INSIDE THIS ISSUE:

What are some of the most common (and challenging) quality of life issues among patients with atopic dermatitis (AD)?

How do parents of young children with AD manage to maintain optimism in the face of the many issues faced by their families?

How do patients with AD deal with emergency situations that arise in their lives?

What do patients with AD want and expect of their healthcare providers?

THE IMPACT OF ATOPIC DERMATITIS ON QUALITY OF LIFE:

A Patient Perspective
LEARNING OBJECTIVES

Upon successful completion of this educational program, learners should be better able to:

- Identify common quality of life issues faced by patients with atopic dermatitis (AD)
- Analyze the dangers of labeling patients with severe AD as “unique cases”
- Develop strategies to help parents of newborns with AD assist their children overcome sleep-related issues
- Gain knowledge of the potential role of approved and investigational systemic therapies among patients with longstanding, chronic AD

DISCLOSURE STATEMENT

According to the disclosure policy of the Dermatology Nurses’ Association, all faculty, planning committee members, editors, managers and other individuals who are in a position to control content are required to disclose any relevant relationships with any commercial interests related to this activity. The existence of these interests or relationships is not viewed as implying bias or decreasing the value of the presentation. All educational materials are reviewed for fair balance, scientific objectivity, and levels of evidence.

RELATIONSHIPS ARE ABBREVIATED AS FOLLOWS:

E: Educational planning committee
G: Grant/research support recipient
A: Advisor/review panel member
C: Consultant
S: Stock shareholder
SB: Speaker bureau
PE: Promotional event talks
H: Honoraria
O: Other

DISCLOSURES AS FOLLOWS:

Samantha Bittner has disclosed that she does not have any relevant financial relationships specific to the subject matter of the content of the activity.

Catherine Mabee, BA, has disclosed that she does not have any relevant financial relationships specific to the subject matter of the content of the activity.

Jim Hewlett, BA, has disclosed that he does not have any relevant financial relationships specific to the subject matter of the content of the activity.

Michelle Noor, BS, MS, has disclosed that she does not have any relevant financial relationships specific to the subject matter of the content of the activity.

Carrie Cai, PhD, has disclosed that she does not have any relevant financial relationships specific to the subject matter of the content of the activity.

Ly nell Doyle, BA, MBA, has disclosed that she does not have any relevant financial relationships specific to the subject matter of the content of the activity.

Rachael Bronstein, BA, has disclosed that she does not have any relevant financial relationships specific to the subject matter of the content of the activity.

Aisha Bryant has disclosed that she does not have any relevant financial relationships specific to the subject matter of the content of the activity.

OFF-LABEL PRODUCT DISCLOSURE

This activity includes discussion of investigational and/or off-label use of the following products or devices: methotrexate, prednisone/ prednisolone.

PLAN NG COMMITTEE

Linda Markham, BSN, RN, DNC, Executive Director, Dermatology Nurses’ Association, has disclosed that she does not have any relevant financial relationships specific to the subject matter of the content of the activity.

Scott Kober, MBA, Managing Director, Excellibur Medical Education, has disclosed that he does not have any relevant financial relationships specific to the subject matter of the content of the activity.

Kathy Gross, MSN, RN, DNC, has disclosed that she does not have any relevant financial relationships specific to the subject matter of the content of the activity.

Viviana Carter, BSN, RN, TNS, TCRN, has disclosed that she does not have any relevant financial relationships specific to the subject matter of the content of the activity.

Trudy Adamson, MSN, RN, DNC, AP-PD, has disclosed that she does not have any relevant financial relationships specific to the subject matter of the content of the activity.

TARGET AUDIENCE

This activity has been designed to meet the educational needs of nurses, nurse practitioners, and physician assistants. Other healthcare providers may also participate.

ACTIVITY DESCRIPTION

In this issue of Dermatology Nurse Practice, a variety of patients and parents of patients with atopic dermatitis offer their thoughts on the impact of their disease on quality of life.

ACCREDITATION AND CREDIT DESIGNATION

Nurses

The Dermatology Nurses’ Association (DNA) is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center’s Commission on Accreditation. (Provider No. P0072).

The Dermatology Nurses’ Association awards this activity 0.75 ANCC Nursing Continuing Professional Development/Continuing Education (NCPD/CE) Credits. Estimated time of completion is 45 minutes.

METHOD OF PARTICIPATION

There are no fees to participate in the activity. Participants must review the activity information, including the learning objectives and disclosure statements, as well as the content of the activity. To receive CNE credit for your participation, please go to www.dnanurse.org/educational-activities and complete the post-test (achieving a passing grade of 70% or greater) and program evaluation. Your certificate will be available to you in the DNA CE Center upon completion.

COPYRIGHT

© 2022. This CNE-certified activity is held as copyrighted © by Dermatology Nurses’ Association. Through this notice, the Dermatology Nurses’ Association grants permission of its use for educational purposes only. These materials may not be used, in whole or in part, for any commercial purposes without prior permission in writing from the copyright owner(s).
Quality of life is a broad term that encompasses components such as standard of living, community, and family life. Health-related quality of life (HRQoL) assesses qualities directly related to a specific disease or condition, as well as those that are independent of the disease but may be affected by it. HRQoL involves components that are often not captured in disease severity indices and can be easily missed during a scheduled appointment. The concept of HRQoL has evolved over the last decade to include, for example, the concept of how a patient’s actual life situation differs from their expectations.¹

The impact of AD on HRQoL for both the patient and their family is unquestionable. The physical manifestations of a persistent unsightly rash along with the often-uncontrollable itching leads many patients to avoid social situations and become isolated. This can then lead to depression and anxiety, which are significantly more common in patients with AD than the general population. As stated in one study, “the misery of living with AD cannot be overstated for it may have a profoundly negative effect on the HRQoL of children and their family unit in many cases.”²

One study of 239 patients with AD between the ages of 4 and 70 years showed that patients with AD, regardless of age, had inferior scores on vitality, social functioning, and mental health subscales compared with the general population. Patients with AD had inferior mental health scores than those with other chronic conditions such as diabetes and hypertension. Even compared to psoriasis, another chronic dermatologic condition, patients with AD had inferior levels of vitality, social functioning, emotional health, and mental health.³

**DRUG NAMES INCLUDED WITHIN THIS ISSUE**

<table>
<thead>
<tr>
<th>Generic</th>
<th>Brand</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dupilumab</td>
<td>Dupixent</td>
</tr>
<tr>
<td>Baricitinib</td>
<td>Olumiant</td>
</tr>
</tbody>
</table>
"The physical manifestations of a persistent, unsightly rash along with the often-uncontrollable itching leads many patients to avoid social situations and become isolated."

The presence of chronic dermatologic diseases such as AD has been shown to affect many important life choices. A 2012 study by Bhatti et al showed that patients reported that their disease impacted their career choice (66%), job (58%), choice of clothing (54%), relationships (52%), education (44%), not socializing, (34%), and having children (22%).

The psychosocial impact of improperly treated AD is also significant. Multiple studies have shown that the condition increases the risk of attention-deficit hyperactivity disorder (ADHD), depression, anxiety, conduct disorder, and autism among children. Both children and adults with AD also appear to have a higher risk of suicide and suicidal ideation.

In this special issue of Dermatology Nurse Practice, we’ll hear from eight individuals—either patients or parents of patients with moderate-to-severe AD—who will each offer insight into specific ways in which their disease has affected them throughout their lives. Each essay offers pearls of wisdom for the practicing clinician that we hope you will reflect upon as you provide care for your patients with longstanding, chronic AD.

REFERENCES

If I could change my name in my medical files from “Samantha Bittner” to “Unique Case,” I would have done so years ago. That way, new providers would have some sort of warning about what they are going to encounter when they walk into the exam room to meet me for the first time. It would save me those moments of anguish as I see their facial expressions quickly change from upbeat and optimistic to forlorn and sorrowful.

No one wants to be a medical guinea pig. I have heard the medical community tell me, “Well, aren’t you a unique case?” so many times that I’ve lost count. Every time someone utters those words, it makes me want to stop talking altogether. Is that all I am? A strange, interesting case study that needs to be analyzed and deciphered? I cannot put into words how isolated and scared it makes me feel when I hear that phrase from healthcare professionals. And the irony of it all is that I am not quite as unique as I’ve often been made to feel.

