the year. I wear a sunshirt over the bathing suit. The last time I tried, I was stung by jellyfish. I swim and swim and swim in my little crawl stroke. It is difficult to keep swimming because my arms are so weak but I don’t care. It is my favorite thing to do in the entire world and I am so grateful to be in Miami, in the sea, swimming my little swim.

I am very lucky and grateful to be given more life.
DECEMBER 2, 2009: MIAMI, RADIATION BURN AND CAN’T USE MY ARMS

Category: Radiation, Side Effect: Breast Lymphedema/Frozen Shoulder

My chest is killing me. I can barely move my arm. It has been like this for many months, but this is certainly the worst. I keep trying to stretch it.

My Husband and I go for another bike ride. I go for another little mini-swim using only overhand moves. While we eat under the umbrella, My Husband tells me I am red in the entire swath of the radiation area. “No, it can’t be. I have been covered the entire time.”

“You are definitely red. You must get out of the sun.”

“But I haven’t been in the sun.”

I look at myself and wonder how the sun could have gotten to me, but I see that it has. We must leave the beach immediately.

We rush and take an earlier flight home. I collapse. Even a perfect trip is exhausting.

DECEMBER 4, 2009: SCAN TESTS/GREENWICH HOSPITAL
TEXT TO MYSELF

Category: Family & Friends, Side Effect: Osteoporosis

my bones r worsening not improving

i am waiting to have a bone scan

everyone thinks it has been a long time that i have had cancer the bone density technician dr nesselson i have cancer and my father continues to live his life apart and makes no effort to keep up or seem to care my feelings are so intense i don’t know what is going on has the disassociation skill disappeared?

i will remember this
Today is test day. I must take these tests in order to prepare for my first post-treatment visit with Dr. Hollister.

I asked a few friends to accompany me today, but it was too late. Then I remembered a friend who lives in Greenwich and asked her to meet me before the Chest Scan.

It was a cold and blustery day. I tried to use the GARMIN navigation system that My Husband bought for the new Mini-Van to get me to the bone density test. It directed me completely the wrong way and I wound up circling and circling. I called the center over and over before they guided me across the street from the Greenwich Hyatt; a location I know well.

Once I got there, they couldn’t have been nicer. I fill in all the information about the various doctors that the test results must be sent to and that I need detailed results of the test. The technician told me about her form of cancer and asked me if I had had a bone density scan before. “I had one just before I started chemotherapy in April. This test is to find out how much damage, if any, the chemotherapy did.” I said that but I was confident that Dr. Veltmann’s bone density protocol of Calcitonin and the Calcium supplements and Vitamin D were working. After all, he had told me at least a dozen times how women’s’ bone densities were improved on this protocol without the use of bisphsophonates. So, I asked, “What does it show?”

“You are osteopenic in the lower spine, but I can’t tell the gradation she answers. The radiologist will have the breakdown in a few days.”

I concealed my horror, got dressed, thanked her and went to the parking lot.

Just as I got to my car in the whipping rain, my father called. I was freezing, the car was cold, and it was hard to get the phone, but I hadn’t talked to him in at least a week, so I answered.

“Hi. How are you? Just seeing how everything is going?”

“No Dad, I just came out of my bone density test and am on my way to Greenwich Hospital to take another chest scan.”

“Why is anything wrong?”

No Dad, I just have an extremely aggressive form of breast cancer. I will be taking tests for the rest of my life.

“No. It is routine testing. I am seeing Hollister next week and must do this before seeing him.”
“Okay. I just saw Dr. Bassim and I have been unable to complete my physical therapy exercises, so I am not getting better. Also, I promised him a book which I can not find so now I can’t go back there because I am embarrassed. I can’t travel at Christmas time.”

“I already knew all of this, but he had continued to pretend in his head that he would be coming to the US for Christmas and this time I believed because this time I thought…Oh I might be dying from cancer so my father will want to spend time with me…”

“So, you can’t travel right? You are negligent but I guess if you were really interested in being able to travel you would do your exercises and get yourself better.”

“But now that you have money again, you need a different excuse not to travel so now you have it. Intense vertigo which disorients you. You can use this for the rest of your days. Nonetheless, this latest re-nigging hurt more than the one in August, September, October and November. I had hoped he would care this time…but he can’t handle anything up close. I think it was too much to ask him to watch me shave my head.

I was rushing to get to the hospital and to meet my girlfriend. “Dad, I have to go. I am late for another test”.

“Let me know what happens with Hollister.”

“Sure Dad, I will let you know if my cancer comes out of remission and I am given a new kind of prognosis and a different form of a death risk. I guess it is too much to ask of him to participate in this kind of life.”

“Okay.”

I saw my friend for literally 5 minutes in the CAT Scan lobby before she had to go to a meeting. I used up the time venting about my father. She brought me a salad which was great because I had only had my protein shake all day.

They came for me exactly on time. I disrobed and lay down on the table. I was unhappy about taking the test alone and had not realized that contrast was required. I found it profoundly disturbing to have to take another test to see if the spot in my lungs was cancer or not. The spot that has to be monitored; referred to as ‘garbage’ by Dr. Mittelman.

My veins were too hardened and ‘messed up’ for the technician to use so she had to call an IV nurse. “Do you think it will take the IV nurse a long time to get here?” I asked.

“Why?”

“Because I thought I would go and finish my salad”

“But this is a fasting test. You were not supposed to have eaten all day.”
“There must be some mistake because Dr. Hollister ordered this test and I would never have accepted a fasting test in the middle of the day.”

She called Hollister’s office. Indeed, it was a fasting test. The technician comes back and gives me a choice. You can go ahead with the test and risk extreme nausea from the contrast dye or come back tomorrow.

I chose to come back tomorrow morning. Now I was furious. My bones were falling apart, my father didn’t care about me and wasn’t coming home for Christmas, Hollister’s office didn’t care about me enough to provide basic information and Dr. Gaynor thought I should have a PET Scan because my tumor markers were off. I was having a real pity festival.

I called Hollister’s office. “I wasn’t able to take the test because it was a fasting test and no one told me. So, since I didn’t take it how about if I just go straight for a PET Scan?” They put me on hold while they go ask him.

“Dr. Hollister says that you don’t have to take the test if you don’t want to, but you must come in to discuss the PET Scan.”

I re-schedule the test for the following morning. I go home and try to seclude myself for the rest of the day. This testing, re-testing is very stressful, and it is only the first time for the scans. The scans are more stressful than the blood even though I don’t have any veins left from which to easily take my blood.

Why can’t they use my legs?
DECEMBER 4, 2009: RESULTS OF THE 2nd BONE DENSITY TEST

Category: On-Going Treatment, Side Effect: Osteoporosis

Because the 2nd bone density test was taken on a different machine than the first I don’t have a benchmark of progress. In fact, the results are totally different from each other as the first one said I had osteopenia in my neck. Since I know from my back problems and surgery that I have significant degeneration in my spine, this latest report looks more on the mark.

I have no way to know if the Calcitonin is working since the results are not comparable.
DECEMBER 5, 2009: LUNG SCAN TEST/GREENWICH HOSPITAL

Category: On-Going Treatment, Diagnosis,

I take the scan without event at 9am and go about my day with the children as it is Saturday.

DECEMBER 5, 2009: SUPPLEMENTS REVISED

Dr. Warshowsky add more supplements to the list but he and Dr. Veltmann speak to Dr. Gaynor and half of Dr. Gaynor’s list is removed.

The list is still incredibly unwieldy but I don’t know what to remove by myself.
DECEMBER 8, 2009: LUNCH WITH MY FORMER CLIENT
ONCOLOGIST/HOLLISTER

Category: On-Going Treatment, Diagnosis, Radiation, Side Effects, Zometa Study, Family & Friends

I have my first adult, non-medical contact today. I have lunch with my former client/boss. It is the first time someone from the work world has seen the new me with the short brown and gray poodle hair. I am so excited to see him and have lunch in a grown-up restaurant and talk about grown up things like the arrest of Rajaratnam.

But I spend most of our precious time together talking about the stupid cancer and the quest in my head to make sure women find out if they can process estrogen before they take fertility drugs.

He is kind and funny and intelligent and I fall in love with him all over again. He is a good friend and I can see the concern in his eyes as I talk about the cancer process.

Then I run out on him because I have to find out if I have lung cancer and race to Hollister’s office on the train.

When I get to Hollister’s office, I find out that I will not find out if my ‘tumor markers’ are okay because that test result takes at least 24 hours to return. I was supposed to have come in to take my blood work on the same day as my Chest Scan except no one told me.

Again, this is my first time having cancer and I can’t guess the rules of the post-emergency treatment follow up. The staff that was so normally helpful seems uncaring.

I go alone. I see Hollister in his office and he seems surprised that I am alone. No exam room. I pull down my shirt as soon as he comes in to show him how my breast is burnt again. The poor man looks horrified but quickly recovers himself to shrug and say that maybe it was the Flagyl that I was taking for the soft tissue infection.

He then turns his attention to the Lung Scan. He pulls up all the pictures and examines the films himself. I watch him play with the images for a few minutes and a small piece of me is beyond terrified as I watch him work to determine if I have a tumor in my lungs.

He finally turns to me and says, “I am unimpressed with this spot just as I have always been. Let’s see what the radiologist thinks about it.” I really like how he does his own work that way. “The radiology report is also unimpressed. “ We must do this scan again in 6 months.”

We talk about Dr. Gaynor’s blood tests, about my supplements, about my bone density.

“I have a list. My eyelashes all fell out again.”

“Let’s look at your Vitamin levels.” He does and then says, “I don’t know.”

He is by no means callous but clearly is not concerned with such minor issues as body hair.
“Dr. Gaynor wants me to have a PET Scan because of the elevated CA-15 marker.”

“If your tumor markers come back at all elevated tomorrow he will also want me to have the PET Scan but that they have been steady and there is no reason to expose you to additional radiation at this stage. We will monitor your blood”

Dr. Warshowsky told me to ask this question of the oncologists, “If you do find cancer at this stage in my treatment, what would you do about it given my reaction to chemotherapy?”

“Diagnosing cancer at this stage is like diagnosing a pregnancy. You can be 2 weeks pregnant or about to give birth. In your case, you will always be monitored so we can always detect early.” I have no idea what that means. “If cancer came back in some form, we would probably be talking about some type of chemotherapy.”

We discuss the bone density test. He tells me to work on it with Warshowsky.

I tell him, “You told me to go see my dentist. My dentist sent me to the oral surgeon. The oral surgeon said I must pull out my wisdom teeth. Then I got a soft tissue infection and had to have a drain put in my jaw.”

“You must heal for at least 3 months before you receive Zometa.”

We agree to see each other at the beginning of March and that is that except for the tumor markers… He hugs me good-bye and I don’t mind.
DECEMBER 9, 2009: YOUR TUMOR MARKERS ARE FINE

Category: Diagnosis, On-Going Treatment

I am driving back from the integrative ENT’s office with Eldest Son and Brunette Twin in Manhattan. My Husband calls me and tells me that Hollister’s office called but they will not speak to him. The Doctor wants to talk to me only.

I call Hollister’s office and they put me straight through to him. “Your tumor markers are stable. You are one point below where you were last time you had the test taken. You do not need to take a PET Scan. I wanted to let you know this myself.”

I thank him then call My Husband to tell him. Then I call back Hollister’s office and ask that my husband always be given full access to my medical information.

Admin, Admin, Admin…should he have to wait an hour or so to learn that I don’t have to have a PET Scan instead of I do because the tumor markers are MORE elevated?

All contact with the doctors is nerve-wracking.
Dear Dad,

I apologize for losing my temper this afternoon. You have been calling me daily this week for some reason and this has been a very difficult week for me.

You caught me last Friday running from my bone density test during in which I learned that my bones are in decline despite all the medications I have been taking since August to support them. I had hoped that I would at least remain static and was surprised and disappointed by the decline. I talked to you as I was rushing to Greenwich Hospital to take a CT scan with intravenous contrast of my entire chest but mostly to find out if the spot in my lung had changed from the last PET scan in April.

I was unable to take the test because they forgot to tell me to fast. They had difficulty with my veins because I can only use the one arm and I have taken so much blood lately for various tests that the veins have dried up.

I had to take the test Saturday morning. Having cancer tests, waiting for cancer test results and then waiting for doctors to tell you what they mean is incredibly stressful and I must learn how to live with this. I have not yet although I am doing my very best.

The children are incredibly sick. Eldest Son has had a fever between 100-103 for over a week. He has been on antibiotics for a month straight and has a lot of pus in his ears which they keep vacuuming to no avail. He has been to an ENT weekly for several weeks and they are worried that the tube has become dislodged into the wrong place.

Tall Twin has been coughing non-stop for 4 days. Finally, the doctor diagnosed Swine Flu for both of them which has nothing to do with eldest Son’s ears. They may require another surgery soon and I must take him to see his surgeon next week.

All of them are on the nebulizer multiple times a day. Eldest Son has a fractured wrist...the therapists that I must manage are all needy and when they are unmanaged the treatment of the children really suffers.

My Eldest Son is starting to get sick. My Husband has been in bed for 2 days. Now I have the swine flu too.

The cancer diagnoses radically changed the way I am looking at life. The immediate cancer treatment of surgery, chemotherapy and radiation was an ongoing crisis that ended on September 30th. Then the pulling of the wisdom teeth, the infection in my jaw, the constant going to doctors to find out about Zometa and follow up cancer treatment has been exhausting and, in many ways, much more difficult than the ‘crisis/emergency’ treatment. During the emergency, that was all I did...now I am trying to take care of my children and manage my life and have cancer...much harder now.
Contd. Letter to my father…

It is difficult coming to terms with the severity of the damage caused by chemotherapy, surgery and radiation. Moreover, it is beginning to dawn on me that I have a life-threatening illness that will have to be managed for the rest of my life. Somehow, I had been hoping for an ‘end’ after radiation and that was a very faulty expectation. I am trying to adjust my expectations to manage the reality of the treatment.

Furthermore, I still find the fact that I must have tests, constant monitoring and conversations about mortality, reoccurrence and tumors all the time bizarre and mentally and emotionally draining. I expect to eventually find my team of physicians and be set on my course of treatment, but it will take a lot of hard work on my part and it has been exhausting. This is the new course of my life and I have not adjusted to it.

Yesterday, I saw Hollister for my very first quarterly cancer review. He looked at the Lung CT Scan and we discussed next steps. Today he called to tell me that my tumor markers are stable and that I do not need a PET Scan at this time.

