

To all my RARE cancer friends:

I am going to try and make this as short and concise as possible with a few tears and hopefully a few laughs. Also, I hope Spell Check picks up my mistakes!

I am, I thought, a very healthy, just about to be, 70 year old female. I have never broken a bone or had any kind of radical surgery. I have had the usual female stuff, as in hysterectomy and bladder infections. That's it!!!! My family consists of one husband and three sons. We are all close and enjoy each others' company. There were daughter-in-laws but they didn't last. We do have adorable and loving grandchildren. We all live in California. but not close enough to get in each others' way. We are all active and try and share vacations whenever possible.

It just so happens that on Memorial Day weekend, 2008, everyone was at our home for four or five days. We all had much fun and not much sleep. Boy, was I tired. I went to bed the night they left and was so tired that I couldn't get to sleep. I never sleep on my back but since I wasn't sleeping I turned over to that position to talk to myself about getting to sleep. I was in deep conversation with myself and resting my hands on my abdomen when suddenly I felt a HUGE lump. Needless to say, I got no sleep that night. I need to go back a few months now so that you will get the whole picture. I always have a physical in January. I did not that year. Just had the blood work done and figured I was healthy and didn't need to see the doctor. Also had a mammogram. Had an appointment with the gastro Doc. in May to set up a colonoscopy. Saw him in early May and he pushed and punched my abdomen and set up the colonoscopy for the first week of June. He found nothing unusual in May. Makes you wonder, doesn't it??? So now you see we have two problems. I created one by not seeing the internist, and the gastro Doc. didn't pay too much attention to my body. So here we are now back to June and I am having a colonoscopy and I asked the gastro Doc. to tell me what he thought this HUGE lump was. He said I had better get a CT scan. Saw the internist the next day and he ordered an MRI as I am allergic to Iodine. He also asked about pain and symptoms. NO PAIN, NO SYMPTOMS!!! I had nothing but a HUGE lump that I had found the week before because I couldn't sleep. As I left the Doc's office, he said to expect a call from the MRI people and they would set up a time. Not to make light of this but they didn't call and so after a week I checked back with the Doc. and come to find out the paperwork had been misplaced. I am a trusting person and thought that the office staff would be competent. Wrong! Now it is the 4th of July weekend and I am finally having the MRI, but because it is the 4th of July no results are sent to my doctor for three days. He immediately calls me into his office and looks at me and says "We believe you have a very aggressive sarcoma". It takes me a minute and I reply "Thank goodness, I thought I had cancer." And so begins my journey.

My doctor asked if I had a surgeon and of course I replied no. He left the room and me for 30 minutes and came back and said that not a single surgeon at his hospital would touch a sarcoma with a ten foot pole. I am very concerned as I have never heard of sarcoma and all he tells me is that it is very rare. He makes a few more phone calls and

tells me that the Cancer Center at UC Davis has a sarcoma doctor and he will make an appointment for me. After waiting for a few days and not hearing anything from UC Davis we begin calling them every ten minutes or so. Once again, paper work is lost in transition. After finally making contact with Dr. Canter's office, things move very rapidly. Third week in July 2008, I have my first meeting with Dr. Canter. He does a biopsy and sets surgery for Aug. 1, 2008. The day after the biopsy, Dr. Canter calls me to tell me that I really do have a very aggressive type of sarcoma. I am now spending a lot of time on the internet trying to find out what sarcoma is and I am not getting much help. I really didn't learn a lot but I am very frightened. I have a PET scan the day before surgery and get the good news that there doesn't seem to be any other tumor in any part of my body. On Aug. 1, 2008 the tumor was removed and Dr. Canter was very excited because he got it all and the margins were very wide. He had to put in a mesh screen to hold the abdominal muscles together as he had to remove the whole top layer of muscle. Everyone is happy and husband and one son go back to hotel and I go to sleep. The next afternoon, the Physical Therapy guy comes in and tells me I have to get out of bed and walk. Oh no I can't, and he says oh yes you can, and so off I go with a walker for about 2 minutes and I faint. August 2 is a Saturday and my whole medical team is off for the weekend. Never have an operation on a Friday. Now one nurse is shaking the blood pressure machine because he thinks it is broken and another nurse is rubbing my hand and saying she is turning blue. I glanced at the blood pressure and all I could see was 85 over something and I passed out again. In the meantime, a very nice resident who was not with the oncology team decided that I was bleeding out and called my team away from their weekend activities. They arrived and told me they had to open me up again as I was bleeding internally. Signature required. I think I got L on the paper and passed out again. By the time I got down to surgery my blood pressure was under 50 and I was given about 30 seconds to live. After 5 pints of blood and I don't know how many hours I awoke in cardiac ICU. Apparently my heart stopped as I had no blood to go through the chambers. So I learned two things between Aug. 1 and Aug. 2. Never have surgery on a Friday and always do what the PT tells you. If I had not been made to get out of bed and walk, I probably would have been discharged and the blood vessel that burst would have happened in the car on the way home and my poor husband would have a dead body on his hands. None of this is funny but it is exactly as I remember it. After 8 days in the hospital, Dr. Canter pronounced me ready to go home and said I needed radiation. Why? I asked. Big chance of it coming back. He liked a particular radiologist that was not at UC Davis Med Center and would I please go to her. After mentally deciding to have radiation I agreed to see her. She is great. I put 1800 miles on my car for 6 weeks of radiation. Now I have a 5% chance that it will come back in the abdomen. This is great. I have a 60% chance it will metastasize to the lungs. This is better than 65%. I feel very fortunate about my odds. I will be having a PET scan every 90 days for at least 2 to 3 years. I have already had two and all is well. Mentally it is a very large high after the scan and after a month I begin to slide towards a low as the next scan approaches. I know I can do this. I feel so very fortunate to be alive. Writing this story to share with all of you has been very good for me. I am also very fortunate to have had about 4 months of contact with Phyllis Domm through E-mail. She shared so much with me that I feel it was a privilege to have her in my life for such a short time.

After the path report came back no one was quite sure what kind of sarcoma I had and so they sent it off to Harvard. Phyllis and I shared the same pathologist. I have epithelioid sarcoma along with indefinable cells.

Since losing Phyllis, I am now in touch with her daughter-in-law Ashley. I thank her for putting me in touch with all of you. I will keep in touch.

Linda.

UPDATE

January 10, 2010

Since my first and last report to you all I have been busy having PET scans every 90 days. I have very good news. As of 2 weeks ago, my oncologist tells me that "for the time being" I may call myself a cancer survivor. I am so fortunate. I will continue to have PET scans every 90 days for another year and hopefully the thing will not have metastasized. I will then get PET scan every six months. My chances get better every day.

A very happy and healthy New Year to all of you.

Linda

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