



They Call Me Melanoma: as told by Amy Berend Alexander

I cut my leg shaving and it wouldn't heal three weeks later I was diagnosed with melanoma. Melanoma defined as the most dangerous type of skin cancer. It is the leading cause of death from skin disease. It involves cells called melanocytes, which produce a skin pigment called melanin. (us national board of medicine) They took of a small spot on my 25th birthday on December 12th 2005 and diagnosed it as a stage 1 they said I was cured at the time but when I went back for a check-up they did a Sentinel Node Biopsy. The sentinel lymph node is the hypothetical first lymph node or group of nodes reached by metastasizing cancer cells from a primary tumor. (medicine)

At this time I was upstaged to stage 2 Melanoma. At this time I was moved to KU Medical Center and had most of my calf removed it was considered a 2inch wide incision. I was sent home with a drain tube in my leg(a tube to drain fluid from the incision to keep bacteria and build up from occurring). This was a Tuesday by Thursday the drain went dry and the doctors could not see me until Monday so I had to pull the tube out myself and had to keep it sterile and in a clean environment. When I saw the doctors they said I had done a good job. I had also informed them of another spot very small but new. The doctors were unconcerned but I was. Maybe I was a little skeptical but I had a right to be. Two months later I was able to see a different doctor. This doctor listened to me and removed the spot to relieve my fears they tested the spot and everything came back OK.

This was my chance for a new life so I took my vitamins, I wore sunscreen faithfully, and I had quit smoking! After a year and a half I hurt my shoulder nothing big just pain but it wasn't getting better, I started feeling bad not just bad but poor, physically exhausted and drained emotionally. A few months went by and my groin hurt, there was a lump in my lymph node. After fighting with my insurance I was able to have a PET scan (Positron Emission Tomography) –a PET scan can effectively help doctors locate and pinpoint the exact location of the cancer. My cancer showed up in the very first place I had melanoma, in my calf! The Oncologist (Dr who studies and treats cancer- Discover health) discovered a one and a half centimeter nodule and removed it. The Oncologist sent me to MD Anderson in Texas and

I had been upstaged to a 3-b Melanoma in June of 2008. (MD Anderson is one of 40 National Cancer Institute-designated comprehensive cancer centers-MD Anderson web site) I got on a plane for the first time in my life, I was going alone no one could afford to go with me I was scared and shaking getting on the plane. I remember crying the whole way and feeling so alone. When we landed in Texas I remember the staff on the plane thought I was having seizures I was crying so hard. When I was dropped off at MD Anderson I felt like an Ant on the steps of a huge city, MD Anderson is like a city of its own. The doctors who saw me said I had other traces of cancer and did a Radical Node Dissection and removed the 20 remaining lymph nodes. (Radical Node Dissection A surgical procedure to remove most or all of the lymph nodes that drain lymph from the area around a tumor. The lymph nodes are then examined under a microscope to see if cancer cells have spread to them. American Cancer Society) Afterwards I started an experimental clinical study called an Isolated Limb Profusion (Isolated Limb Perfusion works by separating the blood flow of the limb from the rest of the body, and circulating a high dose of a chemotherapy drug through the limb for a short period of time University of Pittsburg Cancer Institute) This was a 14 hour surgery and it killed 75% of my muscle mass. I came out of ICU two weeks later and was unable to walk. In this part of my stay I was kept in a pod and was referred to as a number, not a name. The nurses seemed numb, I assume because they are callous because they see so much of this. The only person who showed any compassion at all was my doctor. My parents showed up and stayed with me until I left the hospital. My Aunt took me to the airport and put me on a plane home, where my parents met me and took me home to my kids. He would hug me and try to reassure me when I had no one else.

I finally was released to a regular room and went through intense physical therapy so that I was able to walk again after two weeks I was able to leave the facility to go home with very strong drugs a walker I could barely use and eight drain tubes hanging here and there. They called me a cab and loaded me up drugged to the core and I flew back to Kansas City just in time for my daughter's birthday the following day. On July 17th 2008 was my daughters' birthday but I was too tired and sore to attend let alone that my immune system was too stressed to be around so many people.

