

# eczema matters

RESEARCH, SUPPORT, AND EDUCATION FOR THOSE AFFECTED BY ECZEMA | WINTER 2019

## ***SQUAD GOALS***

Learn how to put together your own eczema care team. *P.24*

## ***FACES OF AD IN AMERICA***

Six warriors across the U.S. show the diversity of eczema. *P.9*

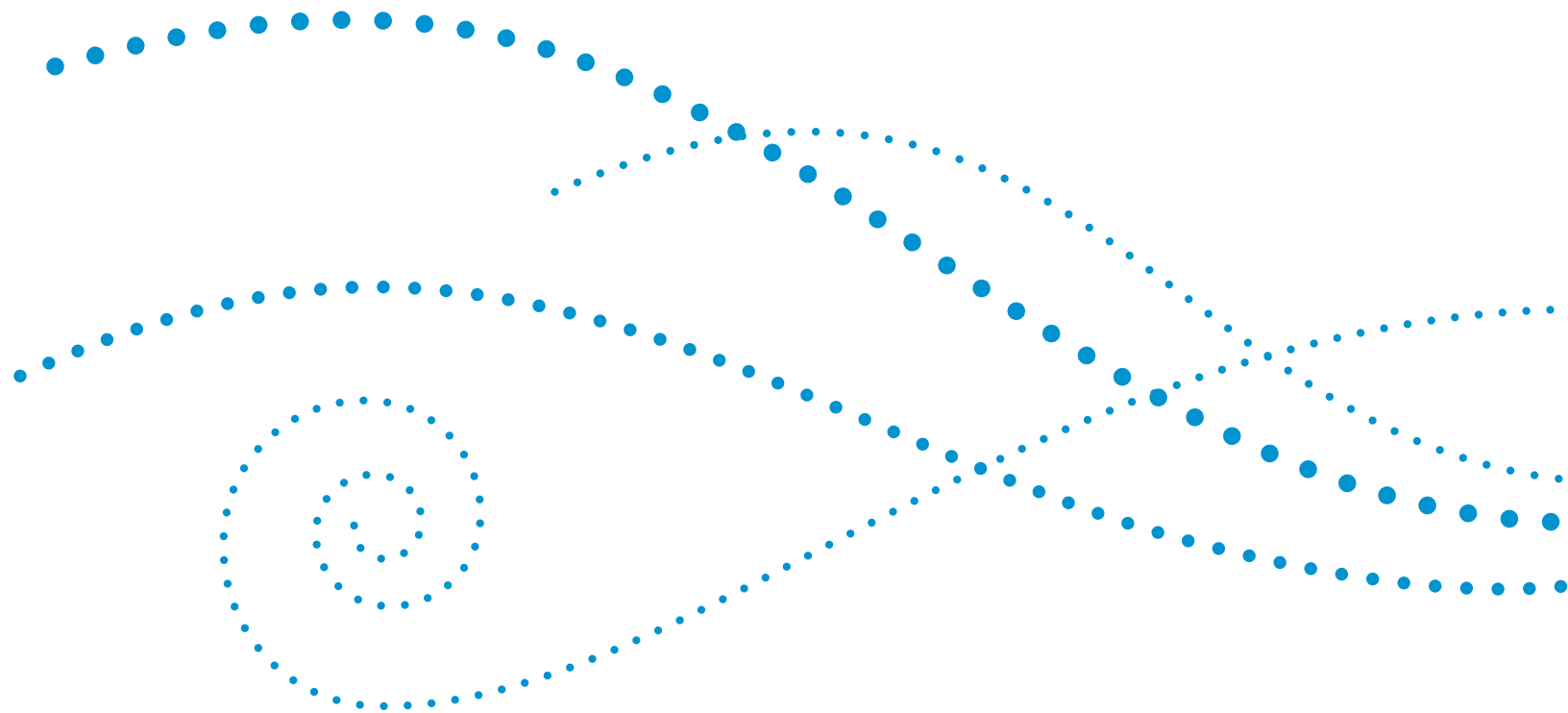
## ***NUTTY FOR COCONUT?***

Get the facts on using coconut oil for eczema. *P.16*



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**Eczema**  
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**NATIONAL  
Eczema  
ASSOCIATION**

### OUR MISSION

The National Eczema Association (NEA) improves the health and quality of life for individuals with eczema through research, support and education.

**NATIONAL ECZEMA ASSOCIATION** is a national nonprofit patient advocacy organization dedicated to eczema education and research. The association was founded in 1988 in Portland, Oregon, by individuals with eczema, nurses, physicians and others concerned with the enormous social, medical and economic consequences of this disease. NEA is governed by a volunteer Board of Directors and advised on medical issues by a volunteer Scientific Advisory Committee. The association is supported by individual and corporate donations. Advertising is accepted for publication if they are relevant to people with eczema and meet certain standards.

*Eczema Matters* provides health information from a variety of sources, but this information does not dictate an exclusive treatment course and is not intended as medical advice. Persons with questions regarding specific symptoms or treatments should consult a professional health care provider who has the appropriate training and experience. Opinions expressed by *Eczema Matters* do not necessarily reflect the views of the National Eczema Association, its Board of Directors, its Scientific Advisory Committee or its contributors.

