



The Rapunzel Project™

The Rapunzel Project
PO Box 963
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March 4, 2025

Dear Chair Pena-Melnyk and Members of the Committee:

We are writing to you to express our OVERWHELMING support for Maryland Assembly HB1187, which would require insurance companies to cover the cost of scalp cooling for patients undergoing chemotherapy. Maryland would become just the second state to require this coverage – incredible, overdue, compassionate support for cancer patients!

The Rapunzel Project is a nonprofit with the mission of creating awareness of the existence and efficacy of scalp cooling, the only way patients can save their hair during chemotherapy. Currently many common chemotherapy protocols have this terribly unfortunate side effect. Studies indicate that 75% of cancer patients say hair loss is the most feared side effect of chemo, and it is estimated that 8% of patients refuse chemotherapy because of hair loss - a potentially life threatening decision.

We almost accidentally discovered scalp cooling in 2009. The Rapunzel Project co-founder Shirley Billigmeier was able to successfully save 90- 95% of her hair through 6 rounds of chemo when she should have been completely bald. We were shocked to learn that few American doctors knew of the process and almost none thought it would work. We founded The Rapunzel Project to create awareness of the process - patients can't make a choice to save their hair if they don't know there is a choice. Naively we thought within 10 years scalp cooling would be the standard of care in the U.S., as it is in the UK. This belief was bolstered by FDA clearances of the process in 2015 and 2017, having evaluated it as being safe and effective.

While awareness is now much higher, and physicians have a positive view of the process, it is often not even recommended to patients for fear that they cannot afford it. Insurance coverage is spotty at best, varies by state and by individual plan, and rarely reimburses adequately even when covered. In 2017 Aetna actually published an acknowledgment that scalp cooling is medically necessary to prevent chemo induced hair loss. But that did not make it a covered benefit! Of note, as of January 2022, Medicare officially approved reimbursement for scalp cooling, but Medicare will not reimburse patients, only clinics. So patients must do their scalp cooling at a participating chemotherapy clinic which stocks the needed scalp cooling supplies. To date most clinics have been reluctant to purchase and carry scalp cooling supply inventory.

Why is saving one's hair so important? After working with patients for 15 years, plus our own personal experience, we can say for the following reasons:

1. Identity. Looking in the mirror and seeing yourself, not a stranger – even if not feeling your best.
2. Privacy. Your illness should not be everyone's business. Whether to protect your children from being frightened about your illness or to prevent others from knowing too much about your health, saving one's hair changes the equation.
3. Empowerment. Being able to do something beneficial for yourself at a challenging time helps create a more positive attitude in dealing with the illness and treatment.
4. Vanity. Not a bad reason, but for most patients not the most important reason.

"Helping chemotherapy patients keep their hair"

Of note, scalp cooling allows hair regrowth to begin even while chemo is ongoing, and prevents damage to the hair follicles, so patients don't end up with "chemo hair" when new growth comes in. Even when scalp cooling isn't fully effective, as can be the case with certain harsher drugs, these patients have a huge jump start on regrowth with normal hair.

Scalp cooling is not for everyone; it is extremely cold, and requires several extra hours sitting in the clinic beyond the chemotherapy infusion time. But most patients tell us it completely changes their cancer journey. They are able to live their lives more normally. Chemotherapy becomes medicine, not punishment which lasts months and even years after treatment until patients successfully regrow normal hair.

We fervently believe that every eligible patient should have the option of scalp cooling; it should not be limited to those who can afford it.

Thank you for your consideration of this important issue.

Kind regards,

Nancy Marshall Shirley Billigmeier

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