Today, I took the twins to another ENT specialist in Manhattan for several hours. Then I drove back to get Eldest Son’s cast taken off and then collapsed from fatigue and my own sore throat.

In the midst of all of this, you call and ask ‘what’s up? And you don’t ever seem to remember what we had talked about the time before whether it be a few days earlier or a week or two earlier. It makes the phone calls bizarre in the face of the constant medical emergency that I seem to have been in for the past several months.

My view of life has changed so radically it is very hard for me to watch everyone go back to ‘normal’ as I never will again. I can no longer manage the pain and disappointment I feel when you say…see you in August, see you in September, see you in October, November…at Christmas and then you remain too ill to travel.

For the first half of my life, you traveled, and I have waited for you to come home. Usually we had no idea when you would show up and oftentimes you missed important childhood dates…always in the same manner. I will try, I might, you can expect me and then you didn’t show.

In the second half of my life, I traveled and spent a lot more time with you than I did in my childhood or that either of my sisters did. You stopped by London, I went to Moscow, you came to The Old Country, later I came to The Old Country and we managed to have a relationship that entailed a few visits a year.

After My Eldest Son was born, your trips to the US were curtailed and I could no longer travel. Then I recovered from my back and began to travel again and saw you a few more times (than anyone else). Now with the cancer diagnosis, I will not travel anymore, and it saddens me considerably to know that we will go back to the pattern of a few days a year that you stop by New York…maybe.

I know that you are ill and that it has been over a year that you are facing this vertigo which is very unpleasant. So it is all sad…the fact that you became ill in the first place, the fact that you are unable to find the passion to at least try the exercises that may or may not make you better and the fact that I will not be doing any traveling except with my children for the next almost 20 years.
Contd. Letter to my father…

So, I wonder when will I spend any time with you again? Just a few days a year, I guess. My sisters adjusted to this relationship a long time ago, but I did not because I did not have the same scenario…but now I do.

Since the end of radiation, I have been unable to manage even the tiniest bit of stress. I told My Eldest Son that you would not only not be joining us in Miami but not at all and he was at first puzzled and then disappointed. It saddens me to have to explain that his grandfather should never be counted upon until he is actually standing in front of you.

For the next third of my life, I would like to set up a new pattern. One in which you don’t set up an expectation of a visit. If when you were here is April you simply said good bye and I will see you someday it would spare us this never-ending game of expectation, planning and disappointment etc.

I have found since the emergency treatment finished that I am having feelings. I usually do not but part of my trying to enjoy and appreciate every minute of my life means that I am also experiencing the negative emotions honestly instead of wiping them away. The joy of the moment is also the pain of the moment.

I would like to visit with everyone for Easter and we will see you then. We can celebrate my recovery then and you will not have to worry how to travel when you are sick. If you some reason you find that you are definitely coming to the U.S., please wait until you have your ticket in your hand and are quite sure of yourself before informing me and by extension my sisters. Please do this for me.

I appreciate your love and concern from a distance, but I would be grateful if you were more honest with your self and your own desires and abilities and therefore, we could stop the cycle of expectation and disappointment. Let us just enjoy each other’s company whenever it occurs no matter how infrequently it may be.

This period of adjustment for me is proving much more difficult than the crisis period so please try to keep up your support and prayers.

Love, TJ
DECEMBER 14, 2009: MEDICAL ADMIN & SWINE FLU

Category: Exhaustion

I call Dr. Warshowsky’s office to make sure they have received the detailed bone density test before I do for my appointment tomorrow to discuss my bone density. I scheduled the appointment because My Husband told me that Dr. Warshowsky told him during his appointment that there was a lot he could do to improve bone density.

The receptionist and I go back and forth repeatedly, and she assures me that she has the detailed breakdown. The receptionist asks me to call Greenwich. Dr. Warshowsky had promised me that he would be the central point of my treatment but it is clear that I must remain the central administrator/co-coordinator of all records, appointments, follow-ups etc. While it is still a relief to have him on board, it does not resolve the administrative burden.

I call Greenwich Hospital and they affirm the test results have been sent to the doctors but not to me because I am only the patient.

I am feeling too overwhelmed and sick to go to Dr. Gitelman’s appointment with Eldest Son. Dr. Gitelman informs me that Eldest Son has no pus. That would be the first time since August. He takes credit for the recovery and does not let me explain that they have been put on Nystatin.

Dr. Asher is a genius.
DECEMBER 15, 2009: E-MAIL SENT TO SMALL GROUP –
SEVERE ALLERGIC REACTION TO TAMIFLU –

Category: Diagnosis, On-Going Treatment, Exhaustion, Side Effect: Osteoporosis, Zometa Study, Family & Friends

Hello,

I am writing my pre-Christmas update. Since I last wrote I . . .

Developed a soft tissue infection in my jaw and had to have a drain put in

Went to Miami to meet with Dr. Joe Veltmann with whom I am participating in the Breast Cancer Study

Contractors have been in the house on and off for many weeks, but it is drawing to a close . . . perhaps even tomorrow they will be finished??

Came back and took the children to see an Integrative Medicine ENT in Manhattan because they were ALL so sick

The boys got swine flu

I was treated preventively with Tamiflu and got a SEVERE allergic reaction to the drug. I was in bed for two full days . . . one in which I did not leave the room as it was spinning so fast

I am finally feeling a little better

Eldest Son saw the local ENT again today and his ears are clear for the time in MONTHS (I think it is the medications the Integrative ENT put him on or the Singular)

Last night I went to a Breast Cancer Support Group at Greenwich Hospital that turned out to be awesome.

I feel that things are Hopefully on the upswing . . .

Love TJ

Hi. I forgot the most important piece of news.

I saw Dr. Hollister for my 1st official post treatment check-up last week.

In order to see him, I had a chest/lung scan the prior week and a bone density scan.

My lungs are stable and will be tested again in 6 months. I will see Dr. Hollister again in the beginning of March and after that take Zometa.

My blood is stable . . . white and red low, 1 tumor marker is elevated but we determined that since it is stable, I will not have a PET Scan at this time.

Trying to get used to managing all this.

Love, TJ
DECEMBER 15, 2009: MEDICAL ADMIN

I go to see Dr. Warshowsky. This is my third visit and I am expecting to be “wowwed” as I was at the other 2 visits.

They do not have my detailed bone density test results. They only have the summary which means nothing. Dr. Warshowsky spends the hour talking about how Zometa is so much stronger than any of the other options for bone density that there is no point in treating my bones as Zometa will wipe out any gains immediately with the first IV.

I update him on the wisdom teeth infection, Tamiflu reaction and discuss vaginal atrophy at length. BUT we don’t have any info on my bones.

I call Greenwich Hospital as soon as I am back home and they tell me I can not get the test results. I speak to the radiologist, I talk to the medical records people, and I leave a lot of messages about needing the breakdown.

I am overwhelmed by the amount of admin required.

Still must figure out what is required for Christmas.
DECEMBER 17, 2009: MY ELDEST SON SAYS THERE IS ‘NO CHRISTMAS SPIRIT’

Category: Family & Friends,

The errands for Christmas are endless but they are not even for Christmas they are for the contractors who couldn’t be nicer but are disrupting the entire house.

I run back and forth between Home Depot and the rug store and the paint store and try to push in some Christmas shopping but I can not. It is too much. Christmas is scaled back in spirit somehow. My Eldest Son tells me that this year there is no Christmas Spirit, so I take him straight from school to Rockefeller Center to see the Christmas lights.

We have a great evening. We park in the street, take a cab to Rockefeller center, go to the Nintendo store, see the Saks light show, go to St. Patrick’s and light candles during mass and then go out the door to Prime Burger an old-fashioned diner opposite the north side entrance to St. Patrick’s where we order 2 rounds of hamburgers and fries and he devours everything.

We walk up to Columbus Circle where a gypsy cab takes us back to the Time Warner Center to watch their light show inside after going to the Holiday Fair on the circle.

While we sit in the upper balcony of Time Warner drinking hot apple cider My Eldest Son explains to me about the boys fighting on the school playground. He says that it keeps happening that they are pushing, shoving and wrestling with each other; sometimes punching out of the sight of the monitors. He tells me that they don’t have Christmas Spirit. I breathe a huge sigh of relief as I find out that it is not me and the cancer and the change in my physic energy (all of which I am sure is nonetheless true) but in fact school fighting that is causing him distress.

My Christmas spirit is in full. I keep feeling a deep urge to go to Mass, but it never gets translated into action.
DECEMBER 18, 2009: REALIZING I LOOK OLD

Category: Family & Friends, Side Effect: Early Menopause

My friend’s sister, who lives down the street from me, invited me to a Ladies Night. Most of the women there were from the neighborhood and almost all of them were 50 years old but their children are older than mine; in high school and college mostly.

When one of the women found out that I have an 8-year-old and 3-year-old twins, she laughed so hard, I thought she would pee in her pants. She told some of the others that and they all had a good laugh.

Later, my neighbor and I talked about 2 of them women there and how young and beautiful they are, and I realized that my days of youth and glamour are completely in my head as I was not included in the comparison. I am no longer thin, dress in sweatpants most of the time and do not ‘take care of myself’ to dress properly. I keep resolving to do so but comfort takes over every time.

I remember when I first moved back from Europe and would see my mother in matching nice sweatpants sets, I was HORRIFIED.

The only upside on all of this is that people seem to treat me better. I don’t know if it is the short brown hair, the gray hair, or the lack of pretence about having bleached blond hair, but it is noticeable.
DECEMBER 21, 2009: I AM OVERWHELMED

Category: Exhaustion, Family & Friends

My Husband is sick again. He spends the entire day in bed. He is in a state of perpetual exhaustion. He has a sinus infection? He has a recurrence of swine flu? He has diarrhea?

He is in bed and I can not/will not go close to him.

I think he has a severe case of PTSD due to the cancer. He exhibits all the classic symptoms I used to have. He has ever increasing rage attacks. He is sick ALL the time. He saves his energy for what he has decided are vital activities (such as WORK) and then the rest of the time he is more or less in various states of collapse.

While his outbursts have always been part of who he is they are becoming much more severe.

I had asked him to leave our home right before Thanksgiving. I was, for the first time serious, as I really and truly thought he would hurt the children.

It is not good to be having such conversations with your husband.

He has NO support whatsoever. His family are not there for him even energetically. In fact, I think they are an energetic drain. He has no friends that he really talks to whatsoever.

One of best friends and a best man at our wedding, has been in town now for several days and has not materialized. He doesn’t have time to see My Husband.

DECEMBER 22, 2009: MEDICAL ADMIN

I finally receive by mail the breakdown analysis of my bone density tests. I am too busy to send to Joe Veltmann and everyone else who needs to know.

DECEMBER 24-25, 2009: CHRISTMAS AND SO TIRED THAT I SLEEP THROUGH THE VACATION HOUSE BEING ATTACKED BY A PHYSCOPATH

Category: Exhaustion, Family & Friends

I had tried to make Christmas as it usually is, but we don’t really have a routine since it alternates with spending x-mas day itself in Miami. We had a quiet time, except for Al complaining, and I was filled with joy to have another X-mas.

I am blessed indeed. I cried at mass on Christmas Eve. The priest’s homily was very short and excellent as it took place after the children’s nativity play. My Eldest Son was sulking the entire time. It is time to get him some help.
DECEMBER 29, 2009: DANGEROUS CRISIS IN MIAMI & MY DECISION NOT TO TAKE ZOMETA AT ALL

Category: Exhaustion, Family & Friends, Zometa Study

We arrived in Miami for our yearly week between Christmas and New Year’s Eve very late on December 26th after spending most of the day at JFK.

My Little Sister, her husband, son and our mother had preceded us by about 36 hours. We were renting a house in North Miami in Keystone Point where we have been going my whole life. We had miraculously found the house after being scammed out of $5000 (which we didn’t know yet) for a house in Fort Lauderdale….

But the house was not vacant. The renter who seemed to be a pornography star or prostitute, did not leave but was chain smoking, drinking heavily and playing very loud music in a room cordoned off with a small piece of string next to the ‘master bedroom’ where My Husband was supposed to sleep. They were not given the keys to the house and kept entering at all times. So, it was not a rental, it was more of a bed and breakfast or really a scam.

My Little Sister and her husband complained about the house while we were in the airport at JFK but there was nothing, we could do about it.

I went to bed at 10:30, quite late for me, in a stupor. I have no stamina whatsoever and the trip drained me completely.

At 2:30 I awoke to shouting and the sound of walkie talkies. I went downstairs to find 2 police officers, My Little Sister, My Sister’s Husband and My Husband talking about the screaming woman who was trying to break into the house. It seemed that My Husband asked her to stop smoking and turn the music down. She said fine and then he locked the doors to the house so everyone could go to sleep.

She went crazy when she found out the doors were locked and tried to break into the house; screaming it’s my house over and over. The police restrained her brutally, but she didn’t care. They left briefly and then came back to arrest her after she tried to crawl in the children’s bedroom. During all of this I was in a stupor. I told my sister and her husband as they went through my bedroom to stop the woman from climbing on the balcony to attack us, that it was surreal. At no time did I become agitated or excited. I was intellectually just saying this was unacceptable from a great distance.

I am that tired.

We stayed at the house another night while the woman was in jail and left the following morning to my brother in law’s tiny 2-bedroom bachelor pad in a high rise in South Beach; all 9 of us. That night, after listening to my brother-in-law bitch and complain about the situation for the entire day, I asked my sister to go to a hotel and get away from me.

She was REALLY upset.
On December 29th, My Eldest Son’s birthday, My Little Sister told me she was very upset and that I was an angry asshole. I guess she classifies her husband and I in the same group of unreliable, volatile people. I begged her forgiveness and she came to My Eldest Son’s birthday party at the Seaquarium anyway. As we sat at lunch, she told me she understood how angry I was about the cancer. She told me I was angry all the time and told me about how I yelled at her the day I was hospitalized in July.

I must examine this because I don’t feel terribly angry. I feel like an idiot who trusted doctors to take what are basically experimental drugs, at experimental doses and came down with some cancer as a result.

So, from the parking lot of the Seaquarium with My Eldest Son sitting next to me having a major crying jag due to disappointment (because his father was working) and exhaustion, I finally had my long-awaited call with my old doctor from Chicago, which I had been eagerly awaiting for months.

Calls with Dr W are a mysterious and amazing gift that must be treated with great reverence. I had been fixated on talking to her in order to solve the great Zometa mystery and here I was without paper and pen in the middle of a parking lot with my son crying on his birthday next to me.