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If there's one thing I've learned about eczema, it's that it doesn't discriminate. Eczema affects everyone no matter your gender, age, race, nationality, religion or political affiliation. In a way, it's oddly comforting to know that, despite the current trials and tribulations around the world, there is at least one thing we all can agree on—*eczema is hard, sometimes impossible, to live with!*

I'm inspired by the Eczema Warriors around the world who have the strength and courage to prop each other up when the going gets tough. Watching you come out of the shadows on social media to help NEA #unhideECZEMA during Eczema Awareness Month in October made it clear to me just how powerful our community can be. Let's keep that momentum going for 2019!

This issue of *Eczema Matters* is all about diversity of disease, including the diverse ways it affects us and diversity among those who have it. Our cover story, Faces of AD in America, on page 9 highlights six individuals from across the U.S. living with atopic dermatitis (AD). Collectively, they demonstrate how AD impacts people from all walks of life in many different ways.

And if eczema isn't complicated enough, wait, there's more! "Eczema" is really an umbrella term for a group of diseases with similar symptoms. Atopic dermatitis is the most common and difficult-to-treat form of eczema, but there's also contact dermatitis, seborrheic dermatitis and others that fall under the eczema umbrella. Dr. Peter Lio walks us through the different types of eczema in this issue's Ask a Doctor on page 30.

Not only can you have more than one type of eczema at the same time, but there could be more than one person in your household battling these different types of eczema. Turn to page 4 to meet parents trying to help their children cope with eczema while dealing with skin issues of their own.

Can life with eczema feel overwhelming at times? Absolutely! But there are ways to make it more manageable. You can always peruse our website for tons of tips and support while you wait for the next magazine or e-newsletter to arrive. Regardless, for now, I'll just say that 2019 is going to be an exciting year for National Eczema Association—and not just because it's our 30-year anniversary. Stay tuned!

Yours,  
Julie Block

## What's the hardest thing about living with eczema that no one would guess?



*The hardest part about living with eczema that no one guess would be the insecurities honestly, not wanting to wear T-Shirts because you have eczema on your arms.*

– queenbere\_nice

*The hardest part about living with eczema that no one would guess would be the stinging and pain we wake up to in the morning and how uncomfortable we feel when we're out because we feel ugly.* – jayceralde

*The hardest part about living with eczema (on your hands) is that it literally hurts to do anything. And it's hard to work out. I can't do floor yoga, or weights, or push-ups.*

– therealnimhstagram

*Not being able to be in the heat outside like everyone else can and not being able to go to outdoor events because it causes a flare-up that lasts weeks!* – lauren.brawner07

*The constant horrible itch that keeps you up at night.*

– ellijade

*I think the hardest part is how no one understands how easily you can get sick! I have all these open cuts all over my body and a compromised immune system. So when "something is going around," that means I'm either getting sick or having a flare-up, which makes you want to hide from the world!* – lillianlove07

*Watching my child in pain and knowing how it feels because I also have it. It breaks your heart.* – cheri.braun

*Personally, the hardest part about living with eczema is there's no UNIVERSAL CURE! While some people are successful at "curing" their mild eczema, there are millions of us that will not be able to "cure" our moderate to severe eczema.* – itchin87

*The hardest part about living with eczema is the mental hardships that come with the condition, like not wanting to participate in social activities because you are afraid they may trigger a flare.* – ccrayne

*It is lonely.* – amber\_haygood

*Even if I have plans to do something, my eczema can sometimes get in the way of me doing them. And that's the hardest part—having to break it to family and friends, having to cancel, having to explain yourself, being embarrassed when my face is flared up. It's hard, but I wouldn't have it any other way because it's made me who I am today.* – herfitlosophy

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[inspire.com/groups/national-eczema-association](https://inspire.com/groups/national-eczema-association)

# When eczema runs in the family

Parents with skin issues of their own strive to help their children deal with eczema.

BY MARGARET W. CRANE

**A**dvocacy comes naturally to Jill Lane, a woman who spent 10 years in the political fray, working on campaigns and fostering civic engagement at every opportunity. A political science professor at North Seattle College, Lane applies her gift for strategic thought and action to the everyday challenges her children face. Both of them have eczema.

Lane herself was 6 years old when she was diagnosed with the condition. Her symptoms remained mild for many years, but in her early 40s, she developed burning mouth syndrome, a rare condition that caused pain and a scalding sensation along her tongue, gums, lips and the roof of her mouth. “I could barely talk, much less eat,” she recalled.

Four years ago, an allergist traced the problem to a wheat allergy. Once Lane stopped eating wheat, her burning mouth symptoms subsided, and her skin cleared as well. Today, all that’s left of her eczema are a few occasional patches.

However, eczema continues to wreak havoc in her family. The Lanes’ 14-year-old daughter Wren’s symptoms have eased since she entered puberty. But their 9-year-old son August has full-blown eczema, along with severe food allergies and eosinophilic esophagitis, an inflammatory condition that affects the esophagus.

“During our summer vacation,” said Lane, “August had a massive allergic reaction to the sheets at our hotel. We had to leave early. We decided to bring our own sheets to an Airbnb rental, and that worked out better—but it was far from perfect. Anything out of our usual routine is hard to adapt to. A problematic air freshener or cleaning product always seems to be lurking in the background.

“We’ve learned that plans aren’t static,” Lane continued. “If we buy tickets to Comic-Con or some other event and the kids are too sick to go, we don’t go. And if we’re invited to a party, we do our best to come, but we may need to cancel at the last minute.”