Whenever providers see “Atopic dermatitis (AD) patient” in my chart for the first time, I imagine they likely are picturing a 24-year-old woman with a few lingering eczema hot spots. What they probably are not picturing is a 24-year-old woman who has gone through topical steroid withdrawal, was pulled out of school for a time because her condition became so severe, and failed treatment after treatment since she was a little girl. For a long time, both because I had never met anyone with a medical history like mine and the way I was treated in nearly every doctor’s office I’ve ever been in, I thought I was “unique.” But I was wrong. And so was the medical community I was exposed to. Through the National Eczema Association, I’ve been able to meet so many other AD patients just like me. I’ve met many young women who failed treatments, were pulled out of school, and went through topical steroid withdrawal. For the first time in my life, these were people who understood how strangely my body functions. I did not need to preface every conversation...
with, “I know this is going to sound unusual, but for some reason, my body just behaves this way.”

The psychological damage of being a “unique case” is severe. Whenever I hear that someone has been diagnosed with a new condition and has found treatment that actually works for them—no matter what the disease or treatment—I become very jealous. I immediately wonder what it’s like to be told that you have “XYZ medical condition” and have that actually be the correct diagnosis. How comforting it must be to get a conclusive diagnosis that does not require endless poking, prodding, and testing to find the mysterious underlying cause of the pain that you are going through. How good it must feel not to have trust issues between your medical provider and yourself.

My healthcare journey has been full of mistrust and crushed hopes because of my “unique case.” By now, every time I walk into a new practice or see a new provider, I am mentally prepared for what I’m likely to hear. Frankly, I’m surprised when I don’t.

“I’ve never seen a case of atopic dermatitis this severe. I’m sorry, but there really isn’t anything left for you to try. This is really a unique case.”

There was a time a few years ago where I actually stopped seeing dermatologists because I couldn’t bear the feeling of being a guinea pig any longer. And this was during a period where my eczema was horrible. I just couldn’t bear standing there in my bra and underwear while dermatology residents looked me up and down.

One of my most painful memories happened when I was 13. I was in an exam room with my dermatologist, my parents, and an infectious disease specialist. My dermatologist asked me if he could bring in some residents to see me because I was—you guessed it—such a “unique case.” Without realizing what I was doing, or what it was going to entail, I agreed. And so, before I knew it, there were a group of maybe 6 or 7 residents staring at me, a 13-year-old girl in her bra and underwear standing in the middle of the room. None of the residents introduced themselves. They started speaking around me instead of to me. They were using terms I didn’t understand at the time—things like “pruritis” and “erythema”—and I quickly became very uncomfortable. Total strangers were staring at me with perplexed looks on their faces like I was some sort of lab experiment. I cannot put into words how ugly I felt in that moment. I felt like a mutant creature.

When I discovered that there is a world of patients just like me, it finally allowed me to hope for better times. And not all of my healthcare encounters have been cringe-worthy. One of my best experiences occurred when I saw a pediatric dermatologist during my late teens who helped research all of the clinical trials that were ongoing for patients with severe AD. He explained to me that there were lots of researchers looking for new treatment options for people like me who had tried and failed medication after medication. That blew me away and opened up a world I didn’t even know existed. Even more importantly, this was one of the few doctors who believed me when I told him what I had been through and didn’t seem to think I was embellishing the truth to get extra sympathy. I did not have to fight for credibility, which is often such a huge struggle for those of us who are labeled as a “unique case.”

I understand, at least from a conceptual basis, that the “unique case” is the interesting one, the one that challenges the skills and abilities of the healthcare community. But I urge you to remember that every “unique case” is a person with real emotions and not a test subject. Picture yourself as a 13-year-old girl or boy standing in a room full of strangers wearing next to nothing and being stared at for even 30 seconds. How would that make you feel?

That “unique case” in your exam room is likely exhausted from having a chronic illness and feels nervous and anxious about what the future holds. I can’t tell you how much I would have appreciated being asked, just once, “How are you doing?” by a new provider before the start of their exam. I have had so many appointments where I had to excuse myself to cry in the children’s bathroom because of how scared I was about my future. I left so many medical appointments feeling convinced that there were no treatment options that could ever possibly work for someone like me, and that I was going to need to suffer with chronic, severe AD for the rest of my life. Fortunately, I’ve learned that that isn’t necessarily true, and I can be hopeful for a better future, both as a young woman and a patient with AD.
They say that every child tells a different story in the life of their family, and that’s certainly true of our three boys—Declan, Connor, and Logan. But there are also overlapping trends within most families, which is also certainly true for us. If you put our sons in a Venn diagram, they would each have their individual space for their personalities and quirks, but giant overlapping regions in the middle devoted to two things—their birthdays and their atopic dermatitis (AD).

OUR FIRST: DECLAN

Declan was a New Year’s baby, born on Jan. 1, 2010, early in the evening. Since Declan was our first, everything was new to my husband and I. We were learning to be parents on the fly, changing our first diapers, waking up in the middle of the night for the first time, and doing everything else that new parents do.

When he was about 2 months old, we noticed that Declan would often scratch his face and rub his elbows and ankles on anything he could find. Once this persisted for a few weeks, we contacted our pediatrician, who told us to apply moisturizer to any skin that appeared dry and that “things should be fine in a few days.” Needless to say, things were not fine in a few days.

Every time we took Declan out in public, we got those stares and comments from random strangers that so many parents of children with AD know so well. “Oh my, what’s wrong with your baby?” As a new mom dealing with the usual challenges of raising a newborn, those comments are enough to make you break down in tears once you hear them over and over. There was nothing “wrong” with my baby. He just had very dry skin, and we were dealing with it the best we could. That unfortunately didn’t stop the staring or random advice—the one I remember best was one woman who told me that my son’s skin was dry because I didn’t
breastfeed him for long enough, and it was my fault he was having issues. Oof.

At Declan’s 4-month checkup, we saw one of the doctors we had not previously met with at our pediatrician’s practice. She was the first one who told us, “Your baby does not need to suffer like this!” She told us to avoid foods that often trigger allergies in children, such as cow’s milk, eggs, and peanuts, and to pay close attention to our son whenever we introduced him to a new food. This was both shocking and upsetting—our family had no history of either AD or food allergies, so this seemed like quite an extreme overreaction. But we were obviously willing to try whatever might be helpful, so we left the pediatrician’s office with a food monitoring plan as well as a prescription for topical steroids. Fortunately, less than a week after we started applying the cream, Declan’s skin began to clear up. Over the next few years, Declan’s skin would flare from time to time, but we had a firmer grasp on his triggers and were always able to quickly get him back to his baseline condition.

Fast forward to today, and Declan’s skin is mostly clear, although he does have allergies to multiple foods. Still, his health issues require little ongoing maintenance.

**OUR SECOND: CONNOR**

We found out that Declan was going to have a new sibling a few months after he turned 2 years old. Frightened that I had done something to cause Declan’s skin and allergy issues, I asked our go-to provider what I could do differently during this pregnancy to prevent a repeat occurrence. She advised me “to eat as your grandmother ate,” and to be sure not to cut out peanuts, tree nuts, and eggs entirely but to just eat them in moderation. And so I did.

Connor was born exactly 3 years and 1 day after his older brother, on Jan. 2, 2013. Obviously, we hoped that Connor wouldn’t share his brother’s skin issues. We noted some minor eczema on Connor’s elbows when he was about 4 months old, but it was not nearly as serious as Declan’s and went away fairly quickly with the use of a petroleum-based ointment. We thought that maybe we had dodged a bullet the second time around. Boy were we wrong!

As Connor’s teeth began to come in around the time of his 1st birthday, his skin issues became dramatically worse. Every time he was outside playing in the grass, or on a hot day, or when he got a cold or an ear infection, his AD flared. What made things even worse was that all of the topical creams that had worked to keep Declan’s AD at bay had no effect on Connor. We spent a lot of money trying to find the right combination of topical steroids, moisturizers, soaps, and detergents. But every time we thought we had finally cracked the code and Connor’s skin cleared up, things once again got worse and we were back to the beginning of the hunt.

