

## My Story

Thank you all for coming. Before we start I would like to play a 3 minute video that I put together, expressing the devastating emotions that come with a diagnosis of cancer.

## STAND BY ME

## QUIZ

### Introduction

My name is Michelle Dirksen and I was Diagnosed with stage 4 Inoperable Ovarian Cancer. The worse there is of all the Gynecological Cancers

### The Facts

Every seven minutes, a woman is diagnosed with a reproductive cancer — cervical, ovarian, uterine, vaginal and vulvar — touching more than 90,000 American women each year. Many are not diagnosed until the late stages of these diseases, and nearly a third will die.

### My Background

In 2004 I was on Section 8 housing and S.S. Disability Benefits

Wanting a better Life for myself I decided to get off section 8 housing, which was a very difficult decision to make. I had no money, was surviving off government programs, I couldn't afford to buy pizzas, go out to dinner, or even buy a stamp sometimes.

I decided I wanted to return to work and start making money.

That was a very hard decision, but I pulled myself up by my boot straps, and did it. Then I was diagnosed with cancer.

### Progression of events

- ⑩ April 1 moved
- ⑩ Lower back pain for some time
- ⑩ Made call on April 21 to see dr Reagan,
- ⑩ Friday May 2 got appt > 11 days passed
- ⑩
- ⑩ Sunday May 4 CT Scan Called from his home large mass possibly cancer
- ⑩
- ⑩ Tues May 6 Gynecological Surgeon told me to call my family > 2 days passed
- ⑩ Beth Israel Gynecological Oncology Surgeon
- ⑩ Did Pelvic Test,
- ⑩ Biopsy,
- ⑩ Blood test,
- ⑩ possible Fallopian Tube Cancer?
- ⑩ It had metastasized and was attached to my
- ⑩ Liver,
- ⑩ Bladder,
- ⑩ Uterus,
- ⑩ Ovaries
- ⑩ Pelvis,
- ⑩ Vaginal Wall

- ⑩ Lungs
  - ⑩ Colon
  - 10 day wait results of biopsy
- > 15 day passed time of initial call  
 > 25 days passed since initial call

### LIFE ENDS

I started doing Research on different types of gynecological cancers Because I didn't know what kind it was and I wanted to know how it would be treated

Immediately think the worse prognosis (less than 1 yr-3-5 years)

- ⑩ What are my treatment options,
- ⑩ Chemo?
- ⑩ Radiation?
- ⑩ Surgery?
- ⑩ What about the side effects?
- ⑩ hair loss,
- ⑩ not responding,
- ⑩ sick,
- ⑩ death?,
- ⑩ what happens to kids?,
- ⑩ work no income
- ⑩ financial help? Where?,
- ⑩ How to get to Dr appts?,
- ⑩ Rides,
- ⑩ Support Groups,
- ⑩ Where did this come from,
- ⑩ What kind of tests,
- ⑩ Who covers co-pays,
- ⑩ Where do I get help,
- ⑩ What does ins cover?, ( \$10-16,000) for chemo
- ⑩ Who can I talk to?

**First thing** I did I made invites for funeral, list of people for kids to call for funeral, Funeral arrangements, Funeral Homes

- ⑩ Cremation,
- ⑩ Town plots,
- ⑩ Financial assets,
- ⑩ living will,
- ⑩ Health Care proxy,
- ⑩

10 days after biopsy Diagnosis came form B.I Inoperable Ovarian Cancer stage 4 metastasis. And was the size for a basket ball.

After diagnosis make appt. for Clonoscopy, Endoscopy very painful!

Then went Hematology Oncologist, BI Talk about treatment options. And prognosis

Car broke down which now I cant afford to fix

Less than 1 year

Now I had an idea of what I was facing.

I didn't like what she had to say, Went for second option at Dana Farber Dr Berlin  
Im losing more time

>30 days

she set me up with Cape Cod Oncology Dr Lovett at the Davenport Mugar Cancer wing at Cape Cod Hosp. Saw him on June 2  
They did a Tumor marker Test

#### Explain Tumor Marker Test

Tumor went from 900 to 1400 in 4 days

There we talked about therapy I could have,

Chemo only. 6 treatment at 3 weeks apart. Total of 18 weeks with

no guarantees. Just depends on how well I do.