Next year, the Lanes are planning a summer staycation, featuring day trips in their own great city of Seattle. “Life doesn’t stop when someone is sick or suffering, so we’ve been figuring out how to do life differently,” she said.

## Eczema care tips from a behavioral health expert



The Lanes’ approach exemplifies the mindset that clinical social worker Jennifer Moyer Darr tries to get across to her eczema patients at National Jewish Health, a Denver-based hospital specializing in lung, heart and immune diseases. “It’s about reframing negative messages and situations and figuring out positive alternatives,” Darr said. Alternatives like a staycation, for instance.

Beyond the benefits of a flexible attitude, Darr offers the following advice for eczema families:

Keep family routines consistent. If it’s dinner-bath-book-bed, do this sequence in order every night.

Know that you can turn to community- and hospital-based resources for treatment, support and education—such as Day Treatment Program for families at National Jewish Health, where Darr is a member of the core team. ►





## The Sirkens

Check out relaxation techniques, such as progressive muscle relaxation and biofeedback. Your primary care physician or specialist may be able to refer you to a practitioner of these and other mind-body modalities.

Assemble a “distraction toolkit” and keep it on hand in the car or wherever it might be needed to help break a child’s itch-scratch cycle.

Start filling your distraction toolkit with ice packs decorated with emojis and colorful animal images, suggested Samantha Casselman, a pediatric nurse practitioner at Phoenix Children’s Hospital.

“I’m also a big fan of fidget toys,” she said. “It’s easy to find these online. Consider investing in a couple of squeeze toys, an infinity cube or a puzzle with moving parts. Choose toys that make clicking sounds or ones that move around but don’t come apart.”

### Coping with 'The Big Itch' as a family

Chicago resident Jennifer Sirken, another member of the intergenerational eczema club, feels that her history with eczema helps her understand what her children are experiencing. The Sirkens’ three sons all have the condition, but just one of them, Liam, is bearing the brunt of its most severe form. The 4-year-old refers to it as “The Big Itch.”

Surprisingly, Liam’s fraternal twin, Aidan, only has a few patches here and there. Connor, the littlest member of the Sirken family, also has mild eczema symptoms.

Eczema and its common comorbidities—allergies and asthma—run deep in the Sirken family. Sirken’s father has a long history

of eczema on his hands. And her husband, who still has allergies, had childhood asthma.

Sirken’s skin erupted after Connor’s birth in 2016. Thankfully, a combination of topical steroids and intensive moisturizing have tamed her symptoms, making it much easier for her to focus on her children’s eczema.

“Whether or not a parent has eczema, it’s a family diagnosis,” said Dr. Robert Sidbury, a pediatric dermatologist at Seattle Children’s Hospital. “Four out of five children with eczema have a family member with eczema, asthma or allergies, including food allergies.”

Sidbury explained that people with eczema lack one important little protein, called filaggrin, that acts as a sealant and locks moisture in the skin. Without it, the skin leaks water and dries out, allowing allergens and irritants to set up shop there and cause trouble.

“Try to attack eczema as a family,” he advised. “Keep regular, consistent habits, from diet to moisturizing rituals.”

Food allergies in particular can create problems within the family, he said, so if a child has allergies to particular foods, consider removing them from the fridge and pantry altogether.

“As for skincare products,” said Sirken, “our policy is if it works for Liam, it works for everybody.” She’s also a big fan of NEA’s Seal of Acceptance™ product list, which includes eczema-friendly personal care products, household products, fabrics and devices, all of which are free from known irritants and allergens. Go to [EczemaProducts.org](https://www.eczema-products.org) for more information. ►



### *A few more takeaway messages for eczema families*

Sometimes, Darr said, parents with eczema who have children with eczema carry around a ton of guilt for their children's plight. "Guilt is totally misplaced. You can't think that you did this. Take the example of twins"—like Aidan and Liam Sirken—"where one has it and the other doesn't. How are you responsible for that?" she asked.

"The most important thing is to be a good role model for your kids," Darr continued. "Teach them good self-care, consistent routines and a willingness to educate others about eczema. There's simply no room for guilt, shame or blame here."

Casselman urges parents to make life as easy on themselves as possible—and on their kids. "Treatment is always very individual, even within families, so if more than one family member has eczema, it can be challenging to stay organized," she said.

Parents can adopt a few simple measures to keep everything on track. For example, "put each family member's medications and skincare products in a separate bin," Casselman suggested. "Instead of restricting moisturizers to the bathroom, leave them out in convenient places where they're likely to be seen and used: on the nightstand, in the car, in the TV room or on a little table near the front door."

Casselman's son has mild eczema on his cheeks, and her daughter's skin is sensitive too, especially in winter. "They didn't like any of the lotions I got for them, claiming that they burned and stung. Luckily, a dear family friend bought them a new product, and my kids accepted it right away—probably because it didn't come from me! They felt they had a choice in the matter, rather than having to just follow their mom's orders."

Moisturizing can be tedious, she noted, so "make it fun. If your little girl has eczema, make moisturizing a princess-y thing. Create a story and embellish the ritual." And if you have a son with the condition, she said, make it an adventure, starring him as the superhero who defeats the eczema monster.