It seemed like we were in a constant cycle of crisis with Connor. His face was always red and splotchy, his eyes were swollen, and his skin would itch and bleed constantly. His hands looked as if they had been burned with open wounds. There were a lot of tears, both from Connor and us, since he was always in a state of discomfort. Most mornings when Connor woke up, there was blood all over his sheets and face. As parents, this was obviously extremely difficult to go through. I felt helpless, like there was nothing I could do to help fix my son’s pain and discomfort. I sat up, night after night, scanning the Internet for anything that could possibly provide Connor with some relief.

Things reached a head in July 2017, when Connor’s little 4-year-old body was attacked with three different viruses. This seemed to supercharge his AD into overdrive. Lesions were everywhere—his face, his eyelids, his hands, his feet, his knees, everywhere. We once again made an appointment with our pediatrician to see if there was anything more we could do. Sitting in the waiting room that day was one of the toughest experiences of my life. As we sat there, people were staring and pointing at Connor. He could tell he was the unwanted center of attention, so he buried his face in my chest and cried. That finally pushed me over the edge, and my Mama Bear kicked in as I announced to the room, “It’s just eczema, people! He is not contagious!”

It’s not easy convincing people—parents, children, strangers—that eczema is not contagious, especially since Connor’s hands are one of his biggest trouble spots. Kids are often grossed out and refuse to hold his hand or play with him. As you can imagine, that hits us all hard. Who wants their kid to be a social outcast because of something completely out of his control?

About the only good thing that resulted from this most serious outbreak was that Connor finally agreed to allow me to apply wet wraps along with his various ointments and moisturizers (he previously refused wet wraps, saying they felt “weird”). In the next few months, there were even some days where Connor asked for
wet wraps in the middle of the day if his hands hurt, along with application every night before bed. We’ve still had some ups and downs these last few years, but with a combination of wet wraps and multi-purpose ointment, Connor’s eczema has generally remained under control. His condition is worst during the early summer months when no matter what we try, he gets an outbreak on his hands, feet, and knees. But his face and eyes no longer break out regularly, and he can play with other children without feeling self-conscious.

OUR THIRD: LOGAN

When I found out that I was pregnant with our third child, my husband and I had resigned ourselves to the fact that this was likely to be “another allergy/eczema kid.” Remember that we were more or less in the middle of the worst of it with our oldest two boys, so I had no excess energy to devote to much else.

In the linear progression of nature, our third son, Logan, was born on January 3, 2016. It makes the beginning of each year quite a week of celebration with all three birthdays crunched into three consecutive days!

So far, we’ve been luckier from a health perspective with Logan. He has some eczema triggers, especially grass, but he hasn’t needed regular care and adjustments to therapy like our other two boys. With Logan, I am finally able to see what it’s like to have a child with soft skin. It really hits home when we are walking somewhere in public, and I am holding one of Connor’s hands and one of Logan’s. The difference in texture is unbelievable. Not that there haven’t been challenges with Logan—the shampoos and body soaps, for instance, that have helped with his brothers, cause Logan to break out in pimples all over his body—but it’s almost been easy this time around. So far.

WHAT I’VE LEARNED

Parenthood is not easy for anyone, but my husband and I often wonder why we didn’t catch a break in the skin health of our sons. There are times that I blame myself—What did I do wrong when I was pregnant? Was it the vaccination shots they all received as newborns? Should I have breastfed them for longer than I did? Could there be something wrong with the water in our home that causes these breakouts? Even today, I still scour the Internet for answers to these and other questions.

When you are a parent, you do anything and everything for your children. We always made sure that our boys knew we were on this skin journey with them. One of the biggest sources of strength helping us to get through our skin and allergy issues was and always is the support we receive from our families. When we’re together, our boys’ skin is never made to be a big deal. They are treated just like all of the other kids in the family. One of our nieces even wears wet wraps when she comes to sleep over so that Connor doesn’t feel like he stands out. Apparently, this same niece had some issues with dry hands during COVID and asked her mom (my sister) to put wet wraps on her hands because, “It works for Connor.” I choked up a little when I heard that.

Another way that we cope as parents is by educating others. Teaching parents of young children with AD about wet wraps and all the other techniques we have used over the years has been extremely rewarding. I know that were in their shoes not that long ago and were searching everywhere for help, so to be a conduit of good information for these families is so gratifying.

I’ve been a regular at our pediatric allergist’s office for the better part of a decade, and they have often been the only ones who have helped me cope during the darkest days. I am not sure if we just lucked out with the providers that we see, but they have always been there whenever I had questions (and I have had a lot of them), they are willing to try new approaches, and they always listen to me and my three boys when we come to see them. While they are undoubtedly the medical professionals, we are the ones living with AD each and every day. Every question we ask or concern we bring up is taken seriously and not dismissed, even if it’s something they’ve heard 4-5 times already that day. They make me feel that we are not alone in this fight -- they care for my children and are always there to help.
During the course of my life, I’ve dealt with a variety of health issues, including asthma, depression, and even skin cancer. With each of these, I felt I had some control in managing my problems independently, and when I needed additional help, there were medical professionals who were able to provide guidance regarding appropriate treatment options.

But atopic dermatitis (AD) was, and continues to be, very different. My issues started quietly approximately 5 years ago, almost like a small grass fire on the side of the road that is easy to ignore before it grows and spreads into a raging inferno. For me, the first sign that something was wrong was when I noticed a few eczematous patches on the inside of each of my legs. Initially, I tried to address it by using a few different over-the-counter lotions from the drug store, but the lotions only seemed to exacerbate the problem and make me even more itchy. Before long, I had a whole shelf full of various lotions that were basically useless. Every morning, I woke up, looked at everything I had tried that hadn’t worked to contain my eczema, and waited for frustration to wash over me.

But the itch! That was the worst part. It never stopped. Day or night, sunny or cloudy, the itch never went away. During the workday, I would sneak off to the restroom almost every hour so I could sit in one of the stalls and scratch my skin. I knew I shouldn’t scratch, but it was the only thing that made me feel temporarily better.

The only other thing that helped was super-hot showers, which seems somewhat counterintuitive. You would think that piercingly hot water would further exacerbate fiery skin and that cool water would calm things down, but it was precisely the opposite for me. The hot water numbed my skin for long enough that it felt almost normal for a short while. My daily hot shower at 2:30 a.m. was the only thing that helped calm my itch and let me get back to sleep for a few hours. I knew it wasn’t healthy for my skin, but I needed to function and saw no other alternative.
As things got worse and worse, and I was forced to turn more and more frequently to these routines that I knew probably weren’t good for my skin over the long term, I felt defeated. I would walk around my house and see the little flakes of white skin everywhere. I would wake up in the morning and see the dried blood on my sheets. I was physically exhausted with the minimal sleep I was getting each day. I felt powerless over what was happening to me. Eczema was taking a substantial mental and physical toll on my body, and I didn’t have the energy to do anything beyond the bare minimum to survive each day. And that’s no way to live.

I knew I needed professional help, so I started with the dermatologist who had treated my skin cancer. He wasn’t an expert in AD unfortunately, so he referred me to a second dermatologist who prescribed topical corticosteroids. I remember listening as she went over when and how to apply them, but it was a lot of information to take in and remember all at once (and remember, I was barely getting by mentally anyway). I went home and applied the topical medications in the manner I thought I had been instructed, but my skin became more irritated, more inflamed, and even angrier. It was then onto a few short bursts of prednisone, which worked well for a few weeks but then, once its effects wore off, my eczema came back worse than ever.

During this time, I started isolating myself at home and canceling plans with friends because I just didn’t have the energy or desire to be out in public. I was getting more depressed and feeling more helpless and hopeless than I ever had up to that point in my life. It seemed like there was no way out. I’d been able to successfully manage so many other physical and mental challenges in my life, but eczema truly seemed to be stronger than I was.

Following another long conversation with my newest dermatologist, she recommended that I try a new medication called dupilumab. However, because this medication was so new (at the time, it had only been FDA approved for a little more than a year), she knew that my insurance was unlikely to approve its use without first trying additional, less expensive medications. First up was methotrexate, which had a long list of potentially serious side effects I worried about. I started taking methotrexate, but a few weeks later, I grew frustrated with this waiting game. Why was my insurance company in charge of my medical care instead of my doctor and I? My mental well-being continued to deteriorate as my skin remained itchy and fiery red.

