

Cold Cap to Minimize Hair Loss During Chemotherapy: A Testimony | BY: STEPHANIE LARSON

Introduction

On August 7, 2017 I heard the words all women fear. My breast biopsy revealed that I had stage one, grade two breast cancer. If I had to be diagnosed with breast cancer this seemed like a best-case scenario, but mine was complicated by an additional pathology finding; my tumor was triple negative breast cancer (TNBC).

I had never heard of TNBC but learned that the tumor does not have hormone (estrogen and progesterone) or HER2 receptors and therefore would not respond to hormone therapy (such as tamoxifen or aromatase inhibitors) or therapies that target HER2 receptors, such as Herceptin.

I researched, asked questions, shared my concerns and became an active member on my care team. My medical oncologist explained that TNBC occurs in approximately 10-20 percent of breast cancers and that the highest risk of recurrence is typically within the first few years following treatment. After five years, the risk of recurrence decreases and by agreeing to chemotherapy I would further decrease my risk of a recurrence. There I was, standing in the statistical line of one in eight women diagnosed with breast cancer, AND in the TNBC 10-20 percent line. So, even with a Stage 1 diagnosis and a tumor about the size of a pea, if I wanted to be proactive and reduce my risk of recurrence I would need to say yes to chemotherapy. And, I was going to go bald, unless I found a solution that would be medically safe and approved by my doctor.

Time to Get Proactive

By nature, I am a happy, confident, independent and very private person. I always look for ways to maintain my healthy lifestyle, making sure all 'guns' are firing – body, mind and spirit. But as I faced the reality of chemo and going bald, I could not help but feel anxious.

For more than 30 years I have been a writer in the healthcare field and nearly all the women I interviewed who were facing or just completing chemotherapy told me the worst part of their treatment – even those who had mastectomies – was losing their hair. I was concerned that losing my hair could jeopardize, if not destroy, my self-confidence and positive attitude. I knew that I needed to be proactive and try to find a way to keep my hair.

I needed to know that even if I didn't find anything, I would have at least tried.

"The impact on cancer therapy induced baldness, known as Chemotherapy Induced Alopecia (CIA), has an enormous psychological and social impact on patients, which can be summarized as: a symbol of cancer for self (constant reminder of their treatment) and others (outwardly visible); personal confrontation of being ill or mortality; vulnerability; powerlessness; shame; loss of privacy; punishment, and change in self and other perception (Freedman, 1994; Pozo-Kaderman et al., 1999).

In fact, according to this data, up to 8 percent of women are reported to reject chemotherapy for fear of CIA.

This last statistic astounded me – not only because women refused the treatment that could greatly reduce their risks of a recurrence but because I knew I might have been, or at least considered being, one of them had I not discovered cold cap therapy.

"Additionally, these negative impacts of CIA may contribute to poor therapeutic outcome, as stress and depression lowers the body's immune function and is highly associated with cancer progression." (Spiegel and Giese-Davis, 2003; O'Leary, 1990).

Finding the data concerning the emotional, social and psychological findings supported my need to find a better solution – not out of vanity but for better outcomes in my physical and mental health. I found a solution that would keep me from going bald; I found cold cap therapy.

What is Cold Cap Therapy

I began my research by literally Googling 'Must I lose my hair during chemotherapy?' That search led me to The Rapunzel Project® (<http://www.rapunzelproject.org/>), where I found information about cold cap therapy. I cannot begin to express how I felt when I learned there was a way to keep my hair! To be honest, I hadn't been hopeful but now, I was ready to take on the world – well, at least my world.

Cold cap therapy is a relatively new treatment in the U.S. that allows chemotherapy patients to keep their hair or minimize its loss. It is a non-invasive, drug-free technique of scalp cooling. The process varies depending on the chosen system. There are several suppliers; some have FDA-clearance and others are in the process of obtaining clearance. There are two types of cold cap systems: machine capping and manual capping.

In most cases, patients rent the caps from a manual system supplier and take them and approximately 45 pounds of dry ice (or more), unless the chemo facility has a bio freezer, to each chemo treatment. The manual system is currently the method by which most American patients have saved their hair and can be used at any location, which makes this the most viable solution, at the time of this writing.

