



The Rapunzel Project™

The Rapunzel Project
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Dear Chair Bagnall, Vice Chair Cullison, and Members of the Committee:

We are writing to you to express our strong support for Maryland House Bill 0393, which would require specified insurers to provide coverage of scalp cooling for patients seeking to preserve their hair while undergoing chemotherapy.

If enacted, Maryland would become just the third state in the nation to mandate this coverage – important, compassionate, long overdue 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 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 co-founder Shirley Billigmeier 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.

Naively we thought that within a decade scalp cooling would become the standard of care in the U.S., as it has long been in the UK. This belief was reinforced when the FDA cleared scalp cooling systems as safe and effective in 2015 and again in 2017.

While awareness has grown and physician acceptance is now high, access remains deeply inequitable. Scalp cooling is often not even 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.

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.

"Helping chemotherapy patients keep their hair"

After working with cancer patients for over 15 years, plus our own personal experiences, 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 children
3. **Empowerment** – Patients can choose to help themselves 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 lasts months or years after treatment until patients successfully regrow normal hair.

We firmly believe that every eligible patient should have the option of scalp cooling; access should not depend on personal wealth, geography, or insurance loopholes. HB 0393 is a thoughtful, humane, evidence-based step toward equitable cancer care in Maryland.

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

Kind regards,

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