



## The Rapunzel Project®

“Patients have the right to know that there is a viable option to save their hair.”

*Nancy, The Rapunzel Project*

**W**e probably all know, or know of, someone who has lost his or her hair to chemotherapy while undergoing treatment for cancer. At CosmoBiz we've spoken with and featured organizations dedicated to helping women deal with hair loss during and after cancer treatment, but what if there was a way to keep your hair even while undergoing chemo?

We recently learned of a new type of therapy gaining in popularity in the U.S. that does just that. We reached out to The Rapunzel Project, a non-profit organization dedicated to helping chemotherapy patients keep their hair during treatment, to learn more about the therapy and their role in spreading information about cold cap therapy to patients who may be able to benefit from it.

Nancy and Shirley, both breast cancer survivors, are the force behind the project, helping women all over the country keep their hair through chemo. Cold Cap Therapy, or cold capping, is the process of wearing a cap or series of frozen caps or helmets during chemotherapy to reduce the amount of hair lost. Basically, it works like this. Extreme cold restricts the blood vessels that lead to the hair follicles. This limits the amount of chemo able to reach them. It also probably slows down the metabolic rate of those cells, so it's not processing the chemo as quickly. Chemo is designed to target fast growing cells because that's what cancer cells are; unfortunately, hair cells are the fastest growing cells in the

body. That's why hair is targeted and killed by chemo.

According to Nancy, throughout the 90's and early 2000's, people in Europe began to experiment with the cold capping process, and they found that the best procedure is to use the caps for 45 minutes to an hour before chemo, then during the infusion, and finally from two to four hours post treatment. Actually, post infusion may be one of the most important times. The body needs

time to process the chemo medications and dilute them as they circulate, so if you keep the cap on post infusion you give the body a chance to dilute the drugs before allowing normal circulation to resume. In this way, most patients are able to keep most of their hair.

Three years after Nancy's bout with cancer, Shirley learned she would need to undergo chemo to treat her disease. Through the friend of a friend, she learned about the little known process of cold capping and decided she wanted to give it a try. Her doctor said "I've heard of it. I don't think it works. I don't have a problem if you try it." Nancy says, "That was all we had to hear." They did research and talked to a lot of previous cap users. Nancy sent out an email to everyone in Shirley's address book and was able to raise the \$7,000 needed to purchase a biomedical freezer for the clinic where Shirley would have the chemo infusions. Since the caps must be kept extremely cold, a freezer or dry ice cooler must be available to keep them at that temperature.

"We never asked anybody's permission," Nan-





Shirley wearing a Penguin Cold Cap

cy says. "If we had ever realized all the impediments that are really out there, we probably would have been much more daunted."

But they were able to convince the clinic to find a place for the freezer, and Shirley began therapy. The medical staff thought they were crazy with all the caps and timers and friends coming to help, but on the day of her third chemo treatment, the whole staff was lined up waiting to see Shirley. She should have lost her hair by that point, and instead she walked in with a full head of hair. There was applause and even a few tears. "It was really a goose bump moment," explained Nancy.

Losing your hair during chemo is a very emotional process. Nancy explained that for many patients, it's that detail that prevents them from having the privacy they crave during such a difficult time. When you lose your

hair, you effectively announce to the world that you've got cancer. "It's not about vanity," explains Nancy. For some patients, keeping their hair can be life changing, though it's not for everyone, notes Nancy. It's very expensive, it's cold, it's awkward, and you need help to make it work. It also works very well with some chemo drugs and less well with others. And although it's appropriate for basically all patients with solid tumors, it isn't appropriate for blood or circulatory cancers. "It's not a fun process, and the technology is still in its infancy... There's nothing to recommend it except the results," says Nancy.

There are two types of cap treatments available. The first is a series of individual caps, from about four to fourteen caps depending on the cap provider you work

with and which type of cooling system you use, a freezer or dry ice coolers. The caps are typically changed every 20-30 minutes for the duration of the capping period, before, during, and after chemotherapy. This is because once the cap goes on the head, it starts to warm and must be quickly replaced.

Nancy stresses that any patient can use cold caps as long as they have access to dry ice, and this is sold at Wal-Mart. Dry ice is the most common way, and it works extremely well. The freezer is a less cumbersome process, but "As long as they have dry ice, they can rent the caps and they can save their hair."

The other type of cap system is a machine that uses a single cap. The first FDA approved cap fall under this category. It's called Dignicap, and it's made by a





Swedish company. They are in the process of rolling out across the country, but it is slow. The company has to negotiate leases with each individual clinic and train staff (the system is administered by the nurses).

There are a number of companies out there patients can rent from or use the machines. Mayo Clinic is in the process of developing their own system. “We root for everyone. We want patients to be able to access this, and the more availability there is the better....The more competition there is the better,” Nancy told us.

She hopes pricing will begin to go down with more competition among companies. She explained that Dignicap prices are determined by the individual clinic that works with them.

## Role of The Rapunzel Project



“We made a decision in the very beginning that our role would not be to help individual patients afford to use the caps. We didn’t know if we would ever have deep pockets—which we don’t. And we didn’t want to be in the position of having to decide who got money and who didn’t. We wanted to help the greatest number of people we could without necessarily having a lot of funds.” Both women see their work as a labor of love and spend most of their free time on the project. The primary purpose is to “create awareness on the existence and efficacy of the cold cap process” so that patients are able to “make an informed choice.” Their first role is to provide information, answer patient inquiries, direct patients to the freezer list on the website where

users can see locations of clinics with biomedical freezers. There’s also a list of providers that have been vetted by the project through data and references. Patients will find important websites, phone numbers, plenty of ammunition to figure out what to do in order to cold cap.

The second role the project plays is donation of freezers. Getting freezers into clinics “serves our purpose of raising awareness because when you have a big freezer in the middle of a clinic, you’re raising the profile of cold caps for everybody; the nurses are more likely to tell new patients about it; the patients are more likely to hear about it from other patients, and it just generally makes the clinic a more supportive environment for the process. The other benefit is it saves every patient the hassle of getting dry ice and handling it,” Nancy explains. The Rapunzel Project has donated over 100 freezers around the country over the last six years, helping a lot of patients make the process more doable and more known.

## What to do to help



Donations are welcome, fundraisers are appreciated, but the way most freezers make their way to a clinic is that a patient or a big supporter in a community gets to the right people and raises interest from the inside. “They contact us and then we tell them how to get a freezer assuming there are funds,” says Nancy. And they’ve never had to turn anyone down in six years. Interest or approval in chemo centers is key to the project’s mission.

Another way to make a difference is distributing literature to salons. Having literature in hair salons has been extremely successful in the past. “Many patients, when they find out that they’re taking chemo, if they need to buy a wig or if they need to shave their head, the person they are most likely to consult may well be their stylist because most patients have relationships with somebody at a hair salon.” Nancy explains that if the stylist gets to talk to the patient in the window after diagnosis and before treatment, “it’s the perfect time to tell them there is another option.” She’s heard from a number of stylists who have told her: “I never want to shave another head. I never want to hold another client while she cries.” “They are really on the front lines. They get it. They’re moved by it,” says Nancy. If you’re interested in placing literature in your salon, contact the project through their website, [www.rapunzelproject.org](http://www.rapunzelproject.org).