

Our Story of Hope

As shared by Jenny and Ava M.



Ava's cutaneous lymphoma journey began early. Born at just 31 weeks and weighing a mere three pounds, she was a fighter from day one. When she was six months old, we started noticing that her skin was very dry and she was always itchy. She started having hypopigmented spots, a discoloration of her skin, all over her legs and face that would become more prominent after sun exposure. She sometimes would also have marks like hives all over her body. Ava's pre-K friends would ask why her skin looked like it did. Family and friends suggested she had vitiligo.

Too young to understand what was going on, Ava always seemed desperate and frustrated, scratching her legs until they bled, trying to feel better.

As her mom, I felt powerless and brokenhearted not knowing what was wrong with my baby or how to make her feel better. Dealing with my own cancer diagnosis, and now Ava's diagnosis, I was confused and overwhelmed as to how everything was going to play out.

DERMATOLOGY ODYSSEY

That's when we started our dermatology odyssey. We first saw an allergist because I thought Ava's itchiness and hives were allergies. We also started seeing a dermatologist who diagnosed atopic dermatitis, a common form of eczema, and prescribed steroid ointments. We changed to unscented laundry detergents, creams, shampoos and conditioners. However, Ava's skin did not improve as we were hoping. It just got a little better, but never really cleared up.

A second dermatologist referred us to our third, an adult dermatology practice at one of the local hospitals. They started her on a monthly injection for eczema, but three months passed and her skin was not improving. That's when the dermatologist decided to finally do a biopsy of two different areas on her leg. This was in August of 2022, when Ava was six years old, turning seven.



We waited close to two months for her results to come back. When the call finally came, I was told Ava had mycosis fungoides (MF) and that she needed to get off the eczema injections. I was really confused. I never heard of this condition. To me it sounded like a fungus infection.

By doing my own research online, I found out that mycosis fungoides is a type of skin lymphoma. I was really scared. I didn't know what to expect. As a cancer patient myself, this was a hard pill to swallow. We started seeing a pediatric oncologist and a pediatric dermatologist at Children's Hospital of Philadelphia.

Ava's treatments have varied. She does have eczema on some parts of her body, as well as MF. We use a variety of ointments: triamcinolone, mometasone, hydrocortisone, and cetirizine to help with her itchiness. We also use healing ointments to keep her skin moisturized. This is very important. But I think the treatment that has turned everything around has been light therapy. Ava currently has had UVB phototherapy twice a week for almost a year. Her skin looks amazing. From time to time she will have flare ups, but we know how to treat it now.

THE CHALLENGES

It can be challenging for Ava to keep up with her school assignments so as not to fall behind while juggling treatments twice a week during school hours. The teachers, nurses and the principal have been wonderful. They are very

supportive of Ava's education and very accommodating to her needs. Twice a week she goes for her UVB light treatments in the morning and then off to school. She sees her oncologist every 6 months and her pediatric dermatologist every 6 months.

Keeping all of our appointments and treatments organized so we both get the care we need with no overlapping is challenging. Fortunately, my 20-year-old daughter is my "right hand," helping with medication applications and taking Ava to appointments when I'm unavailable because of my own cancer treatments. I am fortunate to have the support of my whole family, including my mom, sisters, and my daughters.

What has been more challenging for Ava is that she is a really active and sporty little girl. She has always been interested in sports. We tried soccer and basketball, but with her condition, sun exposure makes her itch. One day, we found the perfect sport for her ice hockey. It's indoors and cool enough that when she skates, even if she sweats, it doesn't bother her like the other sports have. She is also doing Taekwondo and has earned her yellow belt.



Ava is a strong, determined, passionate, kind and loving little girl. I have seen her rise up and be brave about her condition. She is eager to learn more about MF and meet other kids her age who are also struggling with any type of cancer.

WORDS OF ADVICE



Looking back, I wish I would have been more aware that some skin conditions can mimic eczema, and it's important to consider alternative diagnoses. I also wish I would've asked for a biopsy sooner.

I would encourage every parent to be your child's best advocate. Ask as many questions as you need. Ask why this is not getting better. Are there any other treatments we can try? Push for more testing, maybe biopsy the areas sooner. If it doesn't feel right with one doctor, always ask for a referral or a second opinion. Do what feels right for you and your child.