"Feel free to use your imagination," Casselman added. The ability to imagine is a very real superpower, one that parents can harness to keep The Big Itch in check. \*



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### INDICATION

DUPIXENT is a prescription medicine used to treat adult patients with moderate-to-severe atopic dermatitis (eczema) that is not well controlled with prescription therapies used on the skin (topical), or who cannot use topical therapies. DUPIXENT can be used with or without topical corticosteroids. It is not known if DUPIXENT is safe and effective in children.

### IMPORTANT SAFETY INFORMATION

**Do not use** if you are allergic to dupilumab or to any of the ingredients in DUPIXENT.

**Before using DUPIXENT, tell your healthcare provider about all your medical conditions, including if you:**

- have eye problems
- have a parasitic (helminth) infection
- have asthma
- are scheduled to receive any vaccinations. You should not receive a "live vaccine" if you are treated with DUPIXENT.
- are pregnant or plan to become pregnant. It is not known whether DUPIXENT will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known whether DUPIXENT passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins and herbal supplements. If you have asthma and are taking asthma medicines, do not change or stop your asthma medicine without talking to your healthcare provider.

#### **DUPIXENT can cause serious side effects, including:**

- **Allergic reactions.** Stop using DUPIXENT and go to the nearest hospital emergency room if you get any of the following symptoms: fever, general ill feeling, swollen lymph nodes, hives, itching, joint pain, or skin rash.
- **Eye problems.** Tell your healthcare provider if you have any new or worsening eye problems, including eye pain or changes in vision.

**The most common side effects include** injection site reactions, eye and eyelid inflammation, including redness, swelling and itching, and cold sores in your mouth or on your lips.

Tell your healthcare provider if you have any side effect that bothers you or that does not go away. These are not all the possible side effects of DUPIXENT. Call your doctor for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

Use DUPIXENT exactly as prescribed. If your healthcare provider decides that you or a caregiver can give DUPIXENT injections, you or your caregiver should receive training on the right way to prepare and inject DUPIXENT. **Do not** try to inject DUPIXENT until you have been shown the right way by your healthcare provider.

**Please see accompanying Brief Summary on next page.**

**Summary of Information about DUPIXENT® (dupilumab)  
(DU-pix'-ent)  
Injection, for Subcutaneous Use**

**Rx Only**

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**What is DUPIXENT?**

- DUPIXENT is a prescription medicine used to treat adults with moderate-to-severe atopic dermatitis (eczema) that is not well controlled with prescription therapies used on the skin (topical), or who cannot use topical therapies.
- DUPIXENT can be used with or without topical corticosteroids.
- It is not known if DUPIXENT is safe and effective in children.

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**Who should not use DUPIXENT?**

**Do not use DUPIXENT** if you are allergic to dupilumab or to any of the ingredients in DUPIXENT. See the end of this summary of information for a complete list of ingredients in DUPIXENT.

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**What should I tell my healthcare provider before using DUPIXENT?****Before using DUPIXENT, tell your healthcare provider about all your medical conditions, including if you:**

- have eye problems
- have a parasitic (helminth) infection
- have asthma
- are scheduled to receive any vaccinations. You should not receive a “live vaccine” if you are treated with DUPIXENT.
- are pregnant or plan to become pregnant. It is not known whether DUPIXENT will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known whether DUPIXENT passes into your breast milk.

Tell your healthcare provider about all of the medicines you take including prescription and over-the-counter medicines, vitamins, and herbal supplements. If you have asthma and are taking asthma medicines, do not change or stop your asthma medicine without talking to your healthcare provider.

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**How should I use DUPIXENT?**

- **See the detailed “Instructions for Use” that comes with DUPIXENT for information on how to prepare and inject DUPIXENT and how to properly store and throw away (dispose of) used DUPIXENT pre-filled syringes.**
- Use DUPIXENT exactly as prescribed by your healthcare provider.
- DUPIXENT comes as a single-dose pre-filled syringe with needle shield.
- DUPIXENT is given as an injection under the skin (subcutaneous injection).
- If your healthcare provider decides that you or a caregiver can give the injections of DUPIXENT, you or your caregiver should receive training on the right way to prepare and inject DUPIXENT. **Do not** try to inject DUPIXENT until you have been shown the right way by your healthcare provider.
- If you miss a dose of DUPIXENT, give the injection within 7 days from the missed dose, then continue with the original schedule. If the missed dose is not given within 7 days, wait until the next scheduled dose to give your DUPIXENT injection.

- If you inject more DUPIXENT than prescribed, call your healthcare provider right away.
- Your healthcare provider may prescribe other topical medicines to use with DUPIXENT. Use other prescribed topical medicines exactly as your healthcare provider tells you to.

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**What are the possible side effects of DUPIXENT?****DUPIXENT can cause serious side effects, including:**

- **Allergic reactions.** Stop using DUPIXENT and go to the nearest hospital emergency room if you get any of the following symptoms: fever, general ill feeling, swollen lymph nodes, hives, itching, joint pain, or skin rash.
- **Eye problems.** Tell your healthcare provider if you have any new or worsening eye problems, including eye pain or changes in vision.

**The most common side effects of DUPIXENT include:** injection site reactions, eye and eyelid inflammation, including redness, swelling, and itching, or cold sores in your mouth or on your lips. Tell your healthcare provider if you have any side effect that bothers you or that does not go away.

These are not all of the possible side effects of DUPIXENT. Call your doctor for medical advice about side effects. You may report side effects to FDA 1-800-FDA-1088.