It was a casual, off-the-cuff conversation with a friend that finally gave me a breath of hope. One day, I was sharing my frustration with the hoops I was being forced to jump through when my friend suggested to me that I might qualify for participation in a clinical trial of dupilumab. It wasn’t anything I had thought about before, but the possibility immediately gave me hope that I could gain some control over my disease.

I initially looked at open clinical trials at my employer, the University of California-Davis, but there wasn’t anything available there. However, I did see that the University of California-San Francisco (UCSF), about a 90-minute drive from my house, was looking for patients with moderate-to-severe AD to enroll in a pair of phase 4, post-approval surveillance trials looking at the impact of dupilumab on patient quality of life.1,2 I immediately perked up, although I soon realized that there might be logistical issues. For starters, how was I going to be able to take all that time off to drive to and from the clinical trial site every 2 weeks?

I was blessed at the time to have a very supportive supervisor at work who understood how badly I was struggling with my eczema. She said she would allow me to take off as much time as I needed to participate in the trials. That was one hurdle overcome, but now I had to ensure that I qualified for the studies.

For anyone familiar with the clinical trial world, there is typically a laundry list of inclusion and exclusion criteria with any trial. I had an initial phone call with one of the trial managers at UCSF, who told me I would have to wean myself off of all of my current medications before I could participate in these trials. I hesitated for a few seconds before convincing myself that once I survived that 30-day period, I might finally find a treatment that worked for me. Needless to say, that was the longest 30 days of my life. The only thing that kept me from slipping deeper into a dark hole was the light waiting for me at the end of the tunnel.

After those 30 days were up, I went to my initial appointment to ensure that I met the inclusion criteria for the two studies. My parents, who had also been working and advocating on my behalf, came with me to the initial appointment as my support team. Yes, I am a grown man, but you are never too old to need people in your corner!

The good news out of this initial evaluation (which was also, in a way, bad news) was that the current state of my eczema easily qualified me for the studies. The researchers said they could not believe how inflamed, irritated, and red my skin was. They said I had some
of the most severe eczema they had seen from any patient enrolled in the studies. In a strange way, that made me feel validated.

Being a part of these clinical trials wasn’t easy. I had to provide 16 skin biopsies in the first 3 months of the study to help researchers understand why dupilumab was effective on the skin covering some parts of the body but not others. That was a huge, time-consuming hassle, but I knew what I had signed up for. As the studies continued and my skin finally began to clear up, I began to feel empowered in several ways. It felt good to advocate for myself and not just accept the medication that my insurance provider deemed to be “acceptable.” I also enjoyed knowing that my experience was helping current and future researchers understand some of the mechanisms that drive eczema and its effects on the physical and mental well-being of patients.

It’s been more than 2 years since my participation in those clinical trials concluded. Certainly, a lot in our world has changed since then with the COVID-19 pandemic, but I have been blessed with mostly-clear skin and minimal eczema flares since starting on dupilumab (I continued its use following the conclusion of the clinical trials). Although I’m constantly on guard in case my condition evolves over time and my medication stops working as well as it has, I am grateful for the work of researchers who continue to look for solutions to help patients with AD just like me in the future.

REFERENCES


Finally!

After a long school year, it was time to enjoy a well-deserved summer vacation with my family. It was something I had been looking forward to for months, my first time heading to Europe. And not just any old place in Europe, but Paris (!), the city of beautiful architecture and historic artwork.

I packed my suitcase with colorful outfits, comfortable shoes, and everything else I thought I might need while I was gone. Unfortunately, a sinister figure was going to be tagging along on this trip with my family – atopic dermatitis (AD).

By this time, I had lived with AD for most of my 27 years, so I was well prepared to take it on. I refused to let it ruin my joyful adventure in a new, beautiful city. I knew what historically had triggered flares of my AD, so I packed all of the artillery I thought I would need.

Let's see—I knew that one of my main triggers is the dry air on the airplane. So on the morning of my flight, I slathered myself in Aquaphor, one of the thickest emollients available. I put on full-length cotton leggings and a long-sleeved shirt to lock in all the moisture. I even packed hydrating facial masks for the plane ride. “I'll definitely be outsmarting AD this time around,” I told myself.

And that’s not all. I loaded up my suitcase with full-sized bottles of my favorite lotions and moisturizers that I knew I wouldn't find in France. But I left the corticosteroids behind. No way I was going to need those.

I was double, triple, quadruple prepared – there was nothing that was going to stand in my way of the perfect vacation. Right? Right? RIGHT?

WRONG!!
The plane ride went fine, but then I got off the plane, checked into my hotel, and began walking casually toward the Louvre. Something, I could tell, didn't feel right. And yes, slowly but surely, AD made its first appearance. Rashes started to appear on my torso, my back, and my legs. How could this be? I was so ready, so prepared. This was my vacation, and now I had to deal with my AD? But that's the thing about this disease—it will humble you every time you think you have it beat.

I went to sleep that night reasoning that the plane was the issue and that I'd be better in the morning with the help of some Benadryl. On our family's agenda the next morning was a visit to the beautiful Palace of Versailles, which I was excited to see. Well, let's just say I went to sleep a Beauty and woke up a Beast. I couldn't believe it. I didn't even look like myself. My face was inflamed, puffy, and red. My body was covered in rashes larger than I had ever before experienced. AD seemed to be taking on a new form, and boy, was I unprepared. I had no idea what healthcare was like in France, I could barely speak more than a few words of French, and I had no clue where to go for help. Most concerning, I didn't know if I could get any of the medications I used to manage my disease back home.

I visited a pharmacy down the street, which I had been eyeing from my hotel balcony, and they directed me to a local doctor. While pharmacists in France are allowed to prescribe medications for general illnesses, my condition seemed to be out of their jurisdiction. This made me feel like my condition was truly severe; everything sounded so urgent. Here I was, trying to enjoy my first European vacation, and I was stuck dealing with a medical emergency.

Luckily, the doctor I saw spoke near-fluent English. She wrote out a few prescriptions and had me drink an IV steroid fluid (unheard of in the United States). I was desperate, so I did as I was told. Yes, the soldier who had set off ready to play offense against her disease was now reeling on her heels, desperate for relief and totally on the defensive. I was quickly learning that no matter how familiar you are with your usual AD triggers, once you travel abroad to a place with new sounds, sights, and smells, it's a total crapshoot. I had no immediate idea what had caused my tremendous flare and so I put my health totally in the hands of this doctor I had never met before and began the (oh so familiar) process of figuring out what my trigger could have been.

Surely it couldn't have been the dry air of the plane that had done this to me. I mean, I had flown before and things never got this severe. But what else could it have been that set me off? I looked around me, and that's when the lightbulb came on. At least 80% of the people around me were smoking, which is something I wasn't often exposed to in America. The very air I was walking through was filled with a trigger I had never before been around in such a large volume. Can you imagine? This was a detail I had never even considered before I arrived in Paris, and now it was poised to ruin my trip. I mean, who would consider the molecules in the air of a destination city when planning a trip?

I was, however, a little lucky. Not only did I now know what had caused my flare up, but the emergency measures I was prescribed seemed to be working. My rash was going away – not entirely, but enough that I could function. I had to make some concessions, of course. For one, I traded my trendy colored glasses for my sister's large, black sunglasses so I could hide most of my face. My clever Instagram captions contained addendums mentioning the very obvious eczema in my photos (I have found that a great way to take control of something that feels out of my control is by pointing it out before others do.) Interestingly, what was meant to be one of the most adventurous trips of my life became one of my worst eczema experiences.

Unfortunately, patients like me whose AD has followed them since childhood rarely get a break. I constantly have to be on the lookout, assessing the environment around me and thinking about potential triggers of my condition. I can't set aside time for rest and relaxation without worrying about the start of another cycle of itch and inflammation, steroid and side effect. AD never lets us forget that it's hanging out on the corner, ready to pounce when we let down our guard. It doesn't go on vacation when we do. It doesn't take a summer break. No matter how prepared we are (or think we are), there is always another surprise waiting in the wings. That's something I wish my healthcare providers could keep in mind whenever they see patients like me—we expect the best but prepare for the worst (because, as I have learned, it CAN get worse).