I wanted to know only about Zometa, and she wanted to talk about me and my state of health. I wanted to talk to her about all the doctors I have recently met and how their disagreement is very upsetting to me, but she already knew it all.

She told me that I could take the Zometa in very small doses as long as I was in an Intensive Care Unit and watched intensely.

I forgot to ask her about ONJ and need to schedule another appointment.

Just hearing her voice makes me feel warm and cozy.

Dr W explained that the reason Zometa works is that bone density is an indicator and influencer of the immune system. Strong bones mean strong immune system.
JANUARY 8, 2010: Dr. VELTMANN - BLOODWORK

Had a 2 hour phone call with Dr. Veltmann. It seems that he did not receive all the tests that I had reviewed at great length with Warshowsky. He dismissed much of the blood work due to impact of radiation and etc.

He also thought the bone density tests did not make sense and the machine variance was too great.

It was comforting to speak to him. I told him all about Dr. W and my plans to find a genomics company and raise money for them.

I can see the direction now.

Dr. Veltmann says that perhaps I should stop taking ALL of the supplements and start over since I was not improving.

JANUARY 9-10, 2010: MY FAMILY HAS POST TRAUMATIC STRESS DISORDER

Category: Exhaustion, Family & Friends

I really think the entire family, the twins less so, has PTSD. The more I recover, the more everyone seems to fall apart. My husband, for the first time, he seemed to acknowledge there was problem. He was really really mean to My Eldest Son and My Eldest Son at least seemed to be able to say…” Hey, that was really mean. Why did you do that?”

My Eldest Son is having wild mood swings and he is clinging to anger and resentment. When asked about the birthday party he attended and the basketball game he played, the only thing he could relate was “Good EXCEPT, the birthday boy was really annoying. He talked the entire way home about how he was the Best, the Best, the Best. Over and Over and over again.”

I think that perhaps My Eldest Son has become chemically imbalanced as well after keeping EVERYTHING inside all those months that I was so sick. Now everything is coming out? I can’t try to do this alone. I/ We need help.
JANUARY 15, 2010: MEDICAL ADMIN

Category: Zometa Study, Family & Friends

I start making appointments for the next quarter as I must circle back with everyone now that I have decided not to take Zometa.

Dr. Hollister (my oncologist)
Dr. Moore (my other oncologist)
Dr. Martorella (the endocrinologist specializing in post cancer endocrine matters in my case - thyroid damage & osteoporosis)
Dr. Gaynor (the integrative oncologist)
Dr. Estabrook (the surgeon)
Dr. Newman (the neurologist for my migraines)

JANUARY 13, 2010: HELP FOR MY ELDEST SON

Category: Family & Friends

I gave my time with my therapist to My Eldest Son today. It helped him enormously and therefore me. He is like a different boy only a few hours after the session. I have my son back if only for as long as it lasts.

I must get him to talk to her more regularly.

JANUARY 14, 2010: BREAST CANCER SUPPORT GROUP

Category: Family & Friends, Side Effect: Breast Lymphedema/Frozen Shoulder

I attend my second Breast Cancer Support Group at the Hospital. The stories are horrific. I complain about the inability to use my left arm, the chest pain and weakness. One of the women strongly recommends I see a doctor. She says that it is probably lymphedema and tells the story of her lymphedema diagnosis 2 years after surgery.

JANUARY 15, 2010: I STAY UP UNTIL 11:30PM

Category: Family & Friends

I go out to an 8’o’clock show for the first time since diagnoses. Even though we left after the first act, I did not go to bed until around 11:30. Apart from My Husband’s birthday party, that is the latest I have stayed up since diagnosis.
JANUARY 17, 2010: MY ELDEST SON’S ALL-DAY BIRTHDAY PARTY

Category: Family & Friends

My Eldest Son had an all-day birthday party. It was the second major event that I managed all by myself and I was much less drained than at Christmas time. I don’t know if it is the supplements working or the little break at Christmas time, but I feel a little more energetic although I am certainly still tired.

JANUARY 18, 2010: I AM DIAGNOSED WITH BREAST LYPHEDEMA

Category: Side Effect: Breast Lymphedema/Frozen Shoulder

I see Dr. Freedman, Physical Medicine, Greenwich Hospital, who was become an expert in lymphedema. She says it is scar tissue under the armpit and BREAST LYPHEDEMA. I thought it could only occur in the arm and that is what Dr. Estabrook said as well. Dr. Freedman says that the swollenness, the hardness and etc are fluid and that it must be drained to the right side.

She looks at my medication list and tells me that VOLTAREN which I am taking daily for migraines has been shown to cause bad liver damage. Great.

I set up appointments for Greenwich Hospital therapy.

JANUARY 20, 2010: MEDICAL ADMIN & THE DECISION NOT TO TAKE ZOMETA

Category: Zometa Study, Exhaustion, Family & Friends

I have finally recovered from Christmas, our trip and My Eldest Son’s Birthday Party. Time to get back to the doctors. I spend the morning continuing to make appointments.

A gastroenterologist (because Dr. Hollister wants me to have a colonoscopy)

A cardiologist (my heart must be checked after the adriamycin given that I had PVC’s year ago)

I go to see my physical therapist, who it is great to visit with. She works on my armpit and my arm feels better than it has in months and months.

I set up physical therapy appointments.

I request blood forms from Warshowsky’s office and estrogen test from him.

I try to coordinate the appointments for the same day. It doesn’t work too often.
JANUARY 20, 2010: CANCER & BISPHOSPHONATES

Category: Zometa Study, On-Going Treatment

I listen to the CancerCare briefing on the annual San Antonio Breast Cancer conference which took place in December. In the briefing, they discuss a new study which compares Zometa and the Bisphosphonates to Denosumab a Rand Ligand Inhibitor. The Denosumab compares more favorably than Zometa on both reoccurrence and side effects.

I am curious to see what the team has to say.

I talk to my therapist and update her on my progress. She is delighted. I must work on my attachment to God.

JANUARY 21, 2010: MEDICINE

Category: Family & Friends

Had to take the twins to see Dr. Asher. He is SUCH a good doctor and has helped so much. My feelings about the medical field are so mixed.

Once again, I feel constantly pushed for time and torn between obligations. I feel a huge push to write quickly. I wonder what that is about?

JANUARY 22, 2010: BREAST LYMPHEDEMA

Category: Side Effect: Breast Lymphedema/Frozen Shoulder

Met the Lymphedema specialist at Greenwich Hospital. She explained that you are born with a lymph system reservoir at birth. The reservoir is used for trauma or infection so that the body can clear fluid. We reviewed my case history at length and discussed the size of my breasts post-surgery. My left breast was not hugely bigger than the right until after radiation. The lymph node system apparently divides the body into 4 quadrants. Lymph nodes in each of the four quadrants will not automatically pick up extra fluid from another quadrant but the extra fluid from the weakened quadrant can be pushed over to another quadrant in order to clear the fluid.

She explained that radiation can eliminate the ‘buffer’ causing the breast to swell because the lymph nodes on that side can no longer handle the fluid. Since the lymph nodes were blasted during radiation, they became weakened and can no longer handle clearing the breast.

So, for me the goal will be to send the fluid in the upper part of my left breast to my right side and the fluid in the lower part of my left breast to my groin.
JANUARY 22, 2010: E-MAIL CORRESPONDENCE WITH CANCER CARE ABOUT MY ELDEST SON

Category: Family & Friends

Hi TJ,

I did talk with our NY office to see what kinds of programs they have going on right now. They do have a few family events in the works, but do not have flyers printed yet. In order to see what workshops, educational material and services (either in CT or NY) would be best for your family I have few questions that may help.

What have you told your son about your diagnosis and treatment?

I HAVE TOLD HIM THAT I HAD BREAST CANCER, SURGERY, CHEMOTHERAPY, RADIATION AND THAT IT IS GONE NOW. AN UNCLE IN LAW DIED A MISERABLE DEATH FROM CANCER WITHIN A FEW DAYS OF HIS LEARNING OF MY DIAGNOSIS AND I BELIEVE HE HAS ASSOCIATED CANCER AND DEATH. I KNOW ABOUT THE GILDA’S CLUBS GROUPS BUT I WAS AFRAID THAT GOING TO GILDA’S CLUB WOULD ACUTALLY RE-INFORCE THE DEATH VIEW.

What kinds of difficulties has he been having since the diagnosis? At home and at School?

SINCE I HAVE BEEN BETTER; I.E. FOR THE PAST 2 MONTHS, HE HAS BEEN ANNOYED BY EVERYTHING, SAYING HE IS ANGRY WITH ME FOR THE SLIGHTEST LITTLE THING AND HE SPENDS A LOT OF TIME SULKING. HE HAS STOPPED WANTING PLAYDATES AND IN FACT ASKS FOR THEM TO BE CANCELLED IF I ARRANGE THEM BECAUSE HIS FRIENDS ANNOY HIM. THIS BEHAVIOR IS ALL QUITE UNUSUAL FOR HIM.

Has he met any other children who have a parent with cancer? If so, what was that like for him?

NOT TO MY KNOWLEDGE. I HAVE TOLD HIM ABOUT SOME NEIGHBORS BUT THAT IS ALL.

Has he received any counseling either privately or at school regarding the diagnosis?

3 DIFFERENT THERAPISTS (2 AT SCHOOL AS WELL AS MY OWN) HAVE TRIED TO TALK TO HIM ABOUT THE CANCER BUT HE IS TOTALLY SHUT DOWN ABOUT IT.

The more we know the easier it is to locate the right resources. I will be getting a packet out to you after I hear back. I hope you have a good weekend!

I HAVE READ HIM A FEW CHILDREN’S BOOKS BUT I EDITED THEM SEVERLY AS I THOUGHT MOST OF THEM WERE TOTALLY INAPPROPRIATE FOR HIS AGE.

I appreciate your help and guidance.

Yours truly, TJ
JANUARY 25, 2010: BREAST LYMPHEDEMA/FROZEN SHOULDER

Category: Side Effect: Breast Lymphedema/Frozen Shoulder

Had my second treatment of PT with the Lymphedema specialist. She explained how there is a lymph node buffer that can be destroyed with radiation. The fact that I now have breast lymphedema means that my lymph node buffer is gone.

She also explained that there is a 2 month ‘shock’ period to the tissue in the armpit, breast etc after radiation after which is starts trying to regenerate. It is then that scar tissue, muscular damage begins to form. This corresponds almost exactly with the Thanksgiving date of huge pain as opposed to annoying pain beginning.

According to her, 4 months after you stop radiation, the tissue change can cease to keep altering and the final condition can be assessed. That is where I am now? So, what does that mean? That I will never properly be able to use my arms again?

It would be great if someone would tell you this stuff, but they don’t care about anything except saving your life.


Have been in a major funk ever since my doctor day last Friday.

Dr. Estabrook was quite alarmed at the size of my breast and worried about it. She said she had not seen ‘breast lymphedema’ in at least 5 years and that I had been over-radiated. She asked where I had gone and said that she considered it her responsibility over where she referred people.

She was very worried about the series of articles in the NY Times that has been reviewing over-radiation (and death) of patients because no one is really monitoring the technology closely. She insisted that I call Dr. Fass and tell him what had happened.

Of course, Dr. Freedman’s letter to Dr. Estabrook never materialized and I must co-ordinate the communication between all the doctors.

I don’t think that it was the fault of the machine… I just think that like all the rest of my treatments I did not respond well to the typical dose. I think it was probably the last few days that did it when I started breaking into hives again.

The lymph node buffer is now gone forever. I hope that my heart hasn’t been damaged.

After the alarming conversation with Dr. Estabrook, I went to visit Dr. Martorella to discuss my bones. My Husband came along. My Husband has been totally out of it, he left the appointment wondering “Why isn’t everyone talking about your Vitamin D Levels all the time?” I told him that everyone was always talking about my Vitamin D levels. It is good to have him back in the conversation.

Dr. Martorella didn’t seem alarmed at all that I have chosen not to take Zometa. He has been using it for years and didn’t seem to think that it was the end of the world but then again, he is not an oncologist.

We discussed 3 different levels of treatment. 1) Vitamin D in mega-doses. He expects this recent round of tests not to show dramatic improvement and thinks I must be on Vitamin D mega doses for quite sometime. 2) Actinel 3) A new drug called FORTEO which is a hormone that builds bone.

I had a great weekend except for wanting to kill My Husband on Saturday because he hurt My Eldest Son. Then on Sunday we had a great day at home and bought an outside fireplace where we hung out and had dinner around the fire.

On Monday, I completely collapsed and spent the day in bed. I have no idea what happened.
FEBRUARY 5, 2010: MORE REVISIONS TO SUPPLEMENT LIST AFTER VISIT WITH DR. GAYNOR & WARSHOWSKY

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NOT TAKING DUE TO YEAST OVERGROWTH

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FEBRUARY 9, 2010: Dr. GAYNOR, INTEGRATIVE ONCOLOGIST & ZOMETA

Category: On-Going Treatment, Estrogen Health, Zometa Study

I saw Dr. Iacobellis last Friday for Botox. I asked him to give me half of what he had the only time before 18 months earlier. He was very sweet and heard all about my cancer stories and gave me a kiss and wished me well.

He kept going on about how he wasn’t charging me full price, but it was awfully expensive. I don’t care. If I can look in the mirror and not cringe, I will be happy.

I saw Dr. Gaynor last Friday. I had been really stressed out about preparing to see him because he was so incredibly aggressive the first time, I met him. This time he was a completely different person and seems very relaxed about my condition. I was prepared to listen to a tirade about why it was critical I take Zometa but after hearing about what had happened since I last saw him, he just said, “I can understand your fears about being especially sensitive and worrying about the consequences of Zometa.”

He also didn’t think taking bisphosphonates was the best idea.

Too relaxed. I asked about risk recurrence adjustment after making it 1 year and he gestured to some books behind us and told us to look it up ourselves on the curves.

He asked about my stress level, my meditation schedule and about all the supplements. Then he gave me a ton more. What is awesome about him is that he had an answer for every single one of my complaints whereas everyone else has just kind of shrugged their shoulders at them . . .

About my inability to think: Bacopa

About my skin drying and thinning: two supplements

About the fact that I can’t take the yeast concoctions for the immune system because of the yeast overgrowth: more graviola

About the Zometa: don’t worry.

He is an odd bird. Aggressive one minute and not the next. But there is no doubt that as Iacobellis pointed out: He is very very smart.

