

First Person Perspective

BY CHRISTIE MANGIR

Being diagnosed with breast cancer at age 30 and learning I needed chemotherapy was devastating. I did not feel like I had a choice. If I wanted to live, I had to complete an intense regimen of chemotherapies and targeted therapies. Cancer patients do not have many choices, but one of the only things I felt like I could do was to preserve my hair during chemo. I still lost about 50 percent of my hair while cold capping, but I would do it all over again because it gave a sliver of normalcy and confidence when my body and my life felt it had been ripped apart. When I looked in the mirror after losing 20 pounds and having my breasts amputated, my hair was the only thing that allowed me to recognize myself.

Fifty percent of female patients consider hair loss the most traumatic part of chemo, and 8 percent would decline treatment due to potential hair loss.¹ There are many reasons patients choose to preserve their hair: to have a sense of normalcy for their children, to support their self-esteem and mental health, to have control over when and with whom they share their health struggles, and to avoid the looks of pity and discomfort that cancer patients often receive.

I chose to receive treatment at George Washington Cancer Center in Washington, D.C., because my care team thoughtfully engaged me in shared-decision making and were supportive of my desire to preserve my hair. I was one of the first patients to cold cap at my infusion center in 2016, before the newer generation of U.S. Food and Drug Administration-cleared scalp cooling devices became more widespread. Using manual caps meant that my husband had to take time off from work to carry large coolers of dry ice into the infusion center and change my cold cap every 30 minutes for a total of eight hours. It cost us more than \$2,000 because the technology is not covered by insurance. This time commitment and financial burden is not feasible for many patients.

Hair preservation can ease a variety of patient concerns and improve their quality of life, but awareness, affordability, and access continue to be significant barriers. In 2017, my friend and fellow survivor Liz Lord decided to take action to help remove these barriers for patients with cancer in the Washington, D.C., area. Several other survivors and I joined Liz in forming the Cold Capital Fund, a nonprofit that empowers patients across the District of Columbia, Maryland, and northern Virginia to have the option to preserve their hair.

To improve affordability, the Cold Capital Fund provides financial assistance to people who would not otherwise be able to afford cold capping—as of August 2020 we have supported more than 100 patients. We work with local cancer programs to educate care team members about cold capping and our resources, as well advocate for the installation of U.S. Food and Drug Administration-cleared scalp cooling systems in infusion centers to make cold capping more accessible for their patients.

For too long, hair loss was an unavoidable and distressing side effect of cancer treatment. Now that there is a reasonable therapy to mitigate this side effect, we must work to level the playing field to make it available to all eligible patients. Though hair preservation may not be the right choice for everyone, our mission at Cold Capital Fund is to make it an *option* for all patients who would be candidates for this therapy. Learn more about our efforts at coldcapitalfund.org.

Reference

1. McGarvey EL, Baum LD, Pinkerton RC, Rogers LM. Psychological sequelae and alopecia among women with cancer. *Cancer Pract.* 2001;9(6):283-289.

