# Cancer Registry

In November 2009, I was diagnosed with cancer. Had surgery December 4th. Started chemo in January and went through April 2010. Before finishing the chemo, I started getting calls from Providence. She said she was a nurse. I think she was trying to get information from me, because she was doing nothing to help me. On one call, I said "if I get this cancer back" and she said "oh you WILL get it back". What kind of a thing to say to someone that had major surgery and then months of chemo! I told her to never call me back. Then I got a letter from the State of Oregon stating that they knew about my cancer. I don't remember any of the questions on that letter except that it gave me the option to "do not contact". I checked "do not contact" and sent it back. I could not figure out how on earth the State knew about my cancer.

Then in December of 2013 (right before Christmas and the death of my aunt), I received another letter from the State of Oregon (after the "do not contact" letter had been sent). They wanted me to get genetic testing and take an online survey. I called them and asked how many people they sent this out to right before Christmas. I was told it was several thousand. I told them that it was immoral to send this to cancer patients right before Christmas and I wanted my name removed from the registry. She transferred me to Jeff Soule who maintained the registry. I told him to remove me from the registry and he refused. He said he would mark me as "do not contact" and I said that didn't work and to REMOVE me. He refused.

The only person that should contact a cancer patient is their own doctor. Their own doctor is the only one that knows the physical and mental condition of the patient at any point in time.

At this point, I wanted to get to the bottom of this snooping into my personal life and information. It was NOT easy. It seems that everyone is trying to keep it VERY quiet. I started with Providence. First, they said that no one should be collecting my personal information at Providence. Then I stumbled across Providence Cancer in the phone book. I talked to a girl (Lidia Salmen) there. She said that in fact they did collect the information and they pass the information on to the State and others who might want it. My doctor's office said they were getting annual questionnaires from Providence asking if I was alive or dead and my general medical status (attached). If I was going to another doctor, they wanted that information too. Death records are public record, so no need to ask. I wrote a "to whom it may concern" letter to my doctor's office and Providence stating that my information was PRIVATE and they were not to release any information without my written consent now or in the future. My doctor's office said they were legally required to send it to Providence. I called Providence and the same girl told me that she gave the letter to her boss. She refused to give me the name of her boss or the boss' phone number. She said "I will tell you one thing and that is we will continue to collect your information whether you like it or not and will do whatever we want with that personal information".

I contacted Bill Kennemer and he talked to the director of the State Health department. He was told that they would not delete my personal information, because it would mess up their information.

The purpose of the registry is to identify clusters of cancer. The only thing these people need for that is a zip code and type of cancer. End of report! Double counting cases of cancer as an excuse for personal information is not valid, because doctors can report recurrences without providing personal information. All the above are collecting a patient's name, address, social security number, date of birth, and medical records. Providence must also be collecting phone numbers since I didn't give it to them.

Then it came to my attention that the CDC is funding the State cancer registries. The states are giving this information to the CDC!

This is an identity theft issue for cancer patients! It is outrageous that hospitals, the State, and anyone doing research can go in and steal (taking without patient knowledge or consent) personal information on cancer patients. I got this disease through no fault of my own and my identity is NO ONE's BUSINESS except my own. This is NOT a contagious disease! I regret I have no way to help all cancer patients throughout the country. Many of whom have no idea this is happening behind their backs. The CDC can't even protect their own employees from the contagious diseases that they store let alone data that they steal and store on cancer patients. How on earth can the CDC protect the identity of cancer patients from hackers that steal this personal information?

I support cancer research but this has nothing to do with research. It is full of deceit at the expense of unknowing cancer patients. It is unethical. If these people, facilities, etc. want information, they should have honesty and integrity, and ask for written consent up front. They use ORS 432.500 with arrogance (at least Providence and the State). Since these facilities and the State are so deceitful, there should be some assurance that they can't send and store the information in other states, etc.

Please support Senate Bill 564 for the protection of cancer patients in this State. If possible, please extend it to these other medical facilities (such as Providence).

Respectively submitted,

Sharolyn Bowman

Attachments in the mail:

December 2013 letter from the state

January 2014 letter from the state

February 2014 "to whom it may concern" letter

Annual Providence questionnaire sent to my doctors