So, I guess that is the end of the Zometa discussion. Everyone involved in my treatment has washed their hands of it. Everyone who was insistent that I carry on and do it, gave up with only a shrug when I said I wouldn’t. So, I stressed and research and research and research for nothing? NO, I am comfortable in my decision and have found other people with whom I want to consult.
FEBRUARY 28, 2010: WALKING PNEUMONIA FROM AIRPLANE TRIPS TO SOUTH AMERICA?

Category: Exhaustion. Estrogen Health

On Saturday, I try to call my internist but can not find him. I wind up at my children’s allergist who puts me on CIPRO and told me I MUST speak to my oncologist. She says my chest is very tight, very junky and I must be checked out for Pneumonia and get a chest x-ray right away.

I returned from South America last week. The trip was a bad idea except for one thing. For most of the trip, I did absolutely nothing except go to the gym or go for a swim or lie around. I actually even read a complete book for the first time in about 2 years.

I became sick from the airplane trip and did not improve even with 2 rounds of Zithromax. I returned and became much sicker. Dr. Geraci put me on CIPRO which has turned the mucus from green to white for the first time in weeks. I am being checked for walking pneumonia tomorrow.

It is back to the doctors for me, my children and My Husband. My whole life seems subsumed by doctors. I would desperately like to go back to work but clearly I am too weak for much of anything.

Right before my departure, I spoke to Joe Veltmann about the latest rounds of Bloodwork. Both my blood and my 24-hour estrogen test show absolutely no improvement. My immune system is functioning at about 20% of the low end of normal. Despite all the supplements I am taking for estrogen methylation, my ability to methylate has not improved at all in the past year.

I am becoming quite discouraged by it all and having difficulty keeping up an internal good face. I know I must be grateful to be alive, but it is frustrating and scary to not improve with all the efforts I am making. While my diet it not completely strict, it is not that bad, and I do everything recommended.

I wonder if I would be worse off if I had done nothing whatsoever. Dr. Veltmann has confided that I am his first patient not to improve on his regime. This life off the bell curve is scary and tiresome.

I am worried about recurrence. How can I fight cancer, if my immune system which is supposed to stave off errant cancer cells can’t even fight off a little bronchitis?
FEBRUARY 29, 2010: WALKING PNEUMONIA?

Category: Exhaustion

On Saturday, I try to call my internist but can not find him. I wind up at my children’s allergist who puts me on CIPRO and told me I MUST speak to my oncologist. She says my chest is very tight, very junky and I must be checked out for Pneumonia and get a chest x-ray right away.

MARCH 1, 2010: WALKING PNEUMONIA?

Category: Exhaustion

Dr. Hollister’s office told me to call my internist and that my having a chest cold is no longer within the realm of his prevue. (They said this is the nicest possible way, really)

I schedule an appointment for my internist the next day.

Dr. Veltmann told me I should have listened to him and wore a mask on the plane.

Dr. Asher, my children’s ENT specialist in Manhattan, was very worried and insisted I call Dr. Gaynor. Dr. Gaynor is impossible to reach, and his staff is very unhelpful and border on rude. I find even calling his office to leave a message the most stressful out of all the offices I must deal with which is ironic since there is meditation music and a lot of emphasis on the spiritual nature of healing at his office. At the end of the day though, it is based on the Upper East Side of Manhattan and his staff reflects this.

My stress level increases as the doctors around me panic at my condition.

The CIPRO begins to work.
MARCH 2, 2010: NO WALKING PNEUMONIA

Category: Exhaustion

I saw Dr. Paglia, my internist, for a breath of old school medicine. Seeing him is like walking into a Norman Rockwell portrait for real. He exudes a sense of warmth, confidence and caring. I like his long gray silver hair too.

He is the doctor who counseled me originally about picking a surgeon. He said, “Every surgeon you have seen (baring the first one who botched up the excise biopsy) is amongst the top 20 breast surgeons in the tri-state area and that means they are amongst the best in the entire country if not the world. No matter who you go with you will be amongst the best. If you like one of these better because she has blue eyes and that makes you feel comfortable and confident, than that is who you should go with.”

Given that I was doing so much better on the CIPRO he didn’t recommend a chest x-ray. He said, “I don’t hear anything. Whatever I see in the x-ray will not change my treatment of you and I think you have been radiated enough.”

He explains that the reason the Zithromax in South America didn’t work is because it was the wrong drug for bronchitis.

I tell him about how my immune system is not recovering, and he says, “You have been POISONED. It will take a long time to come back. It takes a long time to recover from POISON.” The way he said it was comforting. He talked a little about how it is still too early to know what the long-term damage from chemo and radiation is. He told me some stories about lymphedema and how it is necessary to do the massage every day or the fluid comes right back. He told me, “You must focus on the positive. You are here.”

From him, it was comforting. The message is always the same. You are not dead so therefore you are doing well. But I want to thrive not just be ‘not dead’.

I talk to my best friend about how I am doing absolutely everything right (except I eat white bread sometimes, white rice sometimes and my kids’ cereal frequently) and yet my numbers are moving at an expectedly slow pace. We contrast that with our other best friend who refuses to take her blood pressure medication and wonder who will die first. Even though she is not sick, she has had more stress than both of us. I hope it is not her.
MARCH 4, 2010: MY 1 YEAR ANNIVERSARY OF DIAGNOSIS

Category: Exhaustion, Estrogen Health

I managed to shake off my funk, depression and panic yesterday. I saw Dr. Warshowsky who reviewed the new plan to get my estrogen methylating. He and Dr. Veltmann had a conference call about me before I walked in the room and it seemed to me that only then did Dr. Warshowsky fully understand my genetic SNPs. He explained that my COMT SNP and GSTM SNPs were still compromising my ability to methylate estrogen. He gave me a more supplements and did not take away any and said he thought a drip was not going to help.

After seeing Warshowsky, I talk to Veltmann for ½ and hour. He is also no longer worried about my immune system.

I hope this time they get it right because I am scared by my body’s inability to ‘methylate estrogen’ and the weakness of my immune system.

I have dinner with MY NOT DEAD YET FRIEND who is back from Asia. He is back to his old self and it was a huge relief to see him like this. He is love and confident and happy. I am happy for him.

Next week is a full week of doctor visit after doctor visit after doctor visit. I must get ready for it.
Dear Everyone,

Hello. I am writing to celebrate my one-year cancer in-remission anniversary.

My oncologist says that my anniversary is the date at which I was diagnosed; March 3rd. My surgeon says that my anniversary is the date at which the tumor was completely cleared from the body; March 31st. In the spirit of reconciliation, I have decided to celebrate for the entire month.

My family and I have been trying to make up for so much confinement and isolation with mixed results. We went to Miami with My Little Sister, My Sister’s Husband, My Nephew and Mom after Christmas. Despite the 4 moves we had to make in accommodations and the freezing temperatures, I had a very good time and was happy to be with them.

The entire family went to South America for the first time in 4 years in February. The plane trips were a little too much for me and I got a severe bronchitis from the airplane rides both back and forth. I am finally on the mend from that and now we are going to The Old Country for Easter.

We will have a big celebration in The Old Country to honor March 31st.

After South America, I will be taking two short trips to Chicago and then will figure out how to spend the summer.

I joined a breast cancer support group and My Eldest Son keeps asking me what we do at the group. I explained that we all sit around and complain about having had breast cancer. He asked, “But it is over. Why do you keep talking about it?” I don’t have an answer for that except that the consequences of it are far from over, so we complain about that… It has been very helpful to meet other women going through exactly the same thing. For example, last week I found out that all of them are also having their eyelashes and hair fallout again. I am on my third time and thought it was only me. So, it is really helpful.

I have a lot of medical news which is very boring, but I will share anyway:

1) Big Decision: After extensive research, many doctor’s appointments and becoming incredibly sick from the treatment for swine flu (the medication Tamiflu), My Husband, many doctors and I have decided that I will not take the next stage of treatment, IV infusions of ZOMETA which was to last for 3 years. So, my current conventional treatment is taking Tamoxifen for 4 more years before switching drugs.
2) I was diagnosed with breast lymphedema in December. Lymphedema is when the lymph system in that area no longer works because it is gone, damaged, altered and the remaining ones can’t cope. It is from the removal of the armpit lymph nodes. It causes swelling. Most people get arm lymphedema. But in keeping with all my treatment being off the bell curve I have breast lymphedema which is not so common. Breast lymphedema basically means that I was over-radiated. Arm lymphedema is usually a surgical problem. It is a permanent condition which must be gotten under control. The serious part about it is that the inflamed lymph system continues to interfere my overall recovery and the rebuilding of my immune system back to something like normal. I am in physical therapy 3 times a week to try to help.

3) I continue my participation in the breast cancer study and working with the bio-chemist, Dr. Veltmann who runs it.

4) The new plan is that I am monitored quarterly for at least the next 2 years. That means every quarter I have a whole host of tests which is time consuming and nerve-wracking… but I am adjusting. I am hoping that once my tests come back showing that I am on the right track, it will be less stressful.

My immune system is weak, and I have been on antibiotics much of the time since radiation ended. It has taken me several months to understand that this is ‘normal’ after chemotherapy and that according to the doctors, it may take years for it to recover. I guess, like many other people, I thought that once treatment was over, I would return to ‘my prior normal’ and I kept waiting for that to happen…. It has taken me all this time to figure out that this is my new normal. So in between doctors’ appointments and children’s activities, I am in the process of putting together a website and a book which promotes the concept of this work which is genetic testing. I will send you the site when it is ready, and I look forward to your reactions and to your helping me get the word out about genetic testing.

I can’t thank you for your thoughts, prayers and notes during this wild year of adventure. For checking in on me and keeping me company in this adventure. I hope to see you soon.

Love, TJ

I forgot the most important thing… (chemo brain) Ironically, now that I look like a suburban housewife with cancer, I have actually become a complete bimbo.

Because I have passed the 1 year mark, my reoccurrence risk drops to about 27% instead of 30%. This will stabilize in 4 more years at around 20%.

TJ
Our trip to my father’s town was the most rejuvenating thing that has happened to me in a long time. It had been 5 years since I visited for 2 days to attend the funeral of my good friend and it had been 6 years since I visited for a week with My Eldest Son and My Husband.

I was welcomed at the airport by my cousin, and my father. I cried.

The next day we went for a walk around the property and my father lost his temper at every little question. My father is aging very badly. Living in the 3rd world gives a different sense of age and he is now much much older than my mother who is only 5 years his junior. He had been sick, and I thought that perhaps he would be better on his own turf, but it was not that at all. It does not help that many of his close friends are dead regardless of their age. He seems completely and totally unable to absorb any stress whatsoever. My Uncle J said that it was because he could not cope with my cancer and that it was my cancer that was totally stressing him out. He did not witness any of the treatment except the very beginning, he was not around for the aftermath so I assumed that he would be better able to protect himself. I don’t know, I only know that he is very neglected, and I am not in a great position to take care of him, but I will try now that I feel more like myself.

The 2nd night, we had a family party and some close friends came over. It was hard to catch up with anyone because there were so many people there, but it was great to see everyone. Dad made everyone sing me happy birthday I think because there is no song for “We are so happy you are alive. We are so happy you are alive. We are so happy you are alive.” But I understood the sentiment. Everyone was very happy for me that I was still around.

I was very happy that I was strong enough to withstand the very exhausting trip ½ way across the world.

The 3rd day we went to my favorite place in the world, a Roman ruin right next to the sea and then at night my old graduate school friends had a dinner for me in the jazz club that we used to hang out in (and they still hang out in). Many of them had not seen each other for many months so it was a real celebration. There were a dozen people there at least.

The next day we rested.

Then the 5th day we went to the beach in my favorite place in the world and then went up to the mountains to complete my solemn vow. An old friend of mine and My Husband and I had decided serendipitously that if I came out of this alive, we would climb the highest mountain in the country. There was still snow on it so that wasn’t possible so instead we went for a very short hike at the back of a friend’s house up to a lake. It was a very short little walk, but I was so happy and overjoyed to take it. My girlfriends had arranged for my family to sleep up at her house as they felt it would be too crazy to drive 3 hours in the morning, hike and then drive back. They were right. I don’t even know how to express the closeness that I felt that this group of people did something like this to help me commemorate my ‘still being alive.’ I cried a lot when we left.
Contd. My trip to the old...

The next day was Easter. My eldest son cut the space between his eyebrow and his eye deeply on the church steps as we were walking in, so we turned around and went to the emergency room. My Husband insisted on ordering a plastic surgeon because it was on his face, but they didn’t have any glue at the hospital, and he had to be stitched up anyway.

We left early the next day to Paris where we spent 24 hours and about a $1,000. We stayed at the airport Hilton, took taxis back and forth there, went for a boat ride and had two tourist restaurant meals and then left the next morning….it was about 4 hours in the city from 4 until 8 pm. Eldest Son really loved it and said it was the favorite part of the trip.

It was a completely insane trip, but I managed just fine. I became crabby several times when I was pushing myself too hard, but I was able to push myself for the very first time in a year without becoming very ill. Good stress is still good.
APRIL 14, 2010: E-MAIL SENT TO THANK FRIENDS FOR TRIP

Category: Family & Friends

Dear Z, A, L and N,

I sent you some pictures of our trip. I had the camera on some setting where each file is HUGE so I hope you can see them through the shutterfly site.

That was the most amazing 24 hours I have had in many years and I can’t thank you for arranging it, sharing it and reminding me who I am.

I only have one HUGE regret. There is not ONE SINGLE SOLITARY PICTURE of Z or all the kids.

The rest of my story is this…. I got my purse back with all my IDs from the beach club . . . I was so tired when I came home that I asked my cousin if we could go to church near my house and then go to a restaurant near my house. When we got to church, upon entering, Brunette Twin fell down on the steps and gouged the space between his eyebrow and eye, so we then went to the emergency room for a few hours because My Husband insisted that a plastic surgeon be called . . .

We got back late Tuesday night. On Friday night, My Husband and I were out for our anniversary in Queens. We had been at the place for about 5 minutes and he started complaining of agonizing pain. They brought him to the emergency room in Flushing, Queens to give him morphine etc . . . turns out he has a huge kidney stone. We managed to get him surgery this Monday morning, but he has been in bed on narcotics every 4 hours since Friday. Today was the first day we were able to give him less drugs.

If only all this had happened overseas, we would be ‘stuck’ there. Oh well.

Let me know if you receive the pictures.