With that said, I'll have un latte avec du lait a'voine, with an extra shot of espresso, because life can get tiring when the journey of existing quite literally becomes a juggling act between the Beauty and the Beast.
Even without the COVID pandemic, my life has been a whirlwind of activity these last 2 years. I got married and had my first baby – two major life experiences. Of course, like it or not, my atopic dermatitis (AD) was along for the ride at every turn.

Here are two short anecdotes that highlight some of my most unique and significant struggles during this period that may help you see what some of your patients are going through.

**THE WEDDING DRESS**

While some people try to hide their eczema from other people, I’ve learned to hide it from my mind. While brushing my teeth, I avoid looking in the bathroom mirror. During the COVID pandemic, I meticulously avoided enlarging the little square containing my face in Zoom calls. For most of my life, I tucked my skin into the depths of my nagging subconscious, if only because it has been an effective survival tactic, allowing me to avoid being reminded of that nagging, incessant itch.

When I got engaged several years ago, I was naturally excited. A wedding, I knew from all of those fairy tales, is supposed to be the most cherished and beautiful day of my life. But because of my AD, for months leading up to my big day, I dreaded the pressure of needing to look beautiful.

Most brides spend their time debating whether to don a heart-shaped or strapless neckline for their “Perfect Dress.” I refused to think about necklines altogether. The only solace was that a pandemic wedding meant that my skin would be seen by at most 16 people, socially distanced in my aunt’s backyard.

At my first dress-shopping appointment, I naively asked the shop owner to see only cotton or silk dresses. I got a blank stare in return. “Has no one with severe...
eczema ever gotten married in a wedding dress?” I wondered. I felt I had to explain my skin condition as the rationale for the odd request, bringing the unwanted topic to the forefront of my attention. I could sense a subtle itch begin to tug at the outskirts of my mind. As I prepared to undress in the changing room, my mind began to race, knowing it was impossible to hide from the giant three-way mirrors and bright lights. I warned the store lady helping me change that I had eczema to avoid alarming her with my blotchy skin. “Oh, don’t worry. My cousin has eczema too... on her finger!” she said. I smiled bitterly. It seems like everyone knows someone with mild eczema and tries to empathize. What they don’t know, however, is that this actually makes it harder to convey how much my severe eczema causes me pain and suffering. Once we got past the initial uncomfortable stage, I asked to see dresses that could cover up the rash-like spots on my torso. I was handed dresses with coverage in the form of itchy, beady lace and tulle. Not exactly eczema-friendly materials. My mom tried placing nude-colored cotton cloth under the lace to ease my discomfort, but my aunts shook their heads at the aesthetics. Desperate, I asked a seamstress if she could add an underlayer of cotton to the dress, only to be scoffed at in return. “If you want to change a dress that substantially, it’s probably not the dress for you.” I felt trapped between impossible options: Should I cover up my itchy blotches with (even itchier) lace, or should I expose my blotchy skin, unhiding the painful itch from my mind? My frustration with this conundrum only made the itch creep deeper. As I marched from shop to shop, dragging my family along with me every step of the way, my options continued to dwindle. I could sense the hope in my mom and aunts as their voices rose and fell each time they fell in love with a Perfect Dress because of how beautiful it looked, only to have me tell them that it was not viable because of the material. I bargained with myself in the dressing room, calculating the number of hours I might be able to withstand a Perfect Dress. My mother and aunts, witnessing firsthand how my skin ruled my life, expressed their sympathy, but it only drew further attention to my issues. My body turned red from these deliberations. I was lucky. Eventually, after several hours of searching in numerous dress shops, I was able to find a dress that was perfect for me. The dress sparkled but was also soft to the touch. While many brides get their dresses altered to be skintight, my only alteration was to add a thin strip of cotton underneath the arm bands. On the night before my August wedding, there were thunderstorms that poured massive amount of rain in the San Francisco Bay Area. For days leading up to the wedding, I had pre-emptively loaded my skin with strong steroids and antihistamines, but the unexpected thunderstorms provided extra security—it meant my skin would at least be moist. At the end of my wedding day, I breathed a sigh of relief, knowing that my skin and I had both survived the whirlwind. The endorphins left my skin glistening and soft, despite its usual bumpiness. As my brand-new husband and I drove home, I reveled in the softness of my dress wrapped around me, and silently thanked my eccentric skin for cooperating.

**SWIMMING IN A SEA OF VASELINE**

“You’re an expert now,” the dermatologist assured me. “Whatever best practices have worked for your own eczema, you can try using for your baby.”

I was 8 months pregnant, staring at the Zoom call box with the dermatologist I had managed to get an appointment with to discuss my soon-to-be-born daughter. As a lifelong patient with AD, it was both comforting and terrifying to hear that the most I would be able to do for my daughter was what I had already done for myself my entire life. There apparently was no special potion or secret panacea for babies with AD. For a long time, AD was the reason I had debated whether to have children at all. What if inheriting my genetic predisposition makes my child suffer for her whole life? What if the profound sleep debt of parenthood caused my own eczema to spiral out of control, making me unfit to parent? What if seeing my child’s eczema forced me to be constantly reminded of my own itchy skin?

Determined to prevent my future child from developing AD, I pored over dozens of research publications online but found nothing conclusive beyond what I had already known from my own experience. Incredulous, I asked my own dermatologist to refer me to a pediatric dermatologist for more answers. “Sorry, we can’t actually schedule you for a pediatric consultation before the child is born,” I was told. How then was I supposed to know which probiotics to take during pregnancy,
which foods to avoid, and which baby wet wipes, diaper rash cream, hypoallergenic formula, and nursing pads to buy?

Meanwhile, my ballooning belly stretched out my skin, making my eczema which usually contained itself to my torso to expand and include my waistline. Though I knew that topical steroids were safe to apply during pregnancy, the proximity of my belly to my uterus made me hesitate from slathering on triamcinolone. As I mindlessly scratched my belly, my baby kicked and danced. I wondered if she could hear me scratch. “What if the scratching noise damages her hearing?”

Once my daughter was born, I was on high alert for any signs of eczema. When she was around 1 month old, I noticed the first angry red bumps on her face and forehead. As my daughter grunted uncomfortably and swiped her hand toward her face, I winced. Her itch struck me bone deep. I scolded myself for not taking more probiotics during pregnancy. As I observed the painful red patches on her skin, I felt my own skin tingle and become inflamed from the stress.

At our first visit, the pediatric dermatologist prescribed topical steroids. I sunk into my seat, feeling defeated. It was a drill I had experienced countless times in my life. I could already anticipate my baby using more and more potent steroids throughout her life, with a fate no better than mine.

“Should we bathe her today?” my mom asked when we returned home. Unfortunately, the Internet was split between doctors who recommend daily bathing for babies with AD and those who recommend as little bathing as possible. “Should I apply the 1% or the 2.5% hydrocortisone? When should I do it?” my mom continued, holding up the two tubes and inspecting the medicine label.

For possibly the first time, it dawned on me that I was better equipped to parent a child with AD than my mother ever could be. The generic instructions to “Apply 2x a day for 7 days” do little to help caregivers put science into practice. But for me, it was second nature.

I knew how I would feel if I were in my daughter’s skin. I knew that, had I not bathed for days, even a thick layer of Vaseline would feel irritating. I knew that a daily bath would help me relax, bringing both emotional and physical benefits to my skin so long as the moisture is immediately locked in with Vaseline. I knew that, to put out the flare without overusing steroids, I would apply the stronger steroid on the reddest spots and the weaker steroid on the milder spots. And, though it is never written in any clinician’s after-visit instructions, I knew that going outside for some fresh air would help soothe the itch. I even knew—from my own past—to look out for eczema herpeticum, a dangerous infection that can easily be mistaken for a flare.

So that first day, I treated my daughter’s eczema as I would my own. And then the next day. And the next. Gradually, her angry red skin calmed to a light pink, until it only needed Vaseline for regular maintenance. My dermatologist’s early words (“You’re an expert now”) were more empowering than I would have ever expected.