Financially strapped, didn't know how I was going to pay my rent \$1000.00 month.

- ⑩ Monthly Bill
- ⑩ Car repairs?
- ⑩ Gas
- ⑩ Food
- ⑩ Where do I go,
- ⑩ who do I ask?

Marie comes down couldn't do it without her

- 
- ACS went from there. Referrals etc.
- First treatment on June 25
- 2 days after chemo pain fluid Ambulance ride to cc hospital 3hrs there,
- . Ambulance \$3,630.81
- Emergency Room w/Cat Scan \$6,509.69
- 
- B.I. drainage for 10 days
- Tumor breaks apart and causes cancer cells to fill abdominal cavity
- When I got home extremely tired. Couldn't walk,
- fell down stairs,
- Cook,
- Laundry,
- things as simple as taking ride to Orleans everyday activities came to halt.
- 1 month later Sister was diagnosed stage 3c
- 
- First thing I did was to Called Hospice, Had to get an intake first, then arrange Hha Cna Nurse.
- Still didn't have anyone to do laundry,
- Had to coordinate volunteers,
- rides
- hospice,
- schedules,
- trips into town
- had to pay out of pocket for supplies that ins and hospice doesn't cover.

> 2 months

Went through endless referrals for help.

From there it became a process to try to arrange all the services and help that I needed. Because I Couldn't pay rent or any bills So I had to start making phone calls

After my second chemo I kept a schedule of things that would happen after chemo, 1<sup>st</sup> week 2<sup>nd</sup> week 3<sup>rd</sup> week I wanted to know what to expect

- Day 1steroids,
- 2 day getting tired
- 3 very Joint and muscle pain stabbing
- tired until 6-7<sup>th</sup> day. Then I started to feel more normal.
- You have to remember Chemo is Nuclear Medicine. Made up of Nuclear components. Red/White Blood counts go down, more prone to infections, sickness
- **My side effects were**
- Neuropathy
- Hair Loss
- Taste Buds
- Cravings,
- Grapefruit,
- Oranges,
- Citrusy things. Body telling me what it needed
- 

After fifth treatment talked to surgeon, wanted surgery, financial , why not wait until after last one? Lovett on fence, decided to wait.

**Lying in bed need money,** didn't want to go backwards, wanted a lot of money to make my last years as good as possible especially for kids. Realized I could be dead, in the ground, My thinking got side tracked, don't expect much, happy to be alive, though through the reality of it, I could make it as good as I wanted. Be thankful. Im not asking for a lot of money, it will be OK. I will be ok, it is only what I make of it. Don't be selfish.

### **Things to remember**

Even though you fell good, you are not good. Have to remind yourself you have a life threatening disease which will become apparent if you try to do to much. You're not alone, even though you feel like you are, trust me no one has been more alone than I have. With the help of Hospice, and Social Workers, you will get help, but it wont be everyday, and it wont be all day. You will need to plan and organize all your activities that will need to be done. Volunteers are available through Hospice Organizations and people like HOW.

It will take time, A lot of time, but hopefully the list that I pass out at the end will be helpful. You will need to plan for your finances, bills to be paid weeks in advance. Very few Organizations will be available to help you quickly. Plan on getting help a month in advance.

### **TESTS**

Most people are diagnosed in late stage, no test or screening available

**CA 125** is a Tumor Marker Test not effective for early stages

Normal tumor marker is 0-35  
 Tumor Marker went from 900 to 1400 after  
 1st treatment down to 850  
 Second Treatment 350  
 Third treatment 180  
 Fourth Treatment 35  
 Fifth Treatment 4.2

Look into clinical trials, as it will help for different types of cancer.