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**General information about the safe and effective use of DUPIXENT.**

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use DUPIXENT for a condition for which it was not prescribed. Do not give DUPIXENT to other people, even if they have the same symptoms that you have. It may harm them.

This is a summary of the most important information about DUPIXENT. If you would like more information, talk with your healthcare provider. You can ask your pharmacist or healthcare provider for more information about DUPIXENT that is written for healthcare professionals.

For more information about DUPIXENT, go to [www.DUPIXENT.com](http://www.DUPIXENT.com) or call 1-844-DUPIXENT (1-844-387-4936)

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**What are the ingredients in DUPIXENT?**

**Active ingredient:** dupilumab

**Inactive ingredients:** L-arginine hydrochloride, L-histidine, polysorbate 80, sodium acetate, sucrose, and water for injection

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# FACES OF AD IN AMERICA

SIX ECZEMA WARRIORS FROM ACROSS THE UNITED STATES DEMONSTRATE THE DIFFERENT WAYS ATOPIC DERMATITIS AFFECTS OUR PHYSICAL AND MENTAL HEALTH.

BY KATHRYN JONES

Waking up in the morning feeling ashamed or embarrassed by the appearance of our skin is a painful reality for the 16.5 million adults in America living with atopic dermatitis (AD). Some of us feel compelled to cover up with long sleeves, pants, hats and gloves to hide the tell-tale markings of eczema from the rest of the world. That is what makes atopic dermatitis such an anomaly; it is one of the loneliest yet widespread diseases in America.

In early 2016, the National Eczema Association kicked off a three-part national study in partnership with the Asthma and Allergy Foundation of America, Sanofi Genzyme and Regeneron to determine just how widespread AD really is. Results of the study have been revealed throughout 2018.

The study found that 7.3 percent of U.S. adults have AD, and about 40 percent of them have moderate to severe symptoms, which include dry, oozing or discoloring of the skin, itch, pain and physical discomfort. AD causes sleep disturbances and can take a significant toll on a person's mental health and self-esteem. More than 25 percent of the people who were polled rated their health as fair or poor.

Based on the results of our AD in America study, we've identified several data points that highlight the lesser-known facts about this disease. To help us illustrate these data points, we'd like to introduce six Eczema Warriors from across the U.S. who were brave enough to bring their AD out of the shadows and shine a light on the true impact this disease has on their everyday lives. These are their stories.





# JOSH CHAMBERLAIN

Living with atopic dermatitis has been a lifelong rollercoaster ride for 42-year-old Josh Chamberlain of Taylorsville, Utah.

“As a child, I had it moderately, but there were definitely moments when I looked and felt like a burn victim,” he described. “That can be frustrating for a kid, when you haven’t yet matured into life, and you don’t understand why your skin suddenly exploded into a fiery storm.”

Chamberlain remembers being too self-conscious by the appearance of his skin to date much in high school. “I avoided intimacy and shied away from relationships because I didn’t want to see how the girls would react to my nasty skin,” he said.

By the time Chamberlain graduated high school and met his first wife, “I was pretty much cleared up,” he said. “But then when we started having kids, and I was working a graveyard shift, the stress of being a new father seemed to bring it back.”

His skin finally started to calm down again by the time he reached his 30s. “I went probably seven to nine years where I

hardly had any symptoms. It was the last thing I thought about. But right around the time I turned 39, it came back with a vengeance,” Chamberlain said.

With nearly 90 percent of his body covered in eczema rash, it was the most severe outbreak of his life.

“You put on the long sleeves, pants and hat, and do the best you can. But there were still times when it was shameful and embarrassing for me to go out in public,” he said. “When people stared at me, I could see the pity in their eyes, and that was the most depressing part of it for me. I’m a positive person who warms up to people quickly and easily, but I did not want to be social at all.”

AD IN AMERICA FACT:  
NEARLY 1 IN 2 ADULTS  
AVOID SOCIAL INTERACTIONS  
BECAUSE OF THEIR  
APPEARANCE.

After trying and failing various treatments, Chamberlain went on the first FDA-approved biologic for AD. “Bless my dermatologist. She’s done a good job to get me where I am now,” he said. “I tried so many different things. It feels like something will work initially, and then after about a month or so, my eczema would evolve and become immune to it. Today, I’m 98 percent clear and living my best life.”

“I AVOIDED INTIMACY  
AND SHIED AWAY  
FROM RELATIONSHIPS  
BECAUSE I DIDN’T  
WANT TO SEE HOW THE  
GIRLS WOULD REACT  
TO MY NASTY SKIN”



# J E N E N E C H E S B R O U G H

Unless you have atopic dermatitis yourself, most people don't realize the impact it has on a person's mental health. Unfortunately, it's common for people living with AD to experience stress, anxiety or depression as a comorbidity, or related health condition, of the disease.

That was certainly the case for 40-year-old Jenene Chesbrough of New York City. One of her earliest memories was when she was about 4 years old—writhing around in bed, screaming and crying because the eczema itch was so unbearable.

"My husband jokes that I should live in a bubble because I am allergic to the world," Chesbrough said. "Grass, mold, fragrances, different water types when I travel—you name it, and I'm probably allergic."

Exposure to mold is what set off one of the worst flare-ups of Chesbrough's life. "It took years to bounce back from it. It affected my mental health in a bunch of different ways. I was a go-getter at work. I had goals that I wanted to meet. But I couldn't sleep at all, which made it hard to function at work," she said.

