

# Interview With A Genetic Counselor

**By Tova Stulman**

Interview with Niecee Singer Schonberger, M.S., Sharsheret's Genetics Program Coordinator, joined the staff in 2007. A Master of Science in Human Genetics from Sarah Lawrence and a Board Certified Genetic Counselor, Ms. Schonberger has provided genetic counseling in all aspects of genetics and, for the past 10 years, cancer genetics. She has published widely on various subjects, is a founding member of the National Society of Genetic Counselors, a past President of the Human Genetics Association of New Jersey, and has served on many committees and organizations committed to the education of the public and physicians regarding the importance of genetics in every aspect of health.

**Tova Stulman: What is the role of a genetic counselor? What is the specific role in your work as a genetic counselor at Sharsheret?**

**Nicole Singer Schonberger:** *The traditional role of the GC is education, risk assessment, and communication of genetic information plus provision and interpretation of appropriate genetic testing, tailored to the history of the patient. At Sharsheret, an information session is provided by phone to callers who have specific questions concerning genetics, often with the recommendation that they meet face-to-face with a genetic counselor for an in-depth discussion of their concerns. No medical advice or referrals are provided in this setting.*

**TS: How is the role of a genetic counselor different than that of a doctor?**

**NSS:** *A doctor addresses the medical aspects of the genetic condition. The GC obtains detailed family information and discusses the genetic basis of the condition, risks of recurrence, appropriate genetic testing, risks to other family members, etc. Most initial genetic counseling sessions last*

*an hour or more and are followed by a results session if testing has been undertaken.*

**TS: Why is breast cancer so prevalent among Ashkenazi Jewish women? Is there anything these women can do to take preventative steps?**

**NSS:** *Breast cancer is prevalent among AJ women because the BRCA gene mutations are present in 1/40 AJ women and men, whereas their prevalence in the non-AJ population is approximately 1/500-1/600. Unfortunately, there is no known way to prevent breast cancer but early diagnosis can greatly improve the course of the disease and survival. Knowledge of one's family history is a key element here, so that a woman identified at high risk based on her history can initiate increased surveillance tactics in order to identify breast changes at an early stage.*

**TS: What is Sharsheret's main role in the Jewish community? Is it about prevention, treatment, emotional support, etc.?**

**NSS:** *Sharsheret's role: Through one-on-one peer support, community outreach, and educational programs, the organization provides culturally sensitive support to young Jewish women fighting breast cancer as well as to those facing the risk of developing breast cancer, and offers related resources for Jewish communities and health care organizations. The Sharsheret Core Programs are: The Link Program, which connects young women facing breast cancer with volunteers who have offered to share their personal and medical experiences. Callers who have been diagnosed with breast cancer or face an increased risk of developing breast cancer are matched on a one-to-one basis with a "Link" who can speak to the Caller's specific concerns. To date, more than 450 women from 35 states have enrolled in the Link Program. Many from the New York area. The Outreach and Education Program*

*encompasses both large- and small-scale efforts to educate health care professionals, breast cancer organizations, and the public at large about the concerns unique to young women facing breast cancer, as well as the culturally specific needs of Jewish women. To date, the Outreach and Education Program has engaged more than 10,000 people. The Quality of Life Program helps young women through breast cancer treatment and recovery with useful materials that address real problems, such as the cosmetic side effects of treatment, and remind them they are not alone in their struggle.*

**TS: What kind of training does one need to take to become a genetic counselor?**

**NSS:** *A GC has a Master's degree in Human Genetics and is certified by the American Board of Genetic Counselors. Sharsheret serves the support and information needs of pre-menopausal Jewish women of all backgrounds. The concerns of pre-menopausal Jewish women facing breast cancer are often different from those of their post-menopausal counterparts. Young women are dating, marrying, having children, and raising children. Their cancers tend to be more aggressive, may result in early menopause, and are associated with higher mortality rates, yet breast cancer research studies often fail to include pre-menopausal women. Young Jewish women face additional concerns, including: the role of Jewish spirituality in daily life with cancer and in healing, religious ritual affected by breast cancer treatment (i.e., wig-wearing and the use of the mikvah/ritual bath post-surgery or during chemotherapy), community pressure surrounding dating, marriage, and fertility, privacy in what is often a tight knit community, and genetic testing for BRCA1 and BRCA2 gene mutations, 8 times more likely to be found in Ashkenazi women than in the population at large.*