Some tests are underway to use your

- ⑩ own immune system to fight the disease
- ⑩ Vaccines
- ⑩ Ovanext

### BRCA 1 and 2

Proteins that would normally stop Gene mutations,

The BRCA1 gene belongs to a class of genes known as tumor suppressor genes. Like many other tumor suppressors, the protein produced from the BRCA1 gene helps prevent cells from growing and dividing too rapidly or in an uncontrolled way.

The BRCA1 gene provides instructions for making a protein that is directly involved in repairing damaged DNA.

The BRCA1 protein interacts with several other proteins, to mend breaks in DNA. These breaks can be caused by natural and medical radiation or other environmental exposures, and also occur when chromosomes exchange genetic material in preparation for cell division.

By helping repair DNA, BRCA1 plays a role in maintaining the stability of a cell's genetic information.

BRCA2 BRCA2 gene helps prevent cells from growing and dividing too rapidly or in an uncontrolled way.

The BRCA2 gene provides instructions for making a protein that is directly involved in the repair of damaged DNA.

### Symptoms / Treatments/Statistical Information

- ⑩ Lower back pain,
- ⑩ bloating
- ⑩ constipation
- ⑩ bladder trouble if it gets this bad, cancer has already spread to other Lymph Node Chains

### Treatments

May be able to do debulking surgery total hysterectomy, (Both Ovaries, Fallopian Tubes, Uterus, Cervix, and other tissue in the abdomen and pelvis)  
 long recover time depending on person

**Chemo therapy**, (Taxol and Carboplatin, most toxic) most common side effects

- ⑩ hair loss,
- ⑩ neuropathy,
- ⑩ muscle and joint pain,
- fatigue,
- ⑩ chemo brain
- ⑩ After chemo Red, white, platelets counts will go down, may not be able to have another treatment until levels return to at least a baseline, or may have a transfusion.
- ⑩

## **Radiation**

**Surgery before or after.** With possible second surgery

## **Remission**

Remember remission doesn't mean it won't come back. If and when it does return, it comes back as a different mutant gene. Will probably need different kind of treatment, as original won't work. When it returns for 3-4 times it's the end of life

## **Statistics**

After 1<sup>st</sup> round 96% may have to continue with another 10-12 cycles, but they don't like to do that immediately because it has a cumulative effect. Prognosis could be 1 in 10 after 5 years. Not definitive

15% will survive stage 3 or 4

After remission prognosis rate is 30% will make it 3-5 years

40-50% will re-lapse

72% will relapse after 5-15 years

65% will die

If disease free for 3 or more years 48% survival rate

After 5 years 48% will survive

If 65 years or older 15% if it is found early will survive

Rarely curative

Smart disease

More than 20,000 women in the US are diagnosed with Ovarian Cancer and more than 15% die annually from the disease

Women with a First Degree Relative (mother, daughter or sister with Ovarian Cancer) have a 3 times higher risk of developing the disease. The risk increases when 2 or more first degree relatives have been diagnosed with Ovarian Cancer

Having a diagnosis of Breast Cancer increases the risk for Ovarian Cancer even when the BRCA GENE 1 or 2 test is negative

Women of North America, Northern Europe, or Ashkenazi Jewish heritage have an increased risk of Ovarian Cancer

Women who have never had children, have unexplained infertility, have not taken birth control pills, or had their first child after the age of 30 are at more risk for Ovarian Cancer

women who started menstruation early are all at a higher risk of developing Ovarian Cancer  
Women who have taken estrogen only replacement therapy after menopause have a higher risk of developing Ovarian Cancer

Recent studies have shown that women who were obese in early adulthood, have a higher risk, and are more likely to die from the disease

Homosexual or Bisexual women have a higher risk of Ovarian Cancer because they are less likely to have children, or take birth control pills

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I'm going to provide you with a List of References and Referrals for Organizations that provide anything from Financial Assistance to Retreats for Children with Cancer.

There are NOT a lot of Organizations that offer Financial Support, because they are ALL non-profits and funds are scarce

There is a lot of organizations that fund Cancer Research

And a 15 Page Informational paper that will describe the ratings for cancers, statistical info, and diagnoses