"I was in a client-facing role at my job, but I hated showing up to work looking like a burn victim. I had to go on short-term disability. I was starting every day off with depression, thinking, 'This is never going to go away. There is no cure. Should I kill myself?' It was very dark."

In early 2016, Chesbrough was invited to participate in a clinical trial. "All of a sudden, I didn't itch anymore. It allowed me to sleep. Sleeping allows your body to heal itself. You become a completely different person. You become a smarter person, a happier person," she said.

Chesbrough offers the following advice for other AD patients who struggle with depression or anxiety: "If you feel isolated or alone, reach out to other people with AD through NEA. Also, check out mindfulness-based stress reduction techniques by Jon Kabat-Zinn. It helps

you think less about the pain and itch," she said.

"My last bit of advice is to stay hopeful. The hardest part of depression for me was feeling like there was no hope. But there are so many treatments now than there were five years ago, with more on the way. We are getting closer to a cure, so there is hope!"

AD IN AMERICA FACT:  
ADULTS WITH AD HAVE  
A SIGNIFICANT MENTAL  
HEALTH BURDEN AND ARE  
MORE LIKELY TO HAVE  
SYMPTOMS OF ANXIETY AND/  
OR DEPRESSION.



"I WAS STARTING  
EVERY DAY OFF WITH  
DEPRESSION, THINKING,  
'THIS IS NEVER GOING  
TO GO AWAY.'"





# M I K E B R I S T O L

Eczema is a lifelong journey for many people. It's common to see signs of atopic dermatitis as early as infancy, and then it fluctuates throughout childhood on into adulthood. But for Mike Bristol of Longmont, Colorado, his first bout with AD began five years ago at the tender age of 51.

"I started to get some patches. They were itchy and weren't going away on their own. I was using lotion and putting on homeopathic stuff, but it wasn't working. Finally, I went to a dermatologist, and they said I had AD. It grew from there, covering different parts of my body at different times of the year. It just wouldn't quit. It was like the beginning of a snowball rolling down the hill, causing an avalanche of different side effects."

Suddenly, Bristol found himself coping with the emotional add-ons of an AD diagnosis: shame, depression, stress, sleeplessness and low self-esteem. "It's like teenage acne. You have these wounds on your face, and your scalp is a mess. Your body image is completely changed. You're compounding how you feel about yourself. It really messes with you psychologically and makes life way less fun," he said.

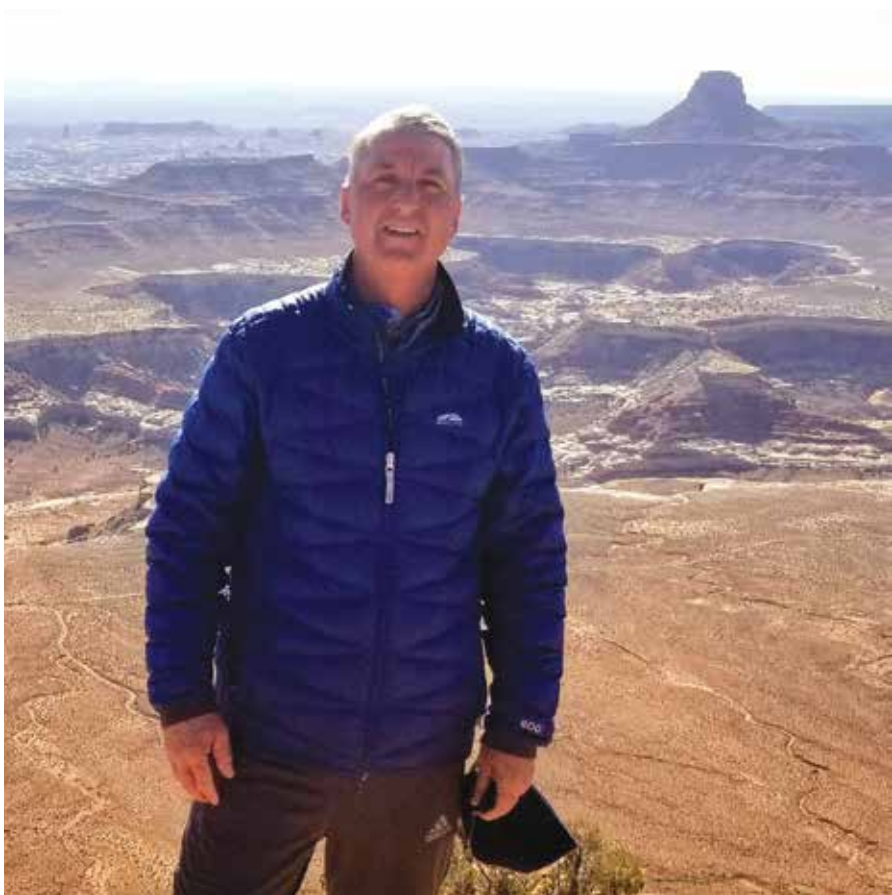
AD permeated every aspect of the executive's personal and professional life. The man who had a knack for getting people's attention in the conference room now dreaded having all eyes on him whenever his skin flared. Business trips grew more cumbersome for Bristol, who often had no idea what sort of exciting, new AD triggers awaited him on his travels. "Not to mention trying to date," added the single parent.

