

A Pathophysiologic Basis for Evidence-Based Treatment of Moderate-Severe Atopic Dermatitis



Patient Experience: Linette

I was diagnosed with atopic dermatitis at age 3. My father and my aunt, who were taking care of me at the time, they were around me the most. The symptoms that I experienced, again from their memory, was intense itchiness. I would get very hot very quickly. My temperature was not being controlled easily again. I would flare up and then not only get itchy but very hot, and then I would crack. My skin would be cracked. A lot of lesions. So when water would touch, I would be in a lot of pain. But mainly, a lot of itchiness.

My initial treatment, as far as it was, was by my pediatrician. My parents told me that they were given topical steroids right away. They were cautioned to use it sparingly, but still it was advised to use topical steroids.

As far as the topical steroids, which symptoms they helped were definitely the itchiness and even overall appearance. My father told me that the symptoms seemed to disappear really within the week. Within the month it seemed to totally clear up. But then he said that as soon as they stopped applying the topical steroids, the rashes and all the other symptoms would come back with a vengeance. So just much worse than they originally appeared. After using the steroids, they would go back and use the steroids again, but they have also tried other forms of treatment as well, such as acupuncture, and they told me some sort of liquid that the pediatrician gave me.

At some point in my life, I did stop topical steroids completely, but they were always that crutch, that safety net. I always knew that. I was always cautioned against using it too much, so I always knew to use it sparingly. When I would flare intensely, I do remember my mother just saying, "Why don't you just apply the steroids," and I was always nervous about it. But sometimes I would say that for a special event or I had to travel, I didn't want to deal with the itchiness and whether or not I'd be able to go out. I just wanted that bandaid.

I did go in a period of my life—it was around my early 20s—where I went completely off of steroids and I just felt that it was the healthier route to go. I went into complete topical steroid withdrawal. The red skin syndrome and everything. I was still able to live a semi-normal "normal for eczema" life. At the beginning, I remember friends saying that I do look like a burn victim and they were worried about me because my skin was so red. And then I noticed my skin was very raw, very tender. Actually I didn't know that it was topical steroid withdrawal at the time. I just assumed that it was a very, very bad flareup, but I also didn't put on the steroids because I just, from the beginning, I just always knew that steroids were not good for me.

When I restarted steroids, it was both oral and topical. I was in a situation when I was living on my own on the East Coast and I knew again ... I think your memory blocks out the bad memories, and it makes you forget the pain that you just went through a decade ago ... In my mind I was thinking, "No, this is just the bandage I need right now, and I'm going to use it just sparingly because what harm is it going to do? Just a little bit every now and then." This is the harm it does, by the way. I did that. I was desperate. I didn't know what else I could do. I had to work. I had to make money. I had to make a living. I couldn't imagine not working and not having the money to live, so I put on the steroids. I took the oral steroids as well. And then that's when Dupixent rolled around.

When I heard about Dupixent, I of course was very excited about it. The first biologic drug approved by the FDA for atopic dermatitis! When I got it, I was nervous, of course, because it's an injectable, but as I used it ... I used it for about 4-5 months, and it can be used at the same time as topical steroids as well. I did both. I barely used the topical steroids as I normally have my whole life. I barely used them, but I did use them every now and then for patches, especially on my chin and my chest.

As I used Dupixent, I noticed after a few weeks that the itchiness had decreased a little bit, by about 30%-40%, and then I noticed a lot of flakiness. But not thick lichenification of the skin. Not that, but very light flakes.

Dupixent was effective in helping some of the symptoms, to relieve some of the symptoms to a certain degree. For itchiness, it decreased it about 30%-40%, but I also noticed that I would still definitely have my intense hot itches in the night. It wasn't a night and day kind of difference, but it was enough that I did notice that itchiness was less, and I was grateful. Then I started getting side effects, injection site reactions. I didn't realize at the time, but they're injection site reactions. Wherever I would inject on my body, I would get this numbing sensation.

As far as basic management when it comes to my eczema, it changed throughout my life. Growing up, I always was taught to shower early in the morning, moisturize like crazy, and then run out the door.

I would use a lot of Cetaphil. I like Cetaphil. I've used Vanicream. I've used CeraVe. I've used so many different lotions. Depending on what part of my body, I would use thicker lotions or balms or stuff, and lip balm and stuff like that as well. But as far as cleansing goes, it was very simple. It was always a cleanser, a very simple cleanser with no scents. I don't wear perfumes. I didn't moisturize too frequently, because it feels uncomfortable.

When I was going through really bad flareups, that was always interesting. It was always painful to be in the shower ever since I was a kid until now. When you shower, when the water touches your skin it's like ... I've been reading a lot of eczema forums and TSW forums, and they're not joking when they say

that it feels like acid on the skin. It's so painful! I remember, as a child, I remember the cops coming to the house after I would scream when they would try to bathe me or give me a shower at night.

Even though it did get me through some hard times, topical steroids, I'll admit, especially when I was a server at a high-end restaurant, it's about your appearance. I'd use it on my face, and it did get me through those shifts at work, and it did let me work as a server. And it did let me do shows and stuff when I was performing, as well. But if I knew what would happen to my skin after that, I would hope that I would never use topical steroids again. Topical steroids can be a bandage, but I don't want to say that it was successful because it also did this.

A lot of people tell us to just stop scratching, and a lot of people tell us that it's just a rash. I can't tell you how crazy that drives us because anyone who has experienced this itch knows that it's a bone deep itch.

As far as just eczema in general, and topical steroid withdrawal in general, the big point I would love to touch upon is the mental and emotional aspect of it. Whenever a doctor would see me, they would see how bad, physically, eczema is. But they would never ask me if I needed a therapist. I think that when patients deal with a disease like this, which is way more than a rash ... Please never say that to your patient ... It's not just a rash. That really messes with their mind and their emotions, everything. It is so difficult to deal with this, especially when we live around mirrors, of course, and everyone around you has an opinion.

Because I know that normal, healthy people are able to get a certain amount of things done in their week that I can only dream of getting done in 2-3 months. That was a very harsh reality for myself. Things like grocery shopping. Things like, just basic things, and when things would get really bad, even things like the bathing or even putting on or taking off clothing was very painful. I literally needed help from other people.

Anyway, there's just so much as far as the mental and emotional aspect of eczema. I think that is just as much as the physical part.