Love TJ
APRIL 15, 2010: MY HUSBAND AND THE HUGE KIDNEY STONE

Category: Family & Friends

We returned from the old country on Tuesday night. On Friday night, My Husband and I went out to celebrate our 13th wedding anniversary. We went to the Spa Castle in Flushing Queens which is one of my favorite places. It is at least a 4-hour event to go there beginning with the entire floor of outside Jacuzzis on the top floor, the saunas and a meal on the middle floor and then ending with the Jacuzzis and steam room in the locker room. It is a Korean spa and a very relaxing place to spend some time. We had been looking forward to it for a while.

5 minutes into the top floor Jacuzzi, My Husband started complaining about severe back pain. The entire drive to the spa he had been talking about how incredibly tough his boxing workout that afternoon had been, how his legs were like Jell-O, how it was hard after so much time not working out during our trip. I assumed he was herniating a disc right before my very eyes. I was so annoyed I wasn’t even going to follow him out of the pool. But follow him, I did, he was standing at the counter saying he was going to throw up, that he was in horrible pain, and I called the young men who worked behind the food counter and told them to get him to lie down somewhere. The manager came, I kept talking about his back and his boxing workout but thankfully no one at all was listening to me. They called the paramedics immediately and they arrived very quickly.

The paramedics asked him a series of questions. Then they look at each other and say, “Kidney Stones”. I say, “KIDNEY STONES!!?? How do you know that?” They tell me nausea, where the pain is, the level of pain, the sudden onset etc. plus they both have had kidney stones. I try to get My Husband to agree to get into the car so I can take him back to Greenwich, but he and the paramedics decide we are going to the emergency room in Flushing. I will follow in my car. I can’t believe this is happening.

I think it must be stress. The emergency room in Flushing is worse than I thought. It is worse than the emergency room at University of Chicago in the middle of Hyde Park. It is worse than any crazy TV show on the air and it is more lively than any TV show. There are at least 4 people in stretchers and 1 doctor for all of them. There is no room in the curtained areas, so stretchers are lined up one after another. It was crazy.

There are people screaming for help. At the end of the night the police bring in a Moroccan guy who they have beaten up badly. They chain him to the bed and continue screaming at him. He refuses medical help and asks for to see the general counsel of Morocco. They tell him he is going to jail as John Doe and no one will ever find him.

Despite the chaos we are treated really well and really quickly. They give him morphine within 25 minutes. Take blood and urine and give him a CT Scan all within 2 hours. He has a huge kidney stone that is too big to pass. They tell us to keep him drugged up until he can be seen by a urologist on Monday and get that thing out.

While I wait to find out if he will be released or will require emergency surgery, I text my friend Joe and ask him to come to the hospital. Instead we wind up talking on the phone back and forth for an hour. He makes his sister come to the house in case My Husband can’t walk upstairs.
Contd. My Husband And The Huge

I make dozens of phone calls on Saturday but only reach the doctors in the suburbs. None of the NYC doctors will accept a page from a non-registered patient and for some reason I don’t feel like pretending.

On Monday morning, all the receptionists are very helpful but we are at the Greenwich doctor’s office and he is able to schedule him for immediate shockwave surgery. It didn’t go as well as it might have and My Husband is still in tremendous pain. I have been nursing him for almost a week but he is not good.

My life is only about medical problems. It is quite extraordinary. I wonder what it means?
APRIL 19, 2010: MY 46th BIRTHDAY AT GREENWICH HOSPITAL

Category: Family & Friends

On Friday, April 15, it became clear to the doctor that My Husband would have to have the stent and if necessary, laser surgery. On Wednesday and Thursday, he woke up in the middle of the night in agonizing pain and on Friday the doctor was able to schedule another ‘emergency’ surgery and get space in the Operating Room at Greenwich.

All of a sudden, we went from an external procedure to a plastic tube several feet long being left inside my husband for at least a week with a possible laser procedure. It was late Friday afternoon and I began to panic. What were we to do? I didn’t want to make the same mistake we had made with my first surgery. Instinctively, I thought that having an operation on your penis, bladder, kidney and all tubes in between at a community hospital in Connecticut instead of at one of the best hospitals in the country in Manhattan a short drive away was incredibly irresponsible and yet there was no choice.

It was Friday afternoon. I had not forced My Husband to go to a Manhattan doctor all week because I thought the shockwave procedure would work. The doctor had told me the odds were 90% that he would not require more than the shockwave and suddenly here we were. I panicked and didn’t know what to do. I couldn’t really leave him in pain, but now no other doctor would take care of him because he was already under the surgical care of the Greenwich urologist because of the shockwave procedure.

Dr. R gave My Husband a shot of ‘Toradol’ which gave him pain relief until Sunday and then suddenly it was back.

On Sunday, my mother and the kids and I drove to Central Park to see the cherry blossoms because last year I was too sick to take my annual trip. By the time I made it to the park last year all the blossoms were on the ground. My friend Jack and I had walked around the reservoir before the blossomed and then my children and I walked around when they were on the ground. This year we were there on the perfect day. It was a bittersweet celebration for me as my husband was lying in bed writhing in pain and I was celebrating without him. But celebrate I must because every old thing that is happening this year is brand new. Cherry Blossoms, Birthdays, everything.

When we came back, My Husband was in a very foul mood and I spent the rest of the day feeling sorry for myself because so one was celebrating me and me and me and me. I just couldn’t shake feeling sorry for myself which didn’t make sense because part of me all day was just happy to be alive.

I was afraid of what was going to happen on Monday. I felt incredibly irresponsible for allowing My Husband to be operated at Greenwich Hospital.

On Monday, they changed the surgery time from 3 until 12:30. The Dr. showed up at 1:30 in surgical scrubs and began to wheel My Husband away. I stayed in the room and waited. I was afraid to leave, afraid to stay because I was starving, afraid of anything bad happening. I was just generally afraid. I learned how to use the Kindle My Husband had bought me for our anniversary. I read about genomics and it helped distract me from the task at hand.
Contd. My 46th birthday…

At 2:30, the Dr came to speak to me. Told me that his ureter was so inflamed it was keeping the stone and all the fragments together. He put the stent in and took out enough of a fragment to send to pathology. He was short and left. He said My Husband would be back in 30 minutes. I did not feel hugely relieved because he said that one form of pain would be replaced by another. Kidney pain for stent pain. The stent should stay in for a week. It just didn’t sound good.

At 3:30, I asked the nurses what had become of him and they told me he was in a lot of pain and had to be given pain medication and wouldn’t be out before 4. I went to CVS to get Advil because I had a horrible migraine. I kept suppressing the fear. He came back after 4 and was taken to the bathroom.

I couldn’t believe that this is where we were a year later. We both agreed that all things being equal this was a million times better than last year’s birthday when I was waiting to start chemotherapy the next day. We came home at 7pm and My Husband remains in bed as I write.
APRIL 21, 2010: MY HUSBAND IS STABLE

Category: Family & Friends

I feel incredibly grateful to God for being able to concentrate on stupid things like my birthday and my mother’s summer trip to Europe.

My Husband appears to be stable after the surgery. He is in a lot of pain, but it is significantly reduced as he has not been living on Vicodin since the stent was put in.

I thank God for everything.

APRIL 22, 2010: MY LYMPHEDEMA & MY BREAST LUMPS

Category: Side Effect: Breast Lymphedema/Frozen Shoulder

The new therapist has done an amazing job of getting rid of the constant pain and I am able to start using my arms again. I have gone back to tiny little weight-lifting and the pain has not worsened which is a huge improvement. I am supposed to do the breast drainage massage every morning and evening. I did not do it in the old Country and have been trying to re-institute since my return. I can do the smoothing I was taught well but when I do the massage it is totally alarming. My entire breast is a serious of lumps and bumps. If I had not just had a mammogram, I would be having a nervous breakdown. If that is the new status of my breast, I wonder how could I ever find a lump on my own?

Dr. Estabrook says that I must not have a mammogram more than once yearly as I have been radiated enough but a friend of mine gets a mammo yearly and then an MRI yearly. I must ask if that is possible.

Who is watching me?
APRIL 27, 2010: MY BREAST CANCER SUPPORT GROUP

Category: Family & Friends

I attended my breast cancer support group for the first time in many weeks last night. I am the only one of the group who has not had a mastectomy so although no one ever says anything, I think they think I have it easy...but maybe not. The mastectomy stories and decision-making process is HORRIFIC...simply HORRIFIC. I have learned a lot about breast reconstruction. More than I ever wanted to know. There is a new girl in the group. She is 10 years younger than me. During a surgery last year in which she was removing breast implants that she had put in when she was 20 years old, they found a 5cm tumor under her nipple. She had had a clear mammogram only a few months earlier.

Every time I go to group, I learn a lot. Every single one of the women is constantly doing research as well... every single one of them has chemo brain which I decided last night is actually a form of self-protection like forgetting what childbirth pain is...

Another one of the women in the group can’t move her arms either...I urged her to go to the PT at Greenwich. One is having a 1-year anniversary party on Saturday and I will miss it because I will be in Chicago. I learned about another integrative oncologist that is located in Greenwich and I requested an appointment. I hope that works out.

My Husband has improved enough to be complaining incessantly. That is good.

We had to cut down a huge huge tree in our backyard today and it was very very sad. Now the animosity with the neighbors will surely increase. I can’t believe how I can’t let it go...I try to pray for not thinking about the backyard neighbors, but I keep returning to it.... I need to be busier? That is not possible.
MAY 1, 2010: MY TRIP TO CHICAGO: MY GRANDMOTHER’S BLESSINGS ON CHEMO CURLS AND YOU LOOK RAVISHING

Category: Chemotherapy, Family & Friends

My Eldest Son and I travel alone to Chicago. We had decided it was too strenuous for babysitter, the twins, My Husband and I to go to My Nephew’s 1st Communion. The trip was to be extremely busy and having the whole family for such a short trip was too much for me. It was a very good thing I had decided that earlier because My Husband was still laid up in huge pain with his kidney stones, the twins continuous sinus infection, ear infection and drainage and a cold on top of all of that was in full force.

My Little Sister picked us up and we sent straight to her house to help prepare for the party the next day. We had dinner with my best friends at a very noisy restaurant. It was so good to have a dinner with three of my favorite people in the whole world. I was relaxed and happy. It has been years since I haven’t felt rushed in everything I did.

My girlfriends could not believe how crazily curly my hair was. When I was a little girl, my grandmother used to give me home hair permanents on a regular basis. She basically forbade me to have straight hair. It was a huge challenge for her since my hair was thin and relentlessly straight. Also, extremely disappointing for her was the fact that I started to go brunette after my first 3 initial years as a white-haired blond. She and my mother began bleaching my hair first with lemon juice when I was 4 or 5 years old and it never stopped. My grandmother thought that ever one should look like Mary Astor and did her best to bring that about. When I didn’t have a permanent, I used to go to sleep with pin curls, curlers or braids so that my hair would be curly in the morning. My entire childhood was spent like this.

My hair was growing in medium brown with gray in tight, tight curls. As my hair grew longer, I had hoped that the curls would straighten out, but they did not. Having curly hair was almost as much of a shock every morning as being bald. I did not recognize the woman staring back at me with the thick curly hair bouncing up high off my head in all directions. I wet it down and put the thickest hair gel I could find on it ever morning pinning it all down with a multitude of bobby pins to look more like myself.

The next day all our family and my brother-in-law’s family came to the church to witness my nephew’s big day. My Sister’s Husband’s family came up to me and said, “You look ravishing. How do you feel?” Then he turned to one of his sons and said, “Doesn’t she look ravishing.” I had only met him once before at their wedding and can’t imagine he remembered what I used to look like so I didn’t understand the complement except the missing part…” for everything you have gone through.” All My Sister’s Husband’s brothers and sister said the same thing. “You look good.” “You look healthy.” They said this with complete surprise. I am not sure what they expected but they have a lot of cancer in their family, so I guess they expected me to look worse.

When my Aunt, my Mom’s sister, saw me the first thing she said was, “Look at your hair. Grandma would be so happy.” She ran her hands through the back of my hair where there were fewer bobby pins and said again, “Grandma would be so happy.”

I said, “Yes, Grandma is up in heaven orchestrating my chemo-induced follicular damage so that I have tight curly hair for the rest of my life. She is saying FINALLY.”
Contd. My trip to Chicago…

We all laugh about it because we know it is true.

With my aunt is my cousin who I have not seen in 20 years. We visit and get to know each other a little bit.

On my father’s side, one of my cousins who I have also not seen in at least 20 years is also there. We visit and get to know each other a little bit. It is relaxing to get to know them and relaxing to be at a party which I don’t host.

My Eldest Son plays with My Nephew’s cousins for the entire afternoon even after I leave to go downtown and visit with my girlfriends.

Five of us get together and they bring me the ‘game ball’ from the breast cancer softball benefit they did the summer prior. It is very touching for me but instead of crying, I laugh. We visit and laugh and share. For them it is a regular part of their lives but for me it is so special and means so much to see them and visit.

My Best Friend watches me have the extreme hot flashes that I always have and asks me if this is how it always is….and I say, “Yes. All Day and All Night but nighttime is much worse.”

MAY 2, 2010: GENE SNPs and ENDOIMETRISIS AND MEDICAL FOLLOW THROUGH

The next day I find that my sister has not followed through on her initial phone consult with Dr. Veltmann. She has severe endometriosis and now that she is older has all kinds of bladder problems. She goes weekly to have steroids injected into her uretha to try to tame the inflammation in her bladder. It is clearly not working.

And yet she has not followed through on any of the genetic tests that Dr. Veltmann sent.

She and I fight.

My website now has over 1300 visitors but I don’t know if any one has contacted Dr. Veltmann. I am clearly not explaining the genetic SNPs properly otherwise how can people continue to risk their lives when a simple test offers so much information.
APRIL 18, 2010: CHEMICAL CASTRATION, HOT FLASHES AND ESTROGEN LEVELS AND ACUPUNCTURE

Category: Side Effect: Early Menopause, Exhaustion

From the day they put the first chemo IV in my arm, I have had mind-bogglingly strong hot flashes. The medical word for what happens when chemotherapy forces a woman into menopause is chemical castration. It is basically the same as having a hysterectomy because the change is abrupt in the same way as a hysterectomy and the body is in shock.

It has taken me an entire year to figure out the pattern of my hot flashes. When it first started, I used to sleep with an ice bag. Most of the time my mother brought me the ice bag but when treatment stopped in October and the winter set in, I stopped using the ice bag and instead sleep with a towel that I use to wipe the drenching sweat off my face and body at night. That is not to say that the hot flashes don’t happen in the daytime; they do but at night sometimes it is just crazy.