*AD IN AMERICA FACT:*  
ALTHOUGH IT'S MORE COMMON  
FOR THE ONSET OF AD TO  
BEGIN IN INFANCY, SOME  
ADULTS WITH AD REPORT  
ONSET AFTER THE AGE OF 18.

Eager for a solution, Bristol and his dermatologist worked together to get a new prescription approved by his health insurer and eventually succeeded. He also found a community of other Eczema Warriors when he attended his first Leaders in Eczema Forum in Denver. His experience there helped form his decision to serve on NEA's Board of Directors.

"I was impressed because, for one, I was relieved to find other people with AD," Bristol said. "And, for two, I found the information available during the breakout sessions very valuable. I enjoyed meeting and learning from medical professionals who really understand the disease."

"IT WAS LIKE THE  
BEGINNING OF A  
SNOWBALL ROLLING  
DOWN THE HILL,  
CAUSING AN AVALANCHE  
OF DIFFERENT SIDE  
EFFECTS."





# K A R E N T R U J I L L O

Atopic dermatitis can have a major influence on our life choices, especially when we grow up with the disease. That's been the case for Karen Trujillo, a 31-year-old registered nurse specializing in dermatology in Huntington Beach, California.

Trujillo, who has lived with AD since she was baby, grew up around nurses. They were her beacons of light during the darkest of times. "I was teased a lot as a kid, but they were so nice to me," she said. "They made me feel comfortable. I remember telling my mom I want to be a nurse when I grow up because I wanted to be like them. It was good to have a goal that young."

Trujillo thought she had her allergies, asthma and eczema under control during her college years. But shortly after beginning her nursing career, her atopic dermatitis came back with vengeance. Between the frequent handwashing required for her job and her allergy to latex gloves, eczema flared on her hands and then spread across her whole body. That was when Trujillo knew she should specialize in dermatology and work with other eczema patients.

"Having eczema brings comfort to the patients I serve," she said. "Feeling alone with this disease is one of the hardest things about having eczema. You long for someone else who understands that sometimes AD can hurt more than just physically—sometimes it can make you feel anxious or depressed. Doctors understand this to a point, but it's a different story when you can say, 'I know how you are feeling because I have it too.'"

*AD IN AMERICA FACT:*  
HALF OF ADULTS WITH AD  
INDICATE THAT AD LIMITS  
THEIR LIFESTYLE, AND THE  
DEGREE OF LIMITATION IS  
POSITIVELY CORRELATED TO  
SEVERITY.

Unfortunately, having open sores on her hands put Trujillo at a high risk of infection, which was especially dangerous considering the number of contagious diseases being researched and treated at her workplace—the dermatology department at a university hospital. "Luckily, I found a job that was perfect for me," she said.

Today, Trujillo works from home as a telehealth nurse for patients with AD. "I miss the in-person patient contact, but I don't miss having eczema on my hands," she said. "I still get to talk and educate my eczema patients and listen to their stories. I know that I am so lucky to get to do what I love doing. Even though I still suffer with flare-ups, I have a more positive outlook."



photos and cover  
image courtesy of  
*Queen of Adventure*

"I MISS THE IN-  
PERSON PATIENT  
CONTACT, BUT  
I DON'T MISS  
HAVING ECZEMA  
ON MY HANDS."



# BRANDON HIPPS

A day doesn't go by without Brandon Hipps of Avon Park, Florida, being reminded of his atopic dermatitis. The 19-year-old college student has been living with moderate to severe AD, hay fever and food allergies "basically my whole life." In fact, he's lucky if he can go an hour without AD popping up in his mind for one reason or another.

Hipps thinks about his AD when he wakes up in the morning with "bloody sheets and scabs everywhere" from scratching himself in his sleep. He thinks about it when he gets in the shower and the water stings his skin. He thinks about it when he slathers on lotions, creams and ointments, causing his clothes to stick to his skin.

Eczema covers Hipps' whole body, from the top of his head to the bottoms of his feet. It's on his hands and sometimes even his lips. That means he thinks about AD whenever he walks, talks, writes, eats or shakes someone's hand. AD rules his life in so many ways that it's hard for him not to think about the disease and how others will react to it.

"It's hard for me to go out sometimes to meet new people because it makes me feel bad about myself," Hipps said. "I'm worried they'll judge me based on my skin. People can be judgmental and say negative stuff about it. I was teased a lot in high school by people who were my close friends and teammates."

*AD IN AMERICA FACT:*  
HAVING AD LEADS TO HIGHER  
LIKELIHOOD OF NEGATIVE  
OVERALL HEALTH RATING AND  
DISSATISFACTION WITH LIFE. AS  
SEVERITY OF AD INCREASES, SO  
DO NEGATIVE IMPACTS ON HEALTH  
RATING AND LIFE SATISFACTION.

An avid fisherman and natural athlete, Hipps had to miss entire semesters of high school and college due to his AD. "I played football all four years of high school. When I was starting my first year of college, my worst flare-up hit. I couldn't even try to find a team to play for, so I ended up going to a local community college. I had to take a semester off this year," he said.

Hipps is working with his dermatologist to try to get his AD under control. "Right now, I'm on an off label systemic treatment. Two weeks ago, I flared when I went off it, so I'm on a double dose of that now," he said. "It's supposed to be the last resort, as far as treatments go, before we try to get me approved for a biologic treatment."