One morning, I was awakened by the sound of my baby crying, reminding me that it was time for her morning Vaseline rub. Simultaneously, however, I felt the inflammation of my own skin. The pins-and-needles sensation all over my body made it difficult to get out of bed. Wanting desperately to attend to my own skin first, I felt a sudden wave of guilt, comforted only by the well-known airplane safety instructions reminding parents to put on their own oxygen masks before that of their child’s. I jumped out of bed and anxiously rubbed Vaseline all over myself before doing the same with my daughter.

Tonight, I bounced my baby in my arms as we danced to music. Noticing her dry skin, I grabbed a large dollop of Vaseline and started spreading it on her arms (conveniently, I already had five big jars of them sprinkled throughout the house). Realizing I had too much Vaseline left on my hands, I glanced around the room, looking for the nearest tissue. I quickly realized there was a better solution as I lathered the rest onto my own dry arms. As I soaked in that familiar sensation of oily goodness, my daughter smiled, innocently peering into my eyes.

We continued swaying to the music, my baby and I—gleefully swimming in our collective sea of Vaseline.
Nearly 16 years ago, I lay in a mussed heap on an antiseptic operating table waiting with bated breath for that first cry that would alert my husband and I of the arrival of our new bundle of joy. As I heard the first squeals intertwined with the cheers of the surgical team, my heart leapt before that brief moment of panic familiar to every mother. Was my child OK? Fortunately, yes, he was fine. But what I had no way of knowing at the time was that this brief moment of panic would be the first of many our family went through during the next few years.

As with all new families, once we were all discharged from the hospital, the three of us settled into our new lives and routines. Every morning, we exhaustedly but happily peeked at our son and ran our fingers through his gorgeous mane of hair. The first moment of panic came about 4 months after he was born when we found ourselves peeking at a bumpy red scalp. The doctor told us it was cradle cap, prescribed a shampoo and some moisturizer, and told us not to worry. We tried our best to keep calm and convince ourselves that things were fine, but within a year of our son’s birth, he was a swollen red mess with patchy baldness, dry and itchy skin everywhere, and a cry that begged for relief. The fight-or-flight alarm bells in my head went off around the clock until, finally, my son was diagnosed with atopic dermatitis (AD).

Our pediatrician quickly referred us to a pediatric dermatologist, who initially prescribed low-dose steroids that my son’s eczema seemed to laugh at. Clothing irritated him. Bathing was a daily battle. Public nursing was out of the question as he could not tolerate his beautiful handmade blankets laid over his head. Our son was miserable, and my husband and I were convinced that we were awful excuses for parents.

Going out anywhere in public was exhausting. There were so many times when acquaintances would come up to us, seeing how miserable and red our son was, and ask us if we had tried a particular remedy or pointedly tell us what we were doing wrong. Some people went so far as to tell us we were coddling our son and paying too much attention to his skin rash that, “He will surely grow out of it in the next few months.” It
was all we could do to keep ourselves composed—these people only saw things for a brief moment of time and had no idea of what we were dealing with on a day-to-day basis.

Of course, our son did not magically get better and did not “grow out of it.” Over the course of the next decade, we changed dermatologists several times, each time having to start over to build a new relationship. We added allergists, new pediatricians, holistic medicine doctors, and even a nephrologist to our medical team. We enrolled our son in clinical trials, put him into therapy and peer counseling sessions, and even tried cryotherapy. We constantly scoured the Internet for scraps of new information. We heard time and time again from friends, family members, strangers (and cousins of strangers) that it was “just a rash.” This was not just a rash. This was the centerpiece of most of our days. Our family had eczema.

Our small family had become an island unto itself. This island, though tired, sad, troubled, financially burdened by treatments, always awake and even afraid at times, still persevered to find an elusive comfort mechanism for our uncomfortable son. We worked tirelessly to keep our son comfortable day and night through his intense itching and pain. We walked down the hallway of our home every hour on the hour during the worst of his eczema flares. I learned the art of sitting upright and holding my child’s hand all night to prevent him from scratching. I could probably easily take a gold medal in the Wet Wrap Olympics for speed.

What our community of friends, family, and strangers could never understand—and I rarely had the energy to even help them try—is that eczema isn’t just a random rash that perhaps they had as a child that went away 3 days later thanks to a little olive oil. AD is an all-encompassing, chronic disease that burrows deep into the psyche of the patient, the patient’s family, and their closest loved ones. It digs into the bottom of the wallets of those who have vowed to protect their child from one more sleepless night by whatever means possible.

As my son grew smarter and more creative, he met the real world head on once he entered school. He was bullied by classmates who did not understand that eczema isn’t contagious and that he did not have “old man hands.” Some days, my son would come home and question his relationship with the world.

“Why did God make me this way?” he would ask. “And why won’t he fix it?”

Our family’s eczema was getting worse.

You can only imagine the heartbreak of a parent who knows that their child is perfect in every way but who feels so badly about himself that he doesn’t even want to look in the mirror. No matter what we tried and where we turned, there was no sustained relief. By the time my son celebrated his 10th birthday, we had moved to the top of the treatment ladder. We had tried two different immunosuppressants without getting any relief. The squeals of pain still echoed off the walls of our home, the itching was nearly unmanageable, and, frankly, we had just about lost hope that things were going to get better. Our decisions had evolved from weighing which type of cream or short-term measure
to try to get some relief for our son to evaluating which potentially toxic medication might be the “silver bullet”
to get his eczema under control.

Whenever we had a doctor’s appointment, my son seemed to take the gold medal for having “just about
the worst case that we have ever seen.” Unfortunately, this never led to gold medal treatment. The best we
usually got was a sympathetic ear and questions of, “How did this get so bad?” So again with the feelings
of parental guilt. And we were still dealing with our day-to-day nightmare, our 5-alarm fire that we were
trying to put out with a water pistol.

But life doesn’t stop just because your child has a chronic disease like AD. My children were aging (we
have another son who is 3 years younger than his older brother and has much milder AD), and the importance
of physical appearance and the ability to concentrate on schoolwork took center stage for my “tween” son.
We knew more dermatologists than we knew cousins. There were more and more school absences every
year, and while I tried to put on a brave face for my son every morning, it seemed like the light around our
lives dimmed a little bit more every day. My son had been through so many ineffective treatments that he
became reluctant to try anything new and was more irritable in general. The overall mood in our house
was pretty dark. Our family had the worst eczema ever.

And then came the breaking point, a few months after
my son’s 12th birthday. It was a terrible flare in his
eczema, the worse he had had in years. There were
several consecutive sleepless nights, around-the-clock
itching, significant pain, and buckets of tears from me
and my son. I was hopeless. Eczema had us.

In the middle of one sleepless night, I surfed the
Internet for some help, as I often did on those nights
where sleep was an impossibility. But this time, it was
different. Instead of searching for a miracle cure, I
searched for someone whose story I recognized, some
family like ours. To my surprise, there were a lot of
people in the clutches of eczema.

For the first time, I found a whole community of people
through the National Eczema Association (NEA) who
had been isolated just like us, who felt like bad parents,
who were depressed and hopeless. Most importantly,
these were parents with children who they wanted to see live life to the fullest without the burden of chronic
itchiness, embarrassment, pain, depression, and a
warped self-image. These parents all felt, whether in
the past or present, that the light was dim.

While I had theoretically always understood that there
is power in numbers, this time I really understood it.
I reached out to someone at NEA who put me in touch
with other people who had undergone so many of the
same challenges our family was going through, and
my son was able to connect with children that were
experiencing the same day-to-day issues as he was.
He learned that he truly was not alone. Yes, our new
village had eczema, but more importantly, our new
village had answers.

This new village, made up of AD patients, parents,
and advocates from around the United States, was a
powerful force. Everyone bonded with the purpose
of providing assistance and information instead of
pointing fingers and telling us that everything was
our fault. Our new village was compassionate, caring,
accessible, and actively working toward rebranding
eczema as more than a “rash.”

A few months after connecting with our new village,
we were able to find a medical team that focused for
the first time on my son as whole person and not
someone who needed to be “cured.” They understood
the benefits of patient-centered decision making and
talked to us as equals. After cycling through another
litany of treatments, my son’s disease is currently more
stable than it has been since he was first diagnosed as
a baby. He still struggles with the psychological scars
of a lifetime of eczema, but he seems empowered by
his ability to advocate for other children with AD and
a belief that there will one day be a cure.