They seem to be the worst when I am exhausted. The only thing that ever helps and sometimes not even then is acupuncture as I am forbidden to take most of the supplements that could help and too scared to take the ones on which there is not sufficient information.
MAY 6, 2010: MY HUSBAND HAS 3rd SURGERY IN 5 WEEKS AT WEILL-CORNELL HOSPITAL

Category: Family & Friends

My Husband and I finally went to see a doctor in NYC about his kidney stones on Monday. That was almost a month past the initial crisis. Dr. Delpizzo a very young guy, probably the first doctor younger than me whom I have trusted, explained how badly the doctor at Greenwich messed up My Husband’s treatment and scheduled surgery for asap. He explained that if we had gone to him first, he would have immediately scheduled to access his kidney through his back because the stone was way too big for laser surgery. Given that he has already had 2 surgeries, he was going to try to see if he could get it out through laser.

ASAP was Thursday. I sit in the recovery room by myself. A surgery that is supposed to take about an hour, which the surgeon though would take two, has taken almost 4 hours. Dr. P came out to speak to me and show me all the stones he retrieved which was basically as much as were ever in there. Clearly, Dr. U in Greenwich was not able to take anything out which was consistent with his first reporting to me immediately after surgery.

I am racked with guilt. How could I have let my husband have surgery in Greenwich after the botch breast biopsy in Yonkers. My extreme anxiety that I felt as the 2nd surgery was confirmed was completely justified.

I feel horrible for failing him and I hope that this will be the end of it for the time being and that they will let me see him.

I don’t know how he went through everything alone because this is difficult. Living without family is ridiculous and I believe too much of a burden. Our friends have medical fatigue from our stories. No one else can tolerate this much crisis. NO one has even asked about him for the past week because the story is going on and on and on.

The surgery has taken so long that all outpatient facilities are closed.
MAY 13, 2010: THE SHRINE TO MY NOT DEAD YET FRIEND TAKEN OVER FOR MYSELF

Category: Family & Friends

When MY NOT DEAD YET FRIEND was kidnapped in Asia, I thought I would never see him again. Our mutual close friend Susan was always hopeful about this situation. She works on a big newspaper and always knew what was going on long before me. I would listen to her updates and how she knew he would be released, and I would think she was completely unrealistic and sheltered from reality.

I put up a picture I got from one of the news releases next to my desk so I could send him energy whenever I looked at it. I figured that even though both MY NOT DEAD YET FRIEND and I had lost the ability to pray he would receive the energy somehow and it might offer him a nanosecond of relief in whatever miserable hell hole he was. I tried to do it many times a day.

He was released a few weeks after my diagnosis and came up to see me a few days later. I thought for sure I must be dying because he had just been through the most horrific experience and he came all the way over from far away New Jersey to see me instead of me going to him. I showed him my shrine to him.

My father came to visit a few days after MY NOT DEAD YET FRIEND release after my first chemotherapy and brought with him all kinds of statues of Jesus and Mary, holy water, holy incense and holy oils from the Old Country. He told me stories about the nuns in the convent praying for me and all my relatives praying for me.

My cousins came out of the blue with e-mails and they were the ones who kept in close contact even though most of them I had not seen in 20 years.

Sometimes, when I was very sick, I would just count all the people supporting me in the universe on both sides of the grave. The well wishes and energetic gifts through them from God or from God through them kept me afloat. Buoyancy in the word and the gift.
MAY 13, 2010: THE FIRST PERSON CALLED DR. VELTMANN FROM MY WEBSITE AND I TALK TO THE SCIENTIST WHO HAS FOUND THE “CAUSE OF CANCER”.

Category: Estrogen Health

Today I speak to Dr Veltmann for the first time in weeks about my site and Prof Cavaliere at University of Nebraska. Dr. V tells me that a woman called who has breast cancer and had done fertility treatments. We assume she called after reading my site. I feel gratified that all my hard work and neglect of my children has paid off.

If my story can save one other life it is worth it all, but I am greedy. Now that one has called, I want many more to investigate. I will never know if they call Genova, but I have done some research and will be able to put up more testing companies within a month or so.

I spoke to Prof. Cavaliere about his more recent work. He explained his lack of funding and I promised him I planned to promote my story and hopefully someone powerful enough would learn about his work and help him help others.
MAY 14, 2010: I MEET AN INTEGRATIVE ONCOLOGIST WHO WANTS TO LEARN ABOUT MY TREATMENT & I AM FAT

Category: On-Going Treatment, Side Effect: Early Menopause

Dr. Boyd is the first oncologist I meet that is genuinely interested in the list of supplements that I am taking. He is the author of Cancer Recovery. He is very familiar with most of the items I am taking and has strong opinions on my list.

But the first thing he discusses is my weight gain since August when I started taking Tamoxifen. He explains that the weight gain is so much that it may negate the benefits of Tamoxifen. He quotes multiple studies showing that the morbidity rate of women with breast cancer with low BMI's is lower than all others. He explains that the single most important thing I should be doing is maintaining a low BMI. In other words, I need to drop at least 25 pounds.

We discuss the weight gain and he explains that a common side effect of chemotherapy is insulin resistance. Given the history of diabetes in my family, it would not be uncommon and would explain the weight gain. He tells me to do research on the drug Metformin. He also strikes terror into my heart. All my life, I have been afraid of diabetes. Much more afraid of it than of cancer as it has been woven into the fabric of my daily life. All of my father’s brothers and my grandfather have died miserable, horrible diabetic deaths while we watched. Before their deaths, there were the terrible mood swings and violence. The words insulin resistance get my full attention.

My weight gain is partially a side effect of Tamoxifen, partially the result of my ‘chemical castration’ or abrupt entry into menopause and the full impact of menopause on my metabolism and partly the result of portion control from the NO WHEAT, NO DAIRY, NO CORN, NO WHITE RICE, BLOOD TYPE B, LOW ALKALINE DIET that I attempt to follow. Unlike most people who can fill up on a big thick steak, I never feel full without bread or pasta. Since I began strictly following all my proposed diets. Dr. Boyd gives me a flyer telling me to exercise at least 5-6 hours a week to decrease my recurrence risk.

We review my supplement list for almost 3 hours. He explains that high levels of folic acid can actually lead to cancer. He stresses that I can not take Vitamin B at the current quantities because although it may redirect DNA pathways, it may also facilitate the tumor along the way.

He speaks convincingly and with a LOT of data. We agree to follow up with Bloodwork and he will speak to Dr. Veltmann.

I leave his office shaken. Who am I to listen to and who can I trust with my recovery and my life? I can not take the views of an oncologist who has clearly studied supplements extensively lightly. I must consider them seriously and research.

Dr. Boyd gives me his book to further my understanding of his methodology.
MAY 15, 2010: I READ DR. BOYD’S ‘CANCER RECOVERY’ BOOK AND A LOW GYCEMIC INDEX DIET

Category: On-Going Treatment, Side Effect: Early Menopause

After even flipping through Dr. Boyd’s book, I feel like an enormous beached whale. The fat rolls on my stomach seem formidable and I vow to starve myself. Of course, this resolution only lasts a few hours before I regress. I begin to worry that perhaps I have become insulin resistant. While I have not had any refined sugar for months and months, I read his lists of foods to avoid and see for example, beets. For the past few weeks, I have gone out of my way to eat as many beets as possible. I have been buying them fresh, cooking them and eating them daily for weeks. My husband has asked me repeatedly what I am doing by saying, “Why are you eating beets all the time. You do realize that beets are a major source of sugar in Europe, don’t you?” I ignored him assuming that a diet of huge quantities of fruits and vegetables was okay all around and yet it isn’t. More discretion is required. I call my girlfriend in Chicago, the one whose husband died an abrupt diabetic death, and tell her I am worried about my insulin resistance. Now she worries, too. I hate to tell her but I wanted someone else to worry with me.

MAY 16, 2010: I ALTER MY SUPPLEMENTS & SCHEDULE A HIP SCAN JUST IN CASE I HAVE BONE CANCER

Category: On-Going Treatment, Side Effect: Osteoporosis

I alter my supplements based on the suggestions of Dr. Boyd. I schedule a hip scan so I don’t have to continue to worry about whether I know have bone cancer because my hip aches all the time and it will not stop. That will put to rest whether it is a muscle spasm, the Tamoxifen or cancer. I am tired of all the doctors and their constant disagreeing with each other.

My goal is now to take as few supplements as possible. I will wait for the results of all the tests I am taking before making any decisions.

MAY 18, 2010: MY HUSBAND GETS HIS STENT REMOVED

Category: Family & Friends

The urologist’s office calls the day before the appointment and tells My Husband to be prepared to have his stent removed in case the x-ray results show that it is possible. He takes the X-ray and then they come to get him for the procedure without telling us the results. I wait around wondering how long it takes to take several feet of plastic out of your penis. I hope that this will relieve some of My Husband’s pain.

Ironically, the pain has drawn us much closer in a way that my pain did not. Somehow watching my struggles did not affect him in the same way as being in excruciating pain for 6 weeks did. I think that is the first time is his life he has ever really been incapacitated and it resulted in him questioning everything
and becoming the man I married again instead of the Wall Street guy he has become the past several years.

It is unfortunate that he had to suffer so much but perversely I am happy that it worked out like this because I have had my husband back for a week or so and it is wonderful. I love him much more even than when I met him. Much more.

MAY 21, 2010: I MEET A PREVENTATIVE MEDICINE INVESTOR

Category: Estrogen Health, Family & Friends

My Husband and I attend a fundraiser for trees in Greenwich. We have no idea how we were invited and we know that we will be asked for funds but we go anyway as we like the cause. It is a very high-level soft sell fund raiser and there are only a few dozen people there at a country club in Greenwich. I meet the first person apart from one of my My Cancer Friend’s who knows all about genetic testing and medicine. The first person apart from Veltmann who knows a lot more than me. We schedule a phone call and he fills me in on the industry. He tells me my idea about spreading the information about estrogen metabolism and my story is by no means crazy. I am encouraged.

MAY 27, 2010: DR. BOYD BLOOD TEST RESULTS

Category: On-Going Treatment

I am typically much more worried about diabetes than cancer. When you watch your own family members die of a particular disease the fear gets genetically transferred. Dr. Boyd’s tests for insulin resistance come back completely negative. I am greatly relieved. One less thing to worry about on the cancer emotional roller coaster.

MAY 28, 2010: DR. BOYD VISIT

Category: On-Going Treatment

I see Dr. Boyd again, but it is a relatively short visit as I tell him I have adjusted all the supplements. We agree that I should maintain a low glycemic index diet and try my utmost to lose weight.
JUNE 1, 2010: DR. VELTMANN VISIT

Category: On-Going Treatment, Estrogen Health

The test results for the Estrogen Test and the other tests that Dr. Warshowsky ordered are back. Dr. Veltmann and I review at length. He disagrees with Dr. Boyd’s request for me to cut back on the B-vitamins and says I should just be more closely monitored by blood for all the supplement levels. We agree that I will be checked to see why my methylation levels are improving. He suspects that my stomach is not absorbing the nutrients properly.

But I have been told that for years about my ‘leaky gut’ syndrome about how my stomach does not absorb nutrients in a proper manner. I could have told him that a long time ago but since I have been taking the huge quantities of Calcium and the Calcitonin, my stomach has totally changed so no one asks me about it anymore.

We decide to cut back all the supplements I am taking to the original list. This is still extensive in my opinion, but it is a return to something reasonable. After all, if the primary researcher of the theories that Dr. Veltmann is pursuing in treatment disagrees with all the supplements, and I have had absolutely no improvement from the original improvement, I see no harm in coming back to basics.

JUNE 2, 2010: MY HUSBAND TELLS ME HE LOVES OUR HOME AND OUR FAMILY

Category: Family & Friends

My Husband’s intense pain for 6 weeks has brought him back to the person he was before almost 10 years on Wall Street changed him. He is appreciative and thankful for our life, our family and even our home. For the first time in many many years he is not complaining about anything. On the contrary he is seeing our children and perhaps me as I see us; as a gift from God.

And this is another Gift from God. To have my husband back, no matter how briefly, is a great gift.

JUNE 15, 2010: DR. ORATZ, BREAST CANCER ONCOLOGIST AT NYC, ONCOTYPE TESTING AND BISPHOSPHONATES AGAIN

Category: On-Going Treatment, Side Effect: Early Menopause

I finally saw Dr Oratz today. I had heard about her since the beginning but never gone to her. She was very thorough, put everything in the computer even though it took longer than making scribbles. She was half an hour late and apologized for it. Her office feels more like a chichi OB/GYB office than an oncology place. No sick patients on view, no sign of an infusion room. She disputed Boyd’s stopping Vitamin D, she wants to send the tumor for oncotype testing in order to make a more informed decision about
my hormonal treatment. She said that people talking about Aromatase-Inhibitors after 2 years instead of 5 years was the result of pharmaceutical company propaganda. She had zero interest in the estrogen metabolism work. She said that it was laboratory work and until it had been in a clinical trial was of no relevance to her whatsoever. She discussed the discipline of losing weight extensively and she was very thin and tiny, I felt like a gross pig standing next to her. She measured me and said I was almost 58 which means I am shrinking.

She was very thorough. She is the first oncologist to insist on the genomic testing of the tumor since my pathology report shows a mixed bag.

She told me to go vegan and that all the protein in the world wasn’t going to help my immune system. She said I received much more chemo than normal. And that we have absolutely no way of knowing why I did not metabolize chemo normally. She told me to do yoga because she has a very bad back. She said it would change my metabolism. She agrees with a low glycemic vegetarian diet. We discussed bisphosphonates at length and she told me is time for me to figure it out. She said that the bisphosphonates were as important as the Tamoxifen. No way to know if insurance will pay for the oncotype testing as she is using it in a way that has only been recommended for less than a year; in order to fine-tune hormonal therapy treatment.

We discussed bisphosphonates again. She said it was just as important as the hormonal therapy and reduced risk by as much as 20%. I don’t know what study she is looking at and must ask her for it.

It is all a bit discouraging as I seek a doctor to oversee my estrogen metabolism work. Dr Boyd was interested but didn’t respond to any of my emails at all and I imagine requires follow up. I haven’t even started, and I am exhausted. It is disconcerting to be the one teaching the oncologists, but I guess that is how it is with medicine. First the lab work and the studies, then the clinical trials and then the doctors… so they are the last ones to know in the chain of medical information?