My house was so busy I had a new hospital bed delivered and set up in my front room. There was home health nurses in and out at all times. The kids and I became very well at keeping logs, charts and journals on how I felt, when did I take last medications bathes and so much more. My children were my biggest care givers along with my best friend who would come and check on me daily and would be sweet enough to wash my hair. I remember a lady from the Elks Lodge made me a basket for my walker so I could get the things I needed when no one was around. I have lymph edema (extreme swelling retention medrx) my skin breaks open from the swelling. In October 2008 when I healed from the surgery I started Adjuvant Interferon Therapy to prevent relapse and to improve my mortality rate by 20 % (AIT Therapy "Adjuvant" Interferon means Interferon being given to try and prevent the melanoma from returning when there are no physical signs of disease present.) And was administered by pick line daily for 8 weeks. I wasn't supposed to lose my hair, but I did, very harsh. What was worse is I was allergic to the Salmonella and it was not beneficial, this was supposed to be a one year treatment, I had to be stabilized by Centerpoint hospital.

I went back to MD Anderson then and every three months afterwards where they would do CT Scans,

MRI's, and various blood works of brain chest abdomen and pelvis. (CT scan-computed tomography scan; MRI magnetic resonance imaging used in detecting structural abnormalities of the body.)

In January 2010 I wasn't able to go to Texas due to finances and family issues I did still see the doctors in Kansas City and didn't feel good. I had to file a grievance to get the insurance to cover the PET scan and the insurance still declined. At the end of February there was a lump in my breast and the biopsy came back negative the node had died. Scans had come back normal. Went back later for a checkup and found a knot over my left kidney, doctor said it looked like a sebaceous cyst after the biopsy came back I found out it was a metastatic melanoma which is stage four melanoma. The doctors were able to order a PET, a CT and a MRI in the PET scan it showed a 2.5 cm tumor on the left kidney a 3.1 cm tumor on the gluteus maximus lymph nodes showed glowing in left breast, right clavicle, and left neck by ear. I had my scans and pathology overnight delivered to MD Anderson and was scheduled for an appointment on May 18th 2010. The doctors told me that if there is a DNA match they have clinical trials and Interlucon II IL2(it is used as an immunosuppressant/ form of chemotherapy).I got to go home for a few days to spend with family and returned the following week with my best friend, now my love of my life and my children. They did a fine needle aspiration in all nodes to determine the right spots. I got to go to the ocean with my boyfriend and family. I was so week he held me so I could stand in the ocean and watch my children play. I think this may be my most cherished memory. I now have to start the rounds of IL2 I am a rather small woman and the doctors say we can do up to 14 rounds of the chemo. (There are only a couple people known to make it through this many rounds in one setting) I have round the clock care and they administer the IL2 every eight hours. My residence is the ICU in isolation while going through the treatment. I live with heart monitors on at all times because my heart could give out. It is so painful they give me Demerol to help with the pain but it still feels like my bones are ripping apart. I took eight treatments the doctors say that is way more than most people. Is this reassuring? My boyfriend drove me back home highly sedated so that I could withstand the drive he stayed at the hospital while I was there as close as he could be. I was home for two weeks and went back to Texas for six more rounds and the doctors had to call in a cardiologist because my heart was beating at 155 beats a minute. I got to come home Sunday June 20th 2010 just in time to see my boyfriend for father's day and to be with my children. On July 14, 2010 return to MD Anderson for restaging to check for progress and to design a new prognosis. If the IL2 is working they will continue with it until my body gives out or the cancer goes away or at least down to a few tumors are left can be removed by surgery. There are over 100 different types of Chemotherapy and as a whole melanoma does not react positively to the different therapies. (MD Anderson) The success rate is very slim but I have a 5% chance of success. My skin is peeling as a side effect and I am very tired. I am holding on to every shred of hope and right now that is 6% survival rate for the next two years. Amy lost her battle with melanoma September 17, 2011 at the age of 30 and left two beautiful daughters behind.