More and more hospitals and chemotherapy clinics are starting to support cold cap therapy. So, before you choose your supplier make sure you talk to your doctor to find out if your hospital/clinic has a cold cap therapy system in place.

The theory behind cold cap therapy is that by freezing the scalp, the blood vessels leading to the hair follicles reduce the amount of chemo drugs that reach the follicles during the period that the caps are worn, putting the follicles 'to sleep' temporarily and limiting their metabolic activity. While the chemo drugs stay in the patient's system longer than the treatment time, they will be at a somewhat diluted strength by the time they reach the follicles.

To maintain the correct optimum temperature during the treatment, caps are changed throughout the duration of the treatment schedule. As one cap comes off it is re-cooled, so the temperature is always consistent from cap-to-cap.

Change times and length of time a person continues the cold capping after her/his last chemo drip is determined by several factors – height, weight, drug(s) being administered, dosage of the drugs, etc.

The success of cold cap therapy can vary depending on the chemotherapy drugs administered.

How I Made My Decision

After carefully studying the information on The Rapunzel Project® site it was clear that I needed to choose the manual cold cap system and would need to supply my own dry ice for each treatment.

I visited the websites of all cold cap system suppliers and evaluated the things that were most important to me – how many clients had used each system and outcome (success) rates. I also read several posts on the suppliers' sites written by people who used the system. I learned about the process and the rules that needed to be followed for the best results. In the end, I chose Penguin Cold Caps™.

Penguin Cold Caps™ was the first cold cap system to come to the U.S., in 2005. The Penguin caps have a unique design and a patented gel that holds temperature for as long as possible. When combined with its UK results, Penguin has more than 20 years of data and experience. Other impressive statistics include:

- Penguin caps are reported to work with almost all chemo drugs and have a high success rate with taxane-based therapy such as Taxotere and Cyttoxans (TC), which is what I would be given.
- The company also reported success rates of approximately 70-80 percent with patients using Adriamycin and Cytoxan (AC,) typically the toughest chemotherapy combination on the hair.

I was impressed with their number of clients and outcome data and began calling and emailing women who were on the company's client referral list, especially those who were given the same chemotherapy drugs and number of treatments as I was scheduled to receive. These women were extremely supportive and willing to talk about their cold cap experience. They all had good things to say about Penguin Cold Caps™. A few women even kept in touch with me as I was going through my treatments to see how I was doing.

I confidently began the online ordering process; I wanted to get the caps a few weeks prior to my first chemo treatment so we could practice. When ordering, in addition to my height, weight, hair type (texture, thickness, etc.), I needed to provide the names of my chemo drugs, their dosages and length of time they would drip. All this information allowed my supplier to custom-build my cold cap instructions. I ordered the kit that included the cooler

on wheels and was told I would receive my instructions via email, which included: a step-by-step scalp cooling instruction sheet; an instruction booklet on the care and management of the caps; and hair treatment guidelines.

Some women I spoke to mentioned that upon receiving their instructions, they literally had a meltdown. But I did not believe this could happen to me after all the research I did and one-on-one interviews I conducted.

However, when I received the email containing the instruction attachments, one thing became perfectly clear. No matter how prepared I thought I was, I completely understood the meltdown comments. Since learning I had breast cancer, this was the ONLY time I had truly lost it! There was so much to sort through and comprehend. I felt it was way too much to ask of the people who would be changing my caps. Frankly, I am not sure whether my tears were those of fear, feeling overwhelmed or that we may not be able to do it and I would go bald. Looking back, I'm sure it was a combination of all of them; facing the reality of what was ahead of me and hoping it worked – not just for me, but for my team who would be going through each treatment with me administering my cold cap therapy.