JUNE 16, 2010: DR. BOYD IS STUDYING THE STUDIES

Category: On-Going Treatment, Estrogen Health

I ran into Dr. Boyd after physical therapy today while waiting for the elevator. I introduced myself assuming he may not know my name, but he laughed and said,” I know who you are!” I have all of your studies in my car. I have been trying to set aside time to read them.” I am greatly relieved and feel that perhaps I have fulfilled my quest to meet an oncologist who knows something about the treatment path I am pursuing even I have to teach him about it.
JUNE 21, 2010: MY BONE DENSITY CONTINUES TO DECREASE & I CRY

Category: On-Going Treatment, Side Effect: Osteoporosis

I have my second bone density test in 6 months. It shows a statistically significant deterioration. 7 months ago, when I took the last one, I was only osteopenic in 1 area. Now I am in 3 out of 4 in only 7 months. This despite the Vitamin D, the twice daily calcium supplements, the huge quantities of magnesium and the medicine Calcitonin. All my efforts are failing. Or are they?

I wonder how bad off I would be without all the interventions. Chemo, chemical castration, estrogen deprivation and Tamoxifen are wrecking havoc on my body. And I was starting to feel so good not quite normal but at least I could use my arms again. Last week, I went for the first normal swim I have had in 15 months. My arm/breast really hurts afterward but I was able to do it despite the lymphedema, scar tissue and atrophy. I thought I was on my way back.

For the first time in months, I cry and cry. My grandmother died like a hunchback. My father is becoming one and I am only 36 years old. I grieve for my body before chemotherapy. I cry and cry and call my best friend, but I can’t reach her. I wonder if I will get breast cancer in my bones because they are weakening.

I guess it is back to the drawing board. The plan to delay decision making about which bisphosphonate to take can not be delayed 4 more years until I switch from Tamoxifen to another type of hormonal therapy as I had hoped. I must carry on reducing my recurrence risk in every possible way.

I go home and schedule a series of more appointments.
MARCH 20, 2012: I HAVEN’T SEEN MY ENDOCRINOLOGIST FOR 6 MONTHS, I MUST UP MY THYROID DOSE AND GO BACK ON BISPHOSPHONATES


March is the big month. March marks 3 years of survivorship. I really prefer to celebrate the last day of September which marks the last day of my radiation treatment, but March turns out always to be a symbolic month as well. The veins in my right arm have completely given out and I am still trying not to use my left arm. I already have breast lymphedema and I really really don’t want arm lymphedema, so I save up all my blood work for once a quarter now when Dr. Hollister takes my cancer/tumor markers. My veins giving out has turned out to be a bit of a mixed blessing. I am no longer able to monitor various ailments more closely because the blood draw is so difficult, so it means I neglect some things.

Like my thyroid for example. I was doing well until Christmas for a time of about 3 months and then it started again. First, the weight gain, then the excessively excessive sleeping and worst of all for the past 2 months, the migraines and intense Charlie horses from the Tamoxifen. I now I should have contacted my endocrinologist months ago, but he needs data; he needs blood. So, I pushed off my visit with him until today. He was well out of date on my health and I can’t believe I had not informed him about all my various ailments.

The blood work showed the story that I already knew; I must up my thyroid dose AND go back on small doses of Actonel and keep upping the dose until I can tolerate higher doses. My bone density exam in June is sure to bring surprises.

Dr. Martorella explained that when you take compounded hormones, it is not unusual for them to work well for a few months and then ebb off in effectiveness. He said that upping my dose was totally normal and I was still in mid-range. We talked about thyroid problems post chemo and radiation and he added information that I didn’t know. He said that infertility medications can really wreak havoc with your thyroid. He said that he treats woman who come in with thyroid issues post fertility treatments.

I am sure it is all linked in. We talked about insulin resistance and Metformin and wondered if all cancer patients would take Metformin in the future. He said let’s look at your glucose markers next quarter and see if you are a candidate. He is such a gentle man and a gentleman.

After my appointment, I drive to Queens to buy a lot of specialty foods that my oldest has been asking for. Today will be our first appointment with a family therapist. I always knew this day would come but I had hoped he would be older. It is so painful to watch him suffer with anxiety and depression. I hope this therapist can help.
MARCH 22, 2012: EMAIL UPDATE TO FAMILY AND A FEW FRIENDS

Hello all,

I am in the middle of my March appointments. I saw Dr. Oratz, the NYU Breast Cancer Oncologist, I had my mammogram, I saw Dr. Martorella, the endocrinologist and I saw Dr. Hollister yesterday. I will see Dr. Estabrook in early April. I also just took my estrogen metabolism 24-hour test and am waiting for the results to review with Dr. Veltmann.

All is fine on the cancer front except that the lab forgot to run my cancer tumor markers. I must decide if I am willing to risk my veins again for the tumor marker test otherwise, I have to wait until June. I think I will wait and then go back in for it. As you may know, I am unable to get blood from my right arm and reluctant to risk my left arm because of the lymphedema risk so the blood draw is a big consideration.

My thyroid is not doing well again with the consequence that I am less able to tolerate the Tamoxifen that I must stay on for 2 ½ more years…. Dr. Martorella is upping my thyroid dose and we will begin experimenting with that again. I have gained a lot of weight, am super fatigued again, the migraines are back and the night leg cramps too. Hopefully, we can fix my thyroid and be back on track again. Dr. Martorella says that the type of synthetic drugs that I am taken often wear off after a quarter or so and the doses must be upped until the body finds the correct level. We have agreed that I will move to desiccated animal thyroid if this latest increase doesn’t work.

I also have to go back on Actonel for the osteoporosis as the last medications appears to have finally worn off based on the test results. I will start that in 2 weeks and see how long I can tolerate…. 

Dr. Hollister has said I must keep my eye on the ball….that all of these side effects from chemo, radiation and Tamoxifen are little price to pay for being alive. He said it a little more diplomatically than that. He said, in fact, that he is optimistic about my prognosis, that I look good and that he thinks I am doing fine. His practice is now officially part of Greenwich Hospital.

Alex and I have decided that I should stop trying to work for the foreseeable future and focus on myself, the kids, house and the foundation. I think that that is enough for the time being but while it doesn’t represent a change to anyone else it is a super big change in mindset for myself….

All is well. I am really looking forward to partying in next week.

Love, TJ

P.S. I have gained over 10 pounds in the last several weeks.
June 12, 2012: MY CHEMO CURLS ARE GONE

Category: Chemotherapy, Friends and Family

I have had a strange relationship with my hair ever since I shaved my head and watched it grow back extremely curly. After spending the previous 46 years trying to add volume and create some kind of a wave with permanents, curlers, braids, curling irons and special shampoos, my curly hair was a constant reminder of the change in my body and my cancer.

For the first year, every single time I caught a glance of myself in the mirror on purpose or by accident, I cringed. The intense curls were an incessant reminder of my breast cancer, the chemotherapy and the damage done to my body. Chemotherapy affects the hair follicles and many people’s hair reverses texture after breast cancer treatment. I had been told by one particularly sadistic and misinformed counselor prior to my second surgery that I almost certainly would come out of chemo with permanently gray hair. When you are facing death, the color of your hair seems so trivial.

Later though, when vanity returns full force, I think how lucky I am to have returned to my natural color. In fact, I hadn’t seen my natural color since I was about 5 years old when my grandmother started altering it with lemon juice, and then Sun-In and the constant permanents. My hair was a big disappointment to her when it started changing from white to brown and she kept trying to change it as long as she had power over my hair.

With the intense curls, I thought about my grandmother every day and how happy she would have been to see me with the curls….finally.

As time went on, the intense curls stuck directly out of my head like Bozo the clown. I invested in a myriad of heavy gels and slicked back my hair every day making sure that it stayed slicked down with dozens of bobby pins. I also initially kept my own natural color for fear of the chemicals but vanity and habit won and after a year I went back to highlights.

Finally, it grew long enough that the weight of the hair made the top part wavy and the bottom part curly. It actually began to look like the hair that I always envied and dreamed of having. I grew to love my chemo curls. I no longer had thin limp hair that had to be washed daily or sometimes even more. I had full, thick, wavy hair with curls at the bottom that didn’t need to be washed daily. Never mind that all this bounty was due to the damage of my body. It finally was the hair that my grandmother had wanted all my life and I finally liked it.

I refused to cut my hair at all. It was a protest against the head shaving and a little victory against death also I had a theory that given that my body had recovered somewhat that must mean that my hair follicles recovered somewhat and that if I cut my hair, the curls and body would disappear.

About 8 months ago I let the hairdresser cut ½ inch off the bottom. I was afraid that the curls would disappear but they did not. I was happy with my full hair that was longer than I had ever had since I was 5 years old.

Last week, I let the hairdresser cut an inch off the bottom continuing in the V-shape that natural hair grows in. My chemo curls are gone. The hair is still wavy but the kinky curls at the bottom that I thought looked so good are gone. Oddly enough, I will miss them.
JULY 5, 2012: MY EXHAUSTION IS TAKING A TOLL

Category: Exhaustion, Side Effect: Hypothyroid, Side Effects, Family & Friends

On April 24th, my eldest son had his 5th grade vaccine. Within 2 days his entire body was on fire. Every joint in his body was aching and he was crying continuously. My husband and I didn’t know what to do. I took him to the pediatrician and asked him to take every conceivable blood test he could think of before I took my son to a psychiatrist.

It turned out he had positive ANA. We turned to the pediatric rheumatologists. The top one finally drugged him into some relief by giving him adult strength Relafen, an anti-inflammatory, twice a day. Finally, after seeing the top 2, 2 orthopedists, and a neurologist we figured out that he had had an intense adverse reaction to the Diphtheria, Pertussis and Tetanus vaccine.

In addition to the joint pain and the constant crying, he also developed an acute sensitivity to touch or pain. His body began to misread pain so that a slight touch felt like an adult’s punch.

In the meanwhile, he developed an anxiety problem about his own body. All the doctors said that it was a totally normal response because that is when anxiety should come into play.

Yes, but they aren’t living with him.

These past 2 months have been amongst the greater challenges of my life. We passed the easy part, researching and researching and researching until we found the answer even though everyone told us to just accept the pain. I am doing a much poorer job of maintaining my patience with him.

It has been so difficult to watch and yet I am fighting my own exhaustion every day as my response to the thyroid medication becomes poorer and poorer. I am not taking 4 times as much thyroid medication as I was about a year ago and the results are worse. The radiation damage just keeps giving and in the meanwhile, it is my son or rather my 3 sons who suffer.

How can I live up to the challenges that their life presents to them when I continue to suffer from the impact of the cancer treatment?

Along the way in the process of taking my eldest to all these doctors, our history was given. The neurologist asked a lot of questions about how my son processed my breast cancer 3 years ago. She said that she thought some of his anxiety about his own body was a leftover worry about mine.

I hear her comments ringing in my ears all day long. I have tried these years never to feel sorry for myself or to feel angry….and it has not been a struggle until lately. I knew quickly after my diagnosis that my breast cancer was ‘self-imposed’ due to my fertility treatments. It was never a big mystery to my about why I had cancer or what I had done to ‘deserve’ it…. In fact, I always wondered about the anger so many women seemed to have about the disease until these past few months.

My anger and rage is bubbling over or is it my guilt that my actions did this to myself and then have made my children suffer so much?

I need a higher thyroid dose….Thank you for allowing me to vent dear readers.
SEPTEMBER 30, 2012

Category: On-Going Treatment, Family & Friends

I celebrated my 3rd year of finishing cancer treatment in Boston this year. I don’t like celebrating the diagnosis date. It seems stupid to celebrate the day I found out I had aggressive breast cancer. I realize the celebration is supposed to be about still being alive but that should be every day. I would rather celebrate surviving cancer treatment.

I went to Boston to go to a workshop. The guide of the workshop was wonderful, but it was too aggressive of a trip as I had to have an endoscopy the day before I traveled. have an ulcer from taking Voltaren daily for my migraines which I started during chemotherapy and never stopped because when I do, I get horrible migraines. My neurologist insisted that I have an endoscopy in order to figure out if the ulcer was bleeding. It was, it is and now I have to stop taking Voltaren daily and take drugs for a month to treat the ulcer.

To celebrate, I have been biking down the Hudson River on the Upper West Side of Manhattan yearly. This year it was even better. I met all my girlfriends at my sister’s house, and we went to a local restaurant. It is much better to be with my sister’s and my life long girlfriends than to be biking alone. It was a happy night, but I was super super tired. Flying immediately after an endoscopy was stupid but I am tired of putting my life off to fulfill my medical requirements.

In order to take care of myself, I skipped a party on Sunday and went to the airport earlier instead of pushing myself further.

OCTOBER 2012: BREAST CANCER MONTH

Category: On-Going Treatment, Family & Friends

Oh, how I loathe Breast Cancer Month!! While I commend the fact that all this fund-raising is going on all over the place and it leads to promising treatments and it has de-stigmatized the disease, I find it a constant reminder that I resent. To see building lit up at the top in pink seems festive and I am not sure that is the right emotion. Anger, sadness, hostility, hope, perhaps…. but such a bright springy color as pink just seems wrong.…..even the NFL players with their bright pink accessories seem to exude festivity. Perhaps they should get a more sad color… to represent breast cancer…like vomit colored green or dying leaf brown or a sickly looking purple. Those colors would represent Breast Cancer better than the festive bright pink which should be reserved exclusively for healthy born baby girls. Now that bright pink represents breast cancer, how do young mothers decorate their girl’s rooms?
SEPTEMBER 20, 2012

Category: Estrogen Health, Side Effects, Family & Friends

It has been so long that I have written but I know exactly where to start. This summer has been one of the more difficult times that I have ever had. My eldest son, who had the adverse reaction to the vaccine in April transformed from an elite athlete with a high tolerance for pain and deep competitive drive to an anxiety ridden reclusive little boy afraid of all of the things that he had loved all his life.

We did not travel this summer. We stayed at home and took care of him. My deep desire to resume seeing the world, my friends and my places, put on hold by another medication gone awry.

I couldn't help but compare going through chemotherapy and this past summer constantly although they had nothing in common except the medical trauma of all involved. I kept asking myself which was worse and I kept thinking that except for the thought that I would have made my children orphans, this past summer was harder. Watching is harder.

I know understand how my husband hasn't really recovered from the stress of cancer treatment and the fear or recurrence. I asked him and some close friends to help me gather data for the Hormonal Cancer Foundation, www.myestrogenbreastcancer.com at the Susan B. Komen walk in Central Park several days ago. My husband arrived late and when he did arrive he was paralyzed. He couldn’t do it. He came back to me with his clipboard and spreadsheets empty and declared.” I can’t do it.” I said, “Of course you can.” And he said, “No. I really can’t. I can’t do it.” He was kept company by my dear friend Hope, constant companion in these tragedies. Her mother died suddenly of pancreatic cancer. She couldn’t do it either. But she did help. She interviewed and talked to dozens of women.