My son turned 15 late last year, and we’re slowly
coming to grips that his life is soon going to require
more independence and self-sufficiency in managing
his condition. AD is a chronic disease that has been
yoked to our family for a long time. I tell people that
my family has eczema because we have all been
affected by the condition on some level, but eczema
will never define who my son is. To me, he’s still that
little bundle of joy, perfect in every way.
I was living in New York City when I first started noticing eczema on my hands and eyelids at age 22. I was just out of college, thrust into a city where I didn't know a soul. I had only been at my job a few months and was just starting to get the hang of the daily routine. At first, I couldn't figure out what was going on with my body. I didn't realize that even a minute of rubbing would lead to a couple weeks of swelling. The whole world of eczema was something new to me—unlike a lot of patients with atopic dermatitis (AD), I never had skin issues as a child.

I knew I needed to see someone for my skin, so I looked up a dermatologist in my health plan's directory. I didn't really have the time or patience to do much research, so it was more or less just a random choice. The initial appointment was pretty brief, no more than 5-10 minutes. The dermatologist confirmed that I had AD and gave me a steroid cream to use on my hands. It wasn't safe to use near my eyes—at least I don't think it was—so I didn't have anything to help with that part of my body.

Over the next few years, my AD spread to other parts of my body. I used topical steroids off and on to manage the worst flares, but it was honestly just something I learned to live with. Five years later as I passed my 27th birthday, I was about to get married, and my body was covered with moderate-to-severe eczema. I took 40 mg of prednisone the day before the wedding just so I could hopefully have clear skin on my wedding day. Fortunately, prednisone always proved fairly reliable for me, and my skin cleared to help me have a perfect wedding day. Unfortunately, I had to taper off of the steroid during my honeymoon. Usually, that wasn't such a big deal, but this time, I had a terrible withdrawal reaction. I don't know if I tapered off of prednisone too quickly, but my body broke out in the worst rash of life. It was even worse than the week before my wedding.

**The Search for the Perfect Provider**

Rachael Bronstein

I knew I needed to see someone for my skin, so I looked up a dermatologist in my health plan's directory. I didn't really have the time or patience to do much research, so it was more or less just a random choice. The initial appointment was pretty brief, no more than 5-10 minutes. The dermatologist confirmed that I had AD and gave me a steroid cream to use on my hands. It wasn't safe to use near my eyes—at least I don't think it was—so I didn't have anything to help with that part of my body.

Over the next few years, my AD spread to other parts of my body. I used topical steroids off and on to manage the worst flares, but it was honestly just something I learned to live with. Five years later as I passed my 27th birthday, I was about to get married, and my body was covered with moderate-to-severe eczema. I took 40 mg of prednisone the day before the wedding just so I could hopefully have clear skin on my wedding day. Fortunately, prednisone always proved fairly reliable for me, and my skin cleared to help me have a perfect wedding day. Unfortunately, I had to taper off of the steroid during my honeymoon. Usually, that wasn't such a big deal, but this time, I had a terrible withdrawal reaction. I don't know if I tapered off of prednisone too quickly, but my body broke out in the worst rash of life. It was even worse than the week before my wedding.

**AUTHOR:**

Rachael Bronstein lives in Miami, FL, with her husband and three children
My AD journey has exposed me to dozens of different dermatology providers through the years. As my AD got worse and worse, I did more research to try to find providers with specific expertise in the management of AD to help me figure out what was going on with my body and ways to fix it. Was it something I was eating, touching, or doing? I didn’t know, but I needed to find out. Ever since my dad died when I was a young girl, I have been extremely independent. Growing up, I was the trusted helper to my mom and expert problem solver. I could not fathom a situation I could not figure out, which is why my AD had me so stumped. I tried everything—doctors, diets, topicals, more doctors, acupuncture, alternative therapies, and yet more doctors—but nothing seemed to help.

I particularly remember the time I was able to wrangle an appointment with one of the top dermatologists at a major academic institution in New York City. He was the department chair, and due to his credentials and background, I was sure that he would be the one with all of the answers to my issues. I sat in the waiting room anxiously waiting for him to share something new with me, some idea that I had never heard before. Instead, he offered me this:

“You have atopic dermatitis that is probably being set off by 25 different things that you’ll never be able to figure out. Just take this steroid cream and see how you do.”

I wanted to cry. I had already been through topical steroids multiple times. They never broke the pattern of flares. The flares led to infection. The infections got me back to the doctor’s office, where I was put on more steroids or oral prednisone or antibiotics. This happened a couple times every year.

The problem with switching providers was that every time I started with someone new, not only did I have to retell my story, but the practice didn’t have a baseline for my skin. To them, my AD always looked “terrible,” while in my mind, while I may not have been doing great, I usually thought that I was doing OK. Too many times, the providers I saw seemed to only have been trained in ways to put out the fire: hit it hard with strong topical steroids, oral prednisone, or antibiotics. It was the same story time after time—young doctors, old doctors, male doctors, female doctors—it didn’t matter. I was rarely asked if I had been on prednisone or antibiotics whenever I went to a new practice, so it was easy for their providers to layer it on. After a while, I refused those treatments. Based upon the many interactions I had had with the healthcare community, it appeared that I was stuck—I had tried everything, but I couldn’t get my skin consistently clear.

The worst time of my skin journey came after the birth of my second child. We had recently left New York City for Florida, and the move triggered another intense AD flare. Eczema covered my body from head to toe. Even showering was unbearable, the water like needles on my skin. I cried in the shower and couldn’t bend my limbs once I was out. It took hours after I applied moisturizer and threw on some old baggy clothes for my skin to soften enough to be even a little bit comfortable. That’s obviously not an ideal situation for anyone, much less the mom of a toddler and newborn. I knew I couldn’t continue like this.

I did lots of research online to try to find a provider who might be able to help me. I found another dermatology “rockstar” (this time, it was a contact allergist) and waited patiently to get an appointment with her. Even before we met, I liked that she had written extensively both in the professional and patient literature about AD, so she seemed to have both the expertise and compassion I was looking for. It took 4 months to get on her appointment book, which was a painful wait. I had to stop nursing my newborn so I could go back on prednisone. That was the only way I could even function.

“I also wish that more providers would arm their AD patients with peer resources to connect them with other individuals going through similar situations.”
But wow, the wait was worth it. Somehow, we got my back clear enough to perform patch testing. I got 150 little patches placed on my back and arms on a Monday afternoon. I went back for an initial assessment that Wednesday and again that Friday. When they removed the patches, we realized that I had had an allergic reaction to each of the patch boxes. Eventually, it was determined that I had nine specific allergens and four more irritants. Numbered handouts were given to me at the conclusion of the evaluation showing me those things to which I was most and least allergic. While the information was overwhelming, at least I finally felt like I had someone on my side who would help me find the answers to the causes of my AD.

By eliminating the products and foods I was allergic to, my skin quickly became about 75% clear. Not great, but way better. Alas, as soon as I felt I was on the right track, my “rockstar” provider moved across the country to California. I felt so sad that this incredible doctor I had been looking for throughout my AD journey was leaving, while also feeling blessed for the time we had spent together and the answers she helped me find.

Years went by, and I continued to have my ups and downs with my AD. Things were never as bad as they had gotten after my initial move to Florida, but they were never great either. When my disease flared, my rash was concentrated on my face, neck, and hands, none of which are easy to hide. I had my third child, and this time was able to nurse her for 9 months while my disease stayed relatively well controlled.

I had a stable relationship with a local dermatologist for a few years, which was OK but not great. We really just worked to maintain my AD instead of trying anything new. Bleach baths were the one reliable approach to keep infections as bay. They usually were effective enough to keep me out of the hospital and off of antibiotics, although there were times that even bleach baths weren’t enough if the infection became especially serious.

It wasn’t until after dupilumab came out that I really fought once again for my long-term health. I made an appointment with another of the dermatology “rockstars” in Miami who was involved in some of the early dupilumab clinical trials. I was a bit leery about trying dupilumab initially—frankly, I wasn’t sure that my AD was severe enough to warrant its use—but I finally decided that I wanted to try to give my body a break from 20+ years of itching.