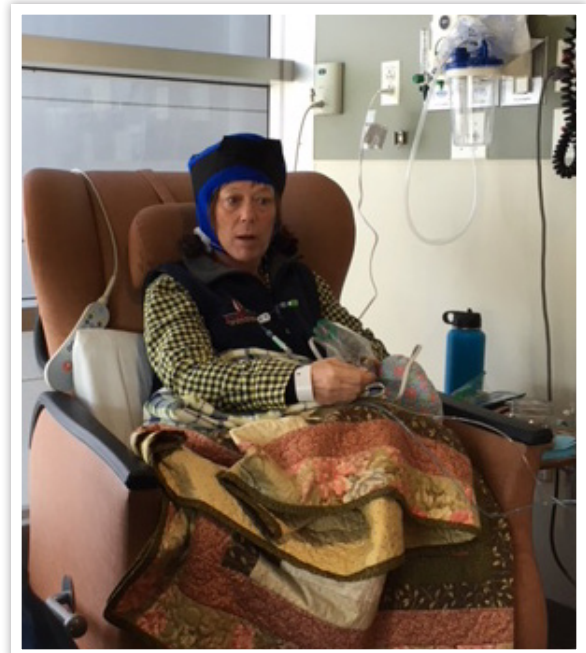
My husband, Michael, assured me I was not asking too much of him and that he could and would do it, because it was important to me. My daughter, Tess, and her husband, Jeff, also agreed. So, like a cold splash of water thrown on my face, I picked myself up and stopped the sobbing and dramatics. The meltdown had ended; we were going to make this work – no matter what.

The materials were overwhelming mostly due to the style in which they were written. We all agreed they were cumbersome, repetitive and needed to be simplified in a more step-by-step bulleted style. Michael calmly took the instruction booklet, punched holes in the 28-page document and put them into a binder. Using a highlighter and colored pen we were able to work through the materials and make notes that would help guide us through the cold capping process. Once we did this, we realized that the process itself was not challenging. In fact, the cap changing went very well after we found our rhythm.

The capping process required that the scalp cooling begin 50 minutes before the first chemo drip and continue throughout chemotherapy and for four hours afterward. The caps were changed every 25 minutes during this time.

During my first treatment, our inclination (with the hospital's permission) was to finish the capping process in a quiet area of the Breast Center. But based on how it was

going during the chemo, my team felt confident they could continue the process on our one hour and 20-minute drive home. We made three stops, each lasting approximately five minutes and by the time we got home we had a little over two hours to go. No question, our first cold cap/chemotherapy day was long and very tiring, but we had one down and only three to go!



Cold Cap: Day One in the Day Hospital



Cold Cap on the way home (first treatment) – it took very little time and we were glad to be heading home!

I am pleased to learn that since my experience with Penguin Cold Caps the materials have been re-written. The representative shared them with me, and I am confident the number of “melt downs” due to the literature should be greatly reduced.

Cold Cap Rules

The decision to go with cold cap therapy required me to be a rule follower to ensure I would achieve the most effective results. As soon as I saw the hair care section, I contacted my hair stylist and enlisted her as my partner in hair – she agreed and was a huge part of my success.

The instructions provide recommendations for before, during and after chemotherapy treatments, which were very helpful. The most important were:

- Drink plenty of water – hydration is essential in both chemotherapy and cold capping
- When to wash your hair – prior to and post your chemo treatment
- No use of chemicals for at least six months after your last chemo treatment (depending on the health of your hair)
- No heat
- No pulling (Why would anyone even contemplate doing this one?)

After my second treatment I had a small area near the bangs (underside of my part thankfully) that got a little burned from the cap. Since that area was sensitive and would continue to ‘burn’ during the last two treatments I emailed the Penguin representative to ask what she would recommend. She suggested that I wear a gauze headband. Problem solved! I purchased four-inch-wide gauze and sewed several headbands. The headbands were thin enough to allow the coldness to reach my part area but kept my scalp from getting too much direct contact with the frozen gel cap.

I would recommend wearing gauze headbands from day-one!

Cost

At the time I chose cold cap therapy it was an out-of-pocket expense.

The irony was that I was given a prescription for a wig, which was covered by insurance. When I researched wigs, the styles/brands I would have considered buying ranged from \$1000 to \$1500. The cost for cold cap therapy for me was \$500 per month, plus the cost of dry ice, which was an additional \$340, bringing the total to \$2040. I then subtracted the dollars I would be saving from the hair appointments I would not be able to keep for nearly one year. I was also reimbursed from Penguin Cold Cap my security fee of \$500.

