The Gift of Hope: My Personal Experience

Lindsay Nohr Beck

Scientific Editor’s Introductory Comment: As part of our conference, we began with a panel of cancer survivors recounting their personal stories of cancer, infertility, and paths to parenthood. Lindsay Nohr Beck not only had a cancer treatment that could potentially impair fertility, but also in a wonderful example of “turning lemons into lemonade,” founded the advocacy group Fertile Hope so that other men and women facing infertility would have a national resource to find information and support. We asked her to share her story with readers of this monograph. For more information, visit www.fertilehope.org or call (888) 994-HOPE.

The scientific information included in this publication impacts people’s lives in profound ways. Facing the risk of infertility from cancer treatments is daunting, but worse is not knowing your risks and options.

When confronted with my second diagnosis of a rare tongue cancer at age 24, I was told that my treatment regimen would now include chemotherapy with an agent that presented the risk of permanent infertility and premature ovarian failure. However, information on my risks and options to preserve my childbearing potential was not readily available.

Naively, until then I had never thought my situation to be a matter of life and death. I beat cancer before and was confident I would again. That all changed, however, when I called my surgeon and told her I refused to have chemo that could destroy my fertility. She kindly but frankly told me that she wanted me alive in 5 years to think about a family rather than dead because I didn’t undergo treatment.

The question was clear—life or motherhood? The answer was obvious, but infertility was still unacceptable. I hated the idea of being a 24-year-old, single, infertile cancer survivor. There had to be something I could do. After all, men can bank their sperm. There had to be an equivalent for women, right?

Wrong. Egg banking is not yet an option, but there are alternatives, which I went on a quest to find. I wasn’t particularly well connected in the medical world, didn’t have the luxury of extra time or energy, and had no idea where to start, but I refused to give up!

For me, a young single woman, embryo freezing was not an acceptable option. I did not have a partner and did not want to use donor sperm. I wanted to freeze my eggs. I stubbornly kept on questioning my doctors, called fertility clinics, scoured the Internet, and reached out to cancer and fertility organizations. Still, I came up empty-handed. Even worse, much of the information I received was discouraging and misleading, if not downright incorrect. I was told over and over again—“you don’t have time, fertility drugs cause cancer, egg freezing is not possible” and so on. There were several organizations addressing infertility and even more addressing cancer, but where the two overlapped, there was nothing.

I resorted to repeatedly calling the same clinics in my area. On my third call to Stanford Medical Center, I was told that it had an egg freezing program but that it was only for young cancer patients. I was thrilled. For the first time in my life, I was happy to be a “young cancer patient!” Time was of the essence. I had to start chemotherapy in 2 weeks, and the cycle for egg freezing took approximately 12–14 days. I was immediately examined; advised of the costs, risks and procedural details; and sent home with a bag of medicine. After 2 weeks of self-administered shots, miserable side effects, and an outpatient surgical procedure, I had 29 eggs safely stored for future use.

I underwent chemotherapy and radiation as scheduled with a new sense of pride, strength, and excitement for the future. Harvesting my eggs was the first positive in a long list of negatives. I now had a reason to fight, to live. Three months later, I was pronounced free of cancer and relieved to have my eggs waiting in the wings as a vehicle to live the life I’d always imagined.

I was extremely lucky. First and foremost, I was told about the risk to my fertility before starting treatment. And second, I was able to preserve what was sacred to me—my fertility. It still astounds me that most cancer patients and survivors do not know that chemotherapy, radiation, and surgery all have the potential to cause permanent infertility, let alone that there are several ways to become a parent after cancer treatment.

My experience exposed a problem, and I founded Fertile Hope as the solution. Fertile Hope is a national nonprofit organization partnered with the Lance Armstrong Foundation to provide reproductive information, support, and hope to cancer patients whose medical treatments put them at risk for infertility. Approximately 10% of the more than 10 million cancer survivors in the United States today were diagnosed in their reproductive years. Moreover, every year over 120,000 more young cancer patients are diagnosed.

Fertile Hope has made great strides since its inception in 2001. We have developed and distributed thousands of free educational brochures, published the first-ever Cancer & Fertility Resource Guide to help patients and survivors navigate the reproductive world, answered thousands of phone calls and e-mails, and presented at numerous professional conferences and patient symposia. Fertile Hope also launched a one-of-a-kind fertility preservation financial assistance program to help increase access to egg-, embryo-, and sperm-freezing treatments.

And as for me, I recently got married. My husband and I are excited about life together as well as grateful to have family-building
options. As you read this publication, I encourage you to provide your patients with the information they need to make educated reproductive decisions throughout their journeys from patients to survivors and beyond. The knowledge you possess is a gift of hope to the patients it touches.

**NOTES**

Lindsay Nohr Beck is the founder and Executive Director of Fertile Hope. Fertile Hope is a national nonprofit organization partnered with the Lance Armstrong Foundation to provide reproductive information, support, and hope to cancer patients whose medical treatments present the risk of infertility.