It is really hard to bear witness. I couldn’t do it either before and tried to walk away from the cancer work, but I cannot. Even though this mission remains not much further away from where I started 3 years ago, I still cannot drop it. I keep thinking that if one woman saves herself through the information, I try to spread than it is worth it. But I feel alone. I rarely get emails from women asking questions.

At the walk, very few of the women I spoke with understood what I was asking or why. Many women didn’t know what type of breast cancer they had. Between the 3 of us, we must have distributed over 500 cards and personally talked to over 200 women. I have not heard from one and it feels lonely out here. I want to make sure women are trying to make babies not breast cancer, but it is hard to listen and obviously I am not communicating well.

I redid the website at great cost and time, but it seems to attract even less people than the original one which was so amateurish. The volunteers who I hired have disappeared and I feel alone again.

And yet, I strongly feel that this information is critical to women’s fertility management. Most of the women I interviewed at the walk did not use either fertility treatments of HRT. I realize now that I should also have been asking them about their use of birth control pills as the older pills, such as the ones that I took 35 years ago were strong and not like the tiny doses that girls take today.

So dear reader, I am whining and complaining today but I will recover and carry on.
MARCH 11, 2013

Category: On-Going Treatment, Tamoxifen, Hysterectomy, Family & Friends

Dear Reader,

It has been such a long time since my last entry. I apologize. The last time I planned to write was in November when I learned I was having a problem with my uterus due to the Tamoxifen. That corresponded with Breast Cancer Month in which I learned a lot about how my foundation was not being successful in helping women.

It has been four years and a week since my diagnosis with Stage 2B breast cancer. It will be a few more weeks until the 4th year mark of finding out about the lymph nodes metastasizes. I became disheartened and for that I profoundly apologize because I have such a wonderful life filled with love and sometimes laughter.

In November, a very good family friend died from ovarian cancer. She was the sister in law of my best friend, and I have known her since I was about 12. She had befriended me these past few years of cancer and I was struck by how far she went out of her way to be around and supportive of me. She was in remission last year and then she wasn’t. Although I believe that we are all connected, I never considered her in my inner circle at all, so it was very odd how I found myself crying hysterically after learning about my uterine problems in November. Although, it was and still probably is a reaction to the Tamoxifen, it was hard to hear about uterine and ovarian cancer risk and how if Tamoxifen was going to cause cancer, the damage had already been done even though it was probably nothing… Nonetheless, in my entire cancer voyage I had never spent most of an entire day crying and feeling sorry for myself. Even as I cried, I wondered why I was crying and attributed it to cancer fatigue…. the syndrome of super intense, sick to death, of the constant monitoring, the drugs, the talks, the doctors, the blood work, the biopsies…. otherwise politely none as cancer fatigue.

It all made sense the next day at noon, when my girlfriend called me to tell me that she had died the day before and that she was now walking into the house to see her brother. So indeed, I had not really been feeling sorry for myself at all but mourning the death of my friend. My girlfriends kept telling me that she was dying, and I kept saying yes, I know but I kept imagining that it was going to be months and months away. I kept imagining that I would have time to say goodbye since I was going to be there only a few days after she died. I sent her comedy videos and protein shakes and flowers and candy. I expected to get a laugh out of her somehow as I know it is the best medicine. And yet death came quickly even though they kept telling me it would.

I always become sad when someone I know of dies from cancer. Until now, mostly I haven’t really known the people I grieved for, but I do now. What a horrible horrible disease and yet I know spend all of my time embraced by the disease as I try to promote the tests which I believe will save people’s lives.

It is a difficult relationship I have with cancer. It shapes and gives meaning to my life and let us hope it does not do so to my inevitable death.

www.myestrogenbreastcancer.com
MARCH 21, 2013: LETTER TO IMMEDIATE FAMILY AND CLOSEST FRIENDS

Category: On-Going Treatment, Tamoxifen, Hysterectomy, Family & Friends

Today, FINALLY, I just finished my rounds of exams that started with my uterine/ovarian testing on March 5th. I believe that was the day that 4 years ago I was diagnosed. As you know I like to celebrate September 30th, the day radiation ended. Between today and yesterday, I have gotten everyone’s opinion and all is clear. I am responding to the tiny tiny amount of Actonel that I am taking for the osteoporosis so that is very good news and I am very relieved about that.

The new plan is that I stay on Tamoxifen for 10 years and then switch to an Aromatase Inhibitor (another breast cancer drug class for post-menopausal women). There may be another treatment option 6 years from now.

I am having side effects from the Tamoxifen in my uterus, but it looks like that is normal and consistent with the known changes that Tamoxifen induces. I am not sure I can contend with the uterine problems for another 6 years so I will discuss the possibility of taking the uterus out at the next round of check-ups in June. If you recall, I went through this exercise 2 years ago and we decided to let well enough alone. I suspect that the consensus opinion will be to leave everything alone.

I am very much looking forward to the next quarter of no cancer doctors.

Love, TJ
AUGUST 2013

Category: On-Going Treatment, Exhaustion, Tamoxifen, Hysterectomy, Family & Friends

I have not been writing lately; cancer fatigue and time. The recurrence, treatment and death from ovarian cancer of my close family friend continues to weigh heavily on me despite my efforts to ignore, deny, disassociate or embrace; especially as my next big cancer decisions involve my uterus and ovaries. My best efforts to deny disassociate ignore delay and embrace have all failed.

I also feel like a broken record. The decisions I face have been on the docket for many months if not a year and I feel like I am going round and round like a hamster in her wheel.

The change in protocol from 5 to 10 years on Tamoxifen has resulted in a flurry of follow up visits to all my NYC doctors. Unfortunately each of them recommended a different course. At the moment I am leaning towards the most aggressive. Here are my options:

1) Stay on Tamoxifen for 6 more years, continue to monitor my uterus and ovaries; don’t worry about cancer because if it develops they can remove it surgically and then monitor my entire body for the rest of my life.

2) Stay in Tamoxifen for 6 more years and DON’T monitor my ovaries and uterus. If I start bleeding the can remove the cancer and monitor my body for the rest of my life.

3) Stay on Tamoxifen for 6 more years and have a complete hysterectomy which entails serious surgical risks. Since I have never done well with surgery the risks are a concern but this would alleviate one of the main side effects from Tamoxifen leaving only the stroke and heart attack risks which I can no longer treat because of my bleeding ulcer.

4) Start Evista which is kind of ‘Tamoxifen lite’ and take that for 6 years. Regardless of my choice, I will start taking Evista when I return from my current business trip to see if I can tolerate. Evista is a bone density drug with musco-skeletal and vaginal side effects so I don’t know if I can tolerate but I will try.

5) Take Tamoxifen for 1 more year and then take an aroma taste inhibitor which based on my reactions to other drugs is unlikely that I will be able to tolerate.

So why have a hysterectomy? One of the primary risks of Tamoxifen is uterine cancer and the risk doesn’t decrease when you stop taking.

I understood that my uterus was becoming increasingly thicker over time but as it turns out it was the errors of the ultrasounds I was having up at the local hospital. Once I went back to the city, to my former radiologist at St Luke’s it appears that all the prior readings were inaccurate. It seems that all of the worry I have loved through for the past 2 years was completely unnecessary and that my uterus was completely normal all along.

Testing resuming in worry, resulting in fear and bad decisions. The breast cancer specialists are telling me not to worry about it that I should just relax and see if I bleed. However, they are the ones who have not wit eased my reactions to drugs.
My Greenwich doctor is the only one who really knows and understands how sensitive having watched me and been responsible almost die from chemotherapy.

All through my cancer odyssey I have secretly thought that women who had prophylactic surgery were acting completely out of fear not science. Now that I face a similar option, I find myself agreeing with them. If I can completely erase my increased uterine and ovarian cancer risk through a hysterectomy, why not do so.

I asked my husband to attend the many appointments I had earlier this month and he was very hostile to the idea of surgery. He kept looking at the risk percentages and absolute numbers and saying this doesn’t make sense. His denial of the strength of my cancer in remission was shattered when Dr. Hollister explained in detail the reality of the risk and the lifelong consequences of the early stage uterine cancer.

Still I agonize about it and have not scheduled the surgical date yet. The surgery is more serious than any of the others I have gone through. The make 2 holes above the ovaries, make a hole in the belly button and use the vagina to take everything out.

Anxiety reduction through surgery. I am all for it. I think I must go back to my breast cancer support group.
I have known my best friend since I was 3 when we moved next door to her and her 6 siblings. It is her sister-in-law, who we have known for 35 years that just died from ovarian cancer. Or as we had taken to refer to each other, “The other Polack with cancer”.

My girlfriend came to visit early in the summer before my children were out of a school. She was tired and so was I, so I didn’t make much of her sleeping and subdued behavior. She said she was exhausted from a rough school year which had just ended. I thought she was also worried about her oldest son who had just gone through a horrific and depressing experience at college. Her daughter was also with her and i thought that might change her behavior too. It didn’t occur to me that something was wrong during her visit. I was glad she was tired as usually when she visits, I am not able to keep up with her and almost always wind up with migraines.

It was a several days after she left that I had to ask, “What’s wrong.” She lied and said nothing I said, “I don’t think so. Tell me what’s going on.” The last thing I expected was for her to tell me that she had a lump in her breast. She had had an irregular mammogram, a biopsy and was waiting for the results. The kind radiologist had shown her the images and told her he thought it was a papilloma which is rarely cancerous, but she wouldn’t know until the biopsy came back. And so, began my best friend’s breast cancer odyssey.

I couldn’t breathe and tried to remain reassuring. I told her I had had several of those in my colon and that they were no big deal.

Then I waited.

A day later she got the results but was told she would have to have surgery to have it removed.

She thought the risk was over until she met her breast surgeon who told her there was a 30% chance it would be cancerous. Then the agonizing wait for surgery and the biopsy results.

The tumor was immediately beneath her nipple so there was a good chance her nipple would be inverted after surgery.

I was to travel there soon. I met her boyfriend and thanked God for him. He provided more support than she would acknowledge. I liked him and could tell that she did too. Normally she dresses a tiny bit better than me but not much but this trip everyday she was dressed cutely, with makeup and ensembles no doubt picked out by her fashionable daughter.

I swallowed every bit of advice that wanted to pour out of my mouth as she told me that she wanted to delay surgery during my first time meeting him.
Surgery finally happened 2 weeks after I went home. I was very anxious. Her sister and boyfriend went with her. Surgery took 2 hours as try had to move tissue around.

The biopsy didn't come back for 3 or 4 days. She called me immediately and it was clean. I could breathe again.

Are you freaking kidding me?

AUGUST 30, 2013: STOPPED TAMOXIFEN – I FEEL LIKE A MILLION BUCKS

Category: On-Going Treatment, Exhaustion, Tamoxifen, Hysterectomy, Family & Friends

In the great confusion about Tamoxifen and my uterus, one of the breast cancer oncologists told me to stop Tamoxifen for a month and then start taking Evista. I seized on the opportunity and stopped immediately. A few days later the new ultrasound showed that my uterus was totally normal and there was nothing to worry about but I decided to take the month off Tamoxifen anyway since I had already stopped for a week.

Within 10 days, my energy resumed and I felt like myself for the first time since at least a year before I was diagnosed. Bouncing with energy, anxious to do things and I was able to finally work hard on the new company I was forming.

I felt like myself and I had a wonderful realization that what I thought was permanent chemo-damage was actually the side-effects from the Tamoxifen. What a relief to know that someday there would be an end to the cloud of fatigue and fragility under which I lived.

Hip Hip Hooray!!! But what if the cancer was creeping back???
OCTOBER 28, 2013: I FACE MY HYSTERECTOMY

Category: On-Going Treatment, Exhaustion, Tamoxifen, Hysterectomy, Family & Friends

I can no longer pretend that my hysterectomy is not a pressing concern weighing down on me like a ton of bricks. It has made my work load impossible. I keep thinking how can I prepare everything in time to disappear for a week, two weeks maybe even 3 weeks and then after that it is Christmas and I will be disappearing again.

The self-imposed work pressure is stupendous. Perhaps it is best though to hide from my surgical anxiety. I am so worried about the surgery itself, the pain, the inevitable migraines, the concern of my children and my husband all being something to bear...not to mention the piling up of emails....

It seems ridiculous to extract all these completely healthy parts of my body because of a future risk and yet ridiculous not to...this week I talked to someone who is fighting cancer with Vitamins. That seems like a sure fire way to die quickly.

Time to start praying more steadily.
Afterword
AFTERWORD

For the patient reader that makes it through the my seemingly endless journey of my initial cancer treatment diary, I will follow up with certain continuing themes.

I had my hysterectomy in order to stay on Tamoxifen for 10 years and not have to be monitored quarterly. All tissue was healthy, and it was only when my mother was diagnosed that I was very grateful that I had the preventative surgery.

It was a godsend that I never went ahead with the Zometa trial. I have tried every single type of bisphosphonate in order to slow down the my osteoporosis and maintain strong bones as per standard breast cancer treatment advice. I have been unable to tolerate even the smallest doses. I take 5mg of Actonel once a month instead of once a day.

My thyroid continues to slowly decline, my lymphedema and frozen shoulder improved but still require vigilance, I struggle continually to maintain a low BMI and am up and down constantly. Now that I have switched to an Aromatase Inhibitor it is even more difficult to stave off obesity. I have a myriad of skin issues related to the cancer treatment culminating in a photosensitive reaction to Tamoxifen just as I was about to switch to an Aromatase Inhibitor.

I continue to fight with my sisters but get along better with my husband.

My father was diagnosed with pancreatic cancer and followed the cancer mortality charts almost to the day. He came to NYC for surgery and chemotherapy at Sloan Kettering before returning to the old country. He lived with me for 6 months. I wish that he was healthy and that I rarely saw him like I complained about in the diary.

My mother was diagnosed a few months after my father left NYC. My mother died 3 years after beginning a heroic journey of staving off death with grace and fortitude guided the brilliant Dr. John Moroney at University of Chicago. She lived far longer than was expected and died much quicker than expected. Both, I believe, by sheer force of will.

I now fear cancer.

My remain passionately committed to improving estrogen function as an adjunct to breast cancer prevention.

I hope that my cancer diary, website and presentations provide some company to other women who felt that they were the only ones who didn’t sail through cancer treatment and shed a tiny bit of light on the mystery of breast cancer.

Yours in Good Health,

TJ