I rented my caps and was charged on a monthly basis – I did not have to pay the total amount up front. Fees are determined by the number of treatments and the length of time the treatments will be administered.

For me, the benefit of cold cap therapy – keeping my hair – far outweighed the issue of my out-of-pocket expenses.

Results

So, what were my results? The short answer is – SUCCESS! Cold cap therapy worked. However, there is more to the story that I need to share.

Except for my one small bald spot caused by freezer burn, I did not have any noticeable hair loss. However, over time, as the old and medium aged hair fell out and the new hair came in, there were some changes in my texture and thickness which required some patience and hair style finessing.

My immediate results were encouraging. Except for my white root outgrowth, I had hair. Throughout my chemo treatment period I was happy to learn that I was shedding the normal amount of hair and my texture and thickness had not suffered. The most difficult part, for me, was that I was not able to color my hair. Of course, the good news was my hair was growing and not falling out – I was NOT bald!

When I began feeling nervous about my shedding, I contacted my Penguin Cold Cap rep who assured me the amount of hair I was shedding was normal. My stylist reminded me about the cycle of hair growth and recommended style solutions that remedied my concerns. I had to realize that I had hair – I did not go bald, not even close. I realized that rather than whine I should be grateful; changing my perspective was the best adjustment I could make for myself and helped me appreciate the hair I had.

I think that because I was doing so well and not noticing much if any difference during my chemo treatments that I got a false sense of security. I'd forgotten that all the women I talked to prior to my treatments said they experienced hair thinning; all of them stated they needed to get a new shorter style.

My 'partner in hair' does not break the rules and kept me on track, giving pep talks as needed, which was often, and reminding me that I had hair and that the hair I had was healthy. I told her that some of the women I spoke with used root concealer on their gray. She did some research and suggested a powdered root concealer with a sponge applicator that followed the cold cap hair care ingredient guidelines. She came to my house to show me how to apply it and even styled my hair for the evening, which was our wedding anniversary!

There were some tough times mostly caused by my root outgrowth, but I never lost more hair than the normal person loses. I am a success story and realize that I owe it all to Penguin Cold Caps™, my cold cap team, a very patient partner in hair, a supportive cold cap representative and my determination to have the best outcome I could possibly have. Following the rules and having the support of a truly great team won the day!

It is important to review this information every so often to keep from becoming overly and unnecessarily anxious:

Shedding hair is normal – for everyone. We all grow approximately 120 new hair bulbs a day and lose approximately the same amount. Shedding is a natural occurrence in hair growth. People who wash their hair once a week will notice more shedding than those who wash their hair every day. This is because the hair that has already shed is sticking to other hairs on the head until the shampoo washes them away.

Cold cap therapy works by protecting the young and medium aged hair bulbs against chemotherapeutic drugs. These drugs accelerate the old age follicles which cause them to shed early, which is why hair shedding occurs.

Cold Cap is Not for Everyone

Let's face it, cold cap therapy is not for sissies! But then, neither is going bald.

The difference for those choosing cold cap is that it is not just cooling your head on chemo treatment days but also

a long-term commitment that starts before chemo begins and continues for a minimum of six months after your last chemotherapy treatment.

I decided to begin the hair care rules before my chemo treatments because I believed it would make my hair and root bulbs as healthy as possible and give the cold capping treatment every advantage.

From my perspective, the cost of cold capping is not the deciding factor but rather the process of the therapy (willing to have your scalp chilled to -32C) and hair care recommendations that must be followed. The hair care packet provided information that covered all aspects of hair and scalp care beyond shampoo and coloring such as swimming in the ocean or swimming pool, exercise, hats and scarves, ponytails and hair clips.

Cold cap therapy demands a strong commitment to sticking to the rules; there is no wiggle room. I needed at least one person who could go with me to all my chemo treatments and hang in there for several more hours. I was so lucky to have a team of three to support me and each other. I kept my hair and felt physically, mentally and emotionally strong throughout my chemo treatment period. I was not sick or weak partly because I did not look sick or weak to others and more importantly, to myself; I maintained my self-confidence and a good self-image.

