

This document is from Nancy Marshall and Shirley Billigmeier, co-founders of The Rapunzel Project, a **nonprofit** organization providing information and advocacy for scalp cooling.

April 12, 2026

Dear Chair Murray and Members of the Senate Health and Human Services Committee,

**We are writing to express our strong support for Rhode Island Senate Bill 2455, which would require insurers to provide coverage of scalp cooling for patients seeking to preserve their hair while undergoing chemotherapy.**

If enacted, Rhode Island would become just the fifth state in the nation to mandate this coverage – important, compassionate, long overdue support for cancer patients. Currently 10 other states are working on similar bills.

The Rapunzel Project's mission is to create awareness of the existence and efficacy of scalp cooling, the only way patients can retain their hair during chemotherapy. Studies indicate that approximately 75% of cancer patients say hair loss is the most feared side effect of chemotherapy, and it is estimated that as many as 14% of patients refuse chemotherapy because of hair loss – a potentially life-threatening decision.

We discovered scalp cooling in 2009, when cofounder Shirley used cold caps during six rounds of TCH chemo and saved 90+% of her hair; she had been expected to become completely bald. At the time few American doctors knew of the process, and almost none thought it would work. We founded The Rapunzel Project to create awareness of scalp cooling. Patients can't choose to save their hair if they don't know that choice is available. Naïvely we thought that within a decade scalp cooling would become the standard of care in the US, as it has long been in the UK. This belief was reinforced when the FDA cleared various scalp cooling systems as safe and effective in 2015 and again in 2017 and 2021.

While awareness has grown and physician acceptance is now high, access remains deeply inequitable. **Scalp cooling is often not recommended to patients by providers for fear that they cannot afford it.** Insurance coverage is spotty, varies by state and by plan, and pays inadequately even when covered. Note that chemotherapy costs tens of thousands of dollars; scalp cooling on average costs \$2500 per patient in total. But for patients facing medical bills, loss of work time, and other stresses caused by their illness, this is often an impossible amount of money.

In 2017, Aetna publicly acknowledged that Scalp Cooling is medically necessary to prevent chemotherapy induced alopecia — yet did not make it a covered benefit. Starting in 2022, Medicare officially approved reimbursement for scalp cooling, but only reimburses clinics, not patients. This restrictive policy means patients can only access this benefit if their clinic has invested in the equipment and supplies, which most have been reluctant to do.

After working with cancer patients for over 15 years, plus our own personal experiences as cancer survivors, we believe hair preservation matters for several deeply human reasons:

1. Identity — patients see themselves in the mirror, not a stranger, even while being treated
2. Privacy — patients can control who knows about their illness; also they can shield their children from the trauma of a strangely bald parent
3. Empowerment — patients can choose to help themselves at a time when they otherwise feel helpless
4. Vanity — not a trivial reason, but usually not the primary motivation

Scalp cooling also protects the hair follicles, allowing regrowth to begin even while chemotherapy is ongoing, and preventing long-term follicle damage. Even when not fully effective, patients experience faster and healthier regrowth.

Scalp cooling is not for everyone; it is extremely cold, and requires additional hours of capping beyond the chemotherapy infusion time. But most patients tell us it completely changes their cancer journey. Chemotherapy becomes medicine, not punishment which last months or years after treatment until patients successfully regrow normal hair.

We firmly believe that every eligible patient (all solid tumor cancers) should have the option of scalp cooling; access should not depend on personal wealth, geography, or insurance loopholes. Senate Bill 2455 is a thoughtful, humane, evidence-based step toward equitable cancer care in Rhode Island.

Thank you for your time and your leadership on this important issue.

Kind regards,

Nancy Marshall and Shirley Billigmeier

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ADDENDUM: We don't know what the proper format is for recommending a change in the language of the proposed bill. The Committee might be interested to know there are NO FDA-approved scalp cooling systems. FDA approval is a specific designation that applies only to Class III medical devices. There are several **FDA-cleared** scalp cooling systems. FDA clearance is a different designation which applies to most Class II medical devices.

There are also some manual (no machine involved, just cold caps) scalp cooling systems that are less user friendly (no machine=more work) but highly effective, which have not needed a clearance because they are rented privately by the patient, brought to the clinic as private property and used by the patient with a private helper. Medical staff are not involved - manual caps are too labor intensive for clinic staff, who are already very busy. Manual caps are the original cold caps. They have about 30 years of documented success with tens of thousands of patients around the world. They have reasonable success even with the harshest drug combo, ACT (machine systems do not); there is also evidence that for patients who have previously lost their hair and are now forced to repeat chemotherapy, they are more effective than the machines. Last, but not least, manual caps can be used at ANY location with a cooler of dry ice. This means patients who do not have geographic access to clinics with machines can still cap and save their hair.

In order to accommodate all of these options and let patients choose what is best for them, New York State, the first state to mandate insurance reimbursement, used broader language. Louisiana, West Virginia and Maryland have all used similar language to New York.

NY - the key language is in green, the link to the full bill is below it.

12 (B) For the purposes of this paragraph, "scalp cooling system" means

13 any device used to cool the human scalp to prevent or reduce hair loss

14 during cancer chemotherapy treatment, provided that such device is

15 designed and intended for repeated use and is primarily and customarily

16 used to serve a medical purpose.

<https://nyassembly.gov/leg/?Actions=Y&Chamber%26nbspVideo%2FTranscript=Y&Committee%26nbspVotes=Y&Floor%26nbspVotes=Y&LFIN=Y&Memo=Y&Summary=Y&Text=Y&bn=S02063&term=2023>

We hope you find this helpful, we are always available if we can provide any further clarity or answer any questions.