It's funny how, once you step away from something, you can finally see it more clearly. I get choked up today when I think about how much I suffered all those years. I’ve been on dupilumab for about 3 years now, and I’ve been completely free of itching and rash that entire time. I haven’t once needed to take topical steroids. I don’t have any more sleep issues, and I don't have to worry about being able to function during the day. I was even secure enough to launch my own financial coaching business earlier this year and became involved in the Miami Eczema School, a special program for patients with AD or parents of children with AD.

Through my healthcare journey, I’ve learned that patients with AD need to do more than just sit back and follow whatever guidance they receive from whatever provider is able to see them. Being proactive not only to find a provider who understands that AD is a chronic condition that ebbs and flows in severity, but also one with the bedside manner to patiently work with me, was the key to getting my disease under control. While all dermatology providers deal with skin issues, not many specialize in AD, and I’ve found that patients with moderate-to-severe AD are among the most challenging for many providers to manage. I am grateful to my local dermatologist in Florida who referred me on to an academic medical center when she reached the limits of her expertise.

I also wish that more providers would arm their AD patients with peer resources to connect them with other individuals going through similar situations. So many of us feel so alone and that “no one else can understand how I feel” when, in fact, there are thousands of patients with debilitating AD dealing with the daily challenges of this insidious condition. I have served on the board of one of these organizations—the National Eczema Association—for the past 4 years, and it’s been an incredibly meaningful experience. I have met so many patients who suffered with AD for years and only found hope when they realized that there were organizations and individuals who they could reach out to for help.

The successful treatment of AD requires a full team effort. You need compassionate health care professionals, a well-informed patient, and an open line of communication between all parties. My hope is that everyone with AD finds their way to clearer skin like I have to help them build a life full of purpose and passion.
As a parent, you live in a world of doubt and uncertainty, regardless of whether you are dealing with your first child or your fifth.

“Am I doing this right? Should I be worried about this? Is this normal?”

Now compound the issue in a child with eczema. There are even more questions, more judgmental stares out in public, and more moments of doubt.

“Should we try this? Is this hurting or helping? Am I following the instructions correctly?”

But then comes the most painful question of all—“Did we do something wrong?”

That moment of introspection, doubt, and, yes, shame is unavoidable in parents of infants with atopic dermatitis (AD). After bouts of itchy days, sleepless nights, and buckets of tears (there is a lot of crying), it’s all you can do to stand tall and say, “WE’RE DOING THE BEST THAT WE CAN!!”

Our family’s eczema story began when our daughter was 6 months old. We had noticed that she had broken out in a rash over various parts of her body that were extremely itchy and simply were not going away. Once our pediatrician formally diagnosed our daughter with AD, she was started on corticosteroids to see if that would make any difference. We also received detailed instructions on bathing, moisturizers, and other skin care fundamentals. Because we were desperate to help our daughter, we were extremely diligent about asking questions and making sure that we knew exactly what to do every day and night.

I remember leaving the doctor’s office after our daughter was diagnosed and receiving an initial treatment plan.

Arming Families with Eczema Superpowers

Aisha Bryant

Author:
Aisha Bryant lives with her husband and two children in Anaheim, CA.
I felt optimistic for the first time in weeks. Finally, something was going to help!

Unfortunately, that optimism soon turned to anger and frustration. We did everything we had been told by our doctor—daily baths and wet wraps, moisturizer in the morning and night, topical corticosteroids to the worst areas, and...nothing. It was like eczema was laughing at us.

It's a heartbreaking and humbling experience having to pin down your 8-month-old to wrap her body so she doesn't tear her skin off because she's so itchy, constantly apologizing and reassuring her that eventually, things will get better. Or hearing her tell you day after day as a 3-year-old, “I can't stop itching. My whole body hurts.”

As a parent, living with a child with severe AD is hard. You wonder if the medications your daughter is being prescribed will stunt her growth or somehow otherwise affect her as she gets older. There is a lot—a lot—of parent/child bonding time. There were countless baths and showers I’d take with my daughter because her skin hurt so much and it was all I could do to soothe her tears.

Along with her diagnosis of AD, my daughter was also diagnosed with asthma in her infancy, and we were in and out of the emergency room several times during the worst of her asthma attacks. In July 2020, after several years of topical corticosteroids that were basically worthless (plus, her skin was becoming discolored), we decided to take our daughter off of corticosteroids against our doctor’s recommendation. There was a short window of steroid withdrawal but nothing too major in the wake of everything else we were going through. Still, we were a little bit lost as to our future plan of attack.

"...it has become quite apparent as of late that many doctors and medical school students are not well equipped with a knowledge of issues among patients with skin of color. There are unique characteristics of black and brown skin, and our skin conditions often manifest in different ways than Caucasian patients."

As a parent, living with a child with severe AD is hard. You wonder if the medications your daughter is being prescribed will stunt her growth or somehow otherwise affect her as she gets older. There is a lot—a lot—of parent/child bonding time. There were countless baths and showers I’d take with my daughter because her skin hurt so much and it was all I could do to soothe her tears.

Along with her diagnosis of AD, my daughter was also diagnosed with asthma in her infancy, and we were in and out of the emergency room several times during the worst of her asthma attacks. In July 2020, after several years of topical corticosteroids that were basically worthless (plus, her skin was becoming discolored), we decided to take our daughter off of corticosteroids against our doctor’s recommendation. There was a short window of steroid withdrawal but nothing too major in the wake of everything else we were going through. Still, we were a little bit lost as to our future plan of attack.

And then, a short time later, our doctor mentioned that dupilumab had recently been approved for children ages 6 years and older (it’s now approved for those ages 6 months and older), and that we might be able to get its off-label use covered by our insurance even though our daughter was only 4 years old at the time. We said we’d think about it—it was a lot to consider. Yes, our daughter was still suffering most days, but this was a new medication we’d have to administer ourselves at home and there was a lot of uncertainty about side effects. Nonetheless, after a lot of discussion, we decided dupilumab was worth a try. And boy, are we glad that we made that decision.

Our daughter started on dupilumab in September 2020, and we noticed a dramatic improvement within weeks. For the first time in her life, she was able to experience things like a normal child—going to the zoo, meeting friends on the playground—without
having to constantly worry about having a reaction to being outside for too long. As parents, we’re now cautiously optimistic that we’ve turned a corner in our eczema battle. We already know that we’re going to continue to do everything we can to help our daughter, and having more weapons (ie, medications) to turn to has given us superpowers we couldn’t have imagined 5 years ago.

I often wonder if the members of the dermatology community know and understand what patients and their families deal with on a day-to-day basis. Furthermore, it has become quite apparent as of late that many doctors and medical school students are not well equipped with a knowledge of issues among patients with skin of color. There are unique characteristics of black and brown skin, and our skin conditions often manifest in different ways than Caucasian patients. Furthermore, differences and beliefs related to things like ethnic foods and diets, exotic soaps, and cultural disease management approaches can have an effect on skin of color that may exacerbate or aggravate AD.

Like many people of color, our skin is a huge part of our identity. We wear it as a badge of honor and homage to our ancestors. As strange as it may sound, AD and other skin conditions are sometimes seen as a direct attack of that identity. The lightening of our skin from continual steroid usage and the dulling of our color from other topical creams is as egregious as the Greeks destroying the noses of the Egyptian monuments. Just something for providers to be mindful of the next time a new patient with skin of color comes in for an initial visit.
The opinions expressed in this publication are those of the participating faculty and not those of the Dermatology Nurses’ Association, Incyte, Pfizer, or any manufacturers of products mentioned herein.

This information is provided for general medical education purposes only and is not meant to substitute for the independent medical judgment of a healthcare professional regarding diagnostic and treatment options of a specific patient’s medical condition. In no event will DNA be responsible for any decision made or action taken based upon the information provided in this activity. Participants are encouraged to consult the package insert for all products for updated information and changes regarding indications, dosages, and contraindications. This recommendation is particularly important for new or infrequently used products.

© 2022. This CNE-certified activity is held as copyrighted © by the Dermatology Nurses’ Association. Through this notice, the Dermatology Nurses’ Association grant permission of its use for educational purposes only. These materials may not be used, in whole or in part, for any commercial purposes without prior permission in writing from the copyright owner(s).