

Lucy's Story

February, 2023

My daughter, Lucy, was born in late 2018, and developed eczema by 4 months old. At 9 months, she saw a dermatologist who prescribed a mild topical steroid cream. The dermatologist also recommended we wrap her in "wet wraps" for a few nights and we followed her instructions. Over the next few years, we used steroid creams once every 6-8 weeks or so for 3-4 days at a time and only on inflamed spots.



By the spring of 2022, the steroid creams had continued to increase in potency and decrease in effectiveness. In late June, we used our final round of steroids on Lucy's skin and turned to homeopathy to treat her eczema and found ways to support her immune system, manage the itch and support her sleep. But after stopping steroid treatment, something happened in Lucy's body - she developed an all-over redness, sensitivity to water, a WILD itch, and a jerking of her limbs. Along with complaints of burning, her skin would flake off in large pieces, a sickly sweet smell came from her skin and her lymph nodes swelled in her neck, arms, sides and groin. She stopped sleeping at night, waking as often as every hour with pain and itch. I began to take seriously the concerns of my homeopath that Lucy had red skin syndrome (or topical steroid withdrawal, TSW). We adjusted our course and started treating her for TSW homeopathically.

By November, Lucy thrashed about with pain nearly every night, suffered from itch attacks and became obsessed with her flaking skin. No one slept. One night it was too much for me to take anymore. I decided to go to a local ER and ask for help. I wanted a stronger antihistamine, something to support her sleep and any recommendations (outside of steroids) that could give her relief.

The wait in the ER was as you would expect, long and uncomfortable. Once in a room, Lucy became increasingly agitated both physically and emotionally. When the doctor finally entered, she stood about 4 feet away from Lucy, staring at her, as I explained what I believed was happening: red skin syndrome as a result of topical steroid withdrawal. I shared the progression of Lucy's skin and my concern for her insomnia and her pain.



Lucy in the ER

The doctor told me she had "never heard of red skin syndrome" and it "wasn't a thing." She stated that while topical steroid withdrawal happens, it is rare and not what was happening to Lucy. I asked her to examine my daughter. "I don't have to," she said, "I already know what this is. This is severe eczema."

I was stunned. We stood in silence for a few moments.

"She needs steroids and antihistamines."

"No," I said. "Steroids caused this reaction in her and she is already on over the counter antihistamines. They aren't working. We need something else."

"What about oral steroids?"

"No," I repeated, "what other options are there?"

“There are no other options. And if you refuse, you are refusing medical care.”

Without a word, I scooped Lucy up and left the hospital. Monday morning, after dropping the older kids off at school, my husband received a voicemail from DCF (Department of Children and Family).

This doctor did not know Lucy had a dermatologist, allergist, chiropractor, homeopath and pediatrician all following her care. But she did not take the time to ask. In fact, she did not even examine my daughter. She did not so much as listen to her breathing, check her pulse or even pick up the sheet she was lying under to look at her skin.

I am lucky, the intake worker I spoke with was familiar with TSW and essentially took down the info about Lucy’s providers and asked to speak with the pediatrician. By the end of the week, the pediatrician had confirmed Lucy’s medical care and the report was “screened out” (not to be investigated). The damage, however, was done.

I filed a grievance with the hospital. It was taken seriously, especially given my place in the behavioral health community, and some good did come out of it. The hospital, however, maintained that Lucy was offered the standard of treatment: steroids.

I filed a complaint with the medical board in my state, alleging the doctor not only acted with medical negligence but abused her power by filing a 51A without due process. I continue to pursue homeopathic support for Lucy. And with the agreement of her pediatrician and a new dermatologist, we are trying other pharmaceuticals for her. I now come to doctors offices armed with files and paperwork. Lucy has tried 2 other drugs and had horrible reactions to both (one allergic and another psychomotor agitation). We are pursuing a third option as I write this.

But the filing of the 51A hangs over my head and over Lucy’s medical care. It is in her record now and my name is on the other side of the system. I can tell you without a doubt that if I were to refuse another type of Western medicine for Lucy, I run a high risk of being accused of medical neglect again. And if there is a next time, I won’t be able to navigate it so easily. As a licensed mental health trauma counselor, I understand how the system works and my rights as a parent - even so, what if the intake worker I spoke with did not have a knowledge of TSW or I wasn’t able to find a supportive and informed doctor to care for my child before this all took place? What about the many other parents or caregivers who are in a similar seemingly impossible situation due to the lack of awareness and education around TSW?

Jennifer, mother of child living in Massachusetts