

Good morning. My name is Rebecca Carr and I am a resident of Lafayette Hill, Pennsylvania. I am a mother, a wife, a social worker and a volunteer. I am also a 4 year survivor of hereditary breast cancer.

In the Fall of 2003, I found a lump in my breast, which turned out to be cancer. This was a shock to me since no one in my family had had cancer in their 30's, like me. In between chemotherapy appointments, my medical oncologist had the good sense to send me to the genetic counselor at my hospital. The counselor mapped out my family tree with me and explained where she saw a red flag. I was surprised to find that that flag was on my father's side of the family. We had to travel up to my great grandmother, who died in her early 30's of what they called "female cancer," what we probably today call ovarian cancer. This was enough to warrant genetic testing, which I did. About a month later the results came back positive for a genetic mutation known as BRCA1. This mutation was the reason that I had gotten cancer. Harboring this mutation gives a woman around an 85% chance of developing breast cancer and a 60% chance of developing ovarian cancer.

This information was at once devastating and liberating. On the one hand, I realized suddenly that everyone in my father's genetic line was at risk and on the other hand I realized that by my getting cancer, and by my visiting with the genetic counselor and getting tested, those relatives would have the option of counseling and testing before they ever developed this terrible disease.

Others in my family have met with genetic counselors and been tested. Some have tested negative and now know that they have no greater risks for cancers than the general population. Others have tested positive and are in a position to make pro-active decisions and have heightened surveillance so that they too, we hope never develop cancer.

In the meantime, I fought my battle and along the way consulted two other genetic counselors at our finest Philadelphia area hospitals, as I struggled to figure out what my genetic mutation meant for my health for the rest of my life. These counselors were able to arm me with the information that I sought, so that I could make the best pro-active decisions for myself and for my family.

I was fortunate to find the good people of FORCE, Facing Our Risk of Cancer Empowered, an organization which serves to improve the lives of individuals and families affected by hereditary breast and ovarian cancer. I am currently the Co-chair of their Philadelphia outreach group and I am proud to read a letter of support from the Executive Director.

- LETTER ON BACK -



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On behalf of Facing Our Risk of Cancer Empowered (FORCE) and the community we serve, I support efforts to establish licensure of trained genetic counselors in Pennsylvania State.

Our members consist of individuals and families at high risk for hereditary cancer. We want to ensure that all interested individuals and their families have access to quality, non-directive genetic counseling with qualified experts about their personal health circumstances and their decision-making regarding genetic testing. Further we endorse the establishment of competency standards to help assure that all health care providers offering genetic services have knowledge about the tests that they are providing and the ability to order and interpret genetic testing appropriately. The lay public has limited ability to determine who is qualified or adequately trained to provide competent genetic counseling. FORCE has compiled case studies of people who received incorrect or inappropriate information regarding their risk for cancer and genetic testing from health care providers who were not properly trained in cancer genetics and the unfortunate outcome when people make medical decisions based on incorrect or incomplete information.

Genetic counselors offer vital expertise for those seeking to learn more about hereditary cancer and health. Through rigorous advanced training, these professionals are uniquely equipped to provide expert guidance to patients and families. Genetic counselors are also growing in number. As the use of genetic testing and other genetics services increases, the demand for genetic counseling is rising. The establishment of standards and licensure for this profession will help to ensure quality for patients and their families.

In establishing licensure standards, we support the requirements set forth in certification by the American Board of Genetic Counseling or the American Board of Medical Genetics as a minimum standard of practice for genetic counselors in every community. We urge the passage of a licensure bill that will ensure that qualified genetic counseling can be obtained by all the citizens of Pennsylvania.

Sincerely Yours,

Sue Friedman, DVM
Executive Director
FORCE: Facing Our Risk of Cancer Empowered

To improve the lives of individuals and families affected by hereditary breast and ovarian cancer.