I chose cold cap therapy because I am a very private person; I have a good healthy lifestyle and I was NOT sick; I believed I was doing chemo as a preventive measure in lowering my risk of recurrence. I am not a 'statement maker'; I simply chose to take control of my situation and maintain my definition of normalcy – while the rest of my world was whirling around me.

My choice to keep my hair and advocacy for cold cap therapy is not meant to in any way cast aspersions, judgments, or negative feelings toward the patients who go bald. I am simply thankful there was an option for people like me. Dealing with breast cancer and its treatments is hard enough; I'm so grateful we all have options that make our path less difficult.

Why Don't More People Know About Cold Cap Therapy?

CIA is a common and distressing adverse effect of many types of chemotherapy. Scalp cooling has been used since the 1970s for prevention of baldness; however, most data regarding this treatment modality are retrospective in nature and use in the United States has been limited by safety concerns, specifically the potential for scalp metastases.

Most of the clinical studies on scalp cooling to date have been done in Europe. The use of scalp cooling is far more prevalent there and insurance covers the cost in many countries. As scalp cooling begins to grow in popularity in the U.S., more studies will be released. In fact, in a study presented at the 2016 San Antonio Breast Cancer Symposium, scalp cooling was found safe and effective in, "...preventing chemotherapy-induced hair loss in women undergoing adjuvant treatment for breast cancer in an interim analysis of the first prospective, randomized trial of a modern scalp-cooling system." (DOI: 10.1200/JOP.17.00038 *Journal of Oncology Practice* 14, no. 3 (March 1, 2018) 149-154.)

And, more recently, studies of scalp-cooling systems performed in the United States were published within the last year adding evidence-based data supporting the efficacy and safety of scalp cooling in preventing chemotherapy-induced alopecia in patients receiving chemotherapy for solid tumor malignancies.

Retrospective data suggest that the incidence of scalp metastases related to scalp cooling is low and should not limit the use of this technology. Logistical issues related to use of scalp cooling include availability of devices, inconsistent insurance coverage, and incorporation of use into typical infusion center workflow.

As these and more studies are released, more women will be empowered to make a choice – supported by their medical team – between going bald or using cold cap therapy to hopefully prevent hair loss.

Summary

If I were asked to share anything I learned along the way, I would say there is never going to be a time in your life when choosing your team will count more. I scheduled second opinion interviews and chose my medical team and facility. It always surprises me when people tell me they'd feel bad about going for a second opinion – they might hurt their doctor's feelings. I cared more about my feelings – who would make me feel more confident? Who would make it easier for me to keep a positive attitude? Where did I feel the safest? Who had the most experience in treating patients like me? Getting breast cancer was not my fault but how I would handle the treatment was within my control and I was going to choose my medical team wisely; a team that would need and want one more person at the table – ME.

I cannot say enough about how well cold cap therapy worked for me and how grateful I am that there was

something that allowed me to maintain my privacy and keep my hair. As I've said earlier – cold cap is not for sissies, especially when the 'burden' of making it happen is up to the individual and her team. But the research is coming in and I could not be happier in knowing that in time – hopefully not another two decades – women will be made aware of cold cap therapy and it will be easier for them than it was for me and the many women who went before me.

Finally, I am not a person with a large circle of friends but those who hiked the trails with me to chat and laugh along the way; friends who stopped over with books and flowers; Master Gardener partners who dropped off flowers and notes and handled our shared projects alone for a while; yoga classmates who called frequently to see how I was doing; a neighbor who always let me talk and made certain we ended up laughing – they all meant the world to me. My team – from family to doctors and nurses and technicians, from hikers to hair stylists and "downward *doggers*" – was the best support I could have ever hoped for; I will be forever grateful.

Resources

<http://www.rapunzelproject.org>

<https://penguincoldcaps.com/us/>

<http://ascopubs.org/doi/abs/10.1200/JOP.17.00038>

Journal of Oncology Practice® An American Society of Clinical Oncology Journal

Nangia R, Wang T, Niravath P, et al: Scalp cooling alopecia prevention trial (SCALP) for patients with early breast cancer. 2016 San Antonio Breast Cancer Symposium. Abstract S5-02. Presented December 9, 2016.