"IT'S HARD FOR ME TO GO OUT SOMETIMES TO MEET NEW PEOPLE BECAUSE IT MAKES ME FEEL BAD ABOUT MYSELF. I'M WORRIED THEY'LL JUDGE ME BASED ON MY SKIN."



# ANNE MARRE BAUTISTA

One of the downsides of having atopic dermatitis is that, even when we're enjoying a few weeks, months or years of having relatively clear skin, we never know when it's coming back. And we don't know what might trigger its return. We're stuck in a constant state of paranoia because we haven't quite figured out what's causing our atopic dermatitis to flare.

What works for some people doesn't work for everyone. For instance, exposure to sunlight can help some people's eczema, but it seems to make 30-year-old Anne Marre Bautista's skin worse. "During my most recent outbreak, the doctor recommended not to go outside because every time I do, and I'm not covered or protected, my skin gets worse," she said.

Avoiding the sun altogether is easier said than done when you live in sunny Los Angeles. Bautista tries to cover up with long sleeves, but it makes her feel too warm, which causes her skin to itch and flare. She can't seem to win either way, and she's left feeling defeated.

"I love being outside. I feel happier. I feel more productive in life. It's really frustrating when you have to limit your activities. It makes you cry because you're so frustrated," she said.

Bautista has noticed that when she's exposed to certain things like pollen, pet dander, dust mites or certain foods, they not only trigger her skin to flare up in an eczema rash—they also seem set off other inflammatory responses in other parts of her body. "All I

know is that whenever I eat sugar, it triggers my eczema and also my arthritis," she said.

Bautista has palindromic rheumatism, a rare, seasonal form of inflammatory arthritis. Although arthritis is not a known comorbidity of AD, she wonders if they are somehow related. "Whenever I'm stressed, they flare up at the same time. Because they are both autoimmune disorders, I suspect a connection," she said.

*AD IN AMERICA FACT:*  
AD SEVERITY IS A MAJOR DRIVER  
FOR DEVELOPING COMORBIDITIES  
OR RELATED HEALTH CONDITIONS.  
WHEN AD SYMPTOMS ARE UNDER  
CONTROL, THE COMORBIDITIES  
IMPROVE AS WELL.

"I don't even focus on triggers anymore; I just focus on the treatments. Before, when I was younger, my mom went to the other side of the spectrum, meaning if she couldn't figure out the trigger, she told me to avoid pretty much everything. I had to avoid a lot of foods. I had to avoid going outside because of the sun. She went to the extreme.

"There's a part of me that did not enjoy my childhood because I had to avoid so many things because of my eczema," Bautista continued. "Now that I'm adult and still can't figure out the triggers, I focus on the treatments that work for my skin instead. I've been more successful in finding a treatment that works than identifying triggers."

Bautista followed her doctor's advice and takes regular bleach baths. She changes her bed sheets every week and sticks to a regimented skincare routine. "Lots and lots of lotion," she said with a laugh. "I put it on in the morning, at night before I go to bed and as often as possible."



"MY ARTHRITIS AND  
ECZEMA USUALLY  
FLARE UP AROUND  
THE SAME TIME."







# GET THE FACTS:

## COCONUT OIL

Does coconut oil help eczema? The answer isn't as clear as you might think.

By Kathryn Jones

**T**hose who attended Eczema Expo '18 probably saw dozens of Eczema Warriors sporting one of our stylish “Yes, I’ve tried coconut oil” T-shirts. After all, if we had a dollar for every time a well-meaning stranger suggested coconut oil as a cure-all for eczema, we’d all be rich, right?

So, what’s the deal with coconut oil? Does it really cure eczema? The short answer is: No. To be frank, coconut oil is not a cure for eczema because there is no cure for eczema at this time.

Eczema is a chronic, or lifelong, health condition connected to your immune system and its inflammatory response.

Ordinary substances we encounter in our everyday lives, such as dust, mold, animal dander or certain chemicals, seem to trigger an allergic response in people with eczema causing their skin to flare up in an itchy, dry or painful rash.

You may be able to treat the symptoms of eczema and reduce its appearance on your skin, but the disease itself never goes away completely. The correct question should be, “Does coconut oil help eczema?” and the answer to that is: ***It depends.***

### HOW DOES COCONUT OIL HELP eczema?

Many health websites tout coconut oil as a miracle product that can do anything from soothing dry, cracked skin and hair to whitening our teeth and freshening our breath. And there’s some truth behind the hype.

Coconut oil contains lauric acid, a nutritious fatty acid, or lipid, also found in breast milk. Lauric acid is used to develop monolaurin, which is an antimicrobial agent that can fight bacteria, fungi, yeast, viruses and other pathogens.

In other words, when you hear people talk about coconut oil having antimicrobial and anti-inflammatory properties beneficial to eczema, they are correct.

Coconut oil has the natural ability to penetrate the skin quickly and efficiently, which can boost hydration, improve skin elasticity, fight itch and reduce the chances of infection. ►



Out of all the natural ingredients used to treat eczema, coconut oil has the most scientific research to back up its legitimacy.

An article published in January 2018 in the *Journal of Traditional and Complementary Medicine* found that coconut oil is effective at reducing the presence of bacteria, fungi, viruses and other pathogens.

Another 2018 study found that coconut oil has anti-inflammatory properties that help protect the skin.

Although multiple disease types have been addressed in the research behind coconut oil, there was one study in particular that focused specifically on children with eczema.

Results of that study, published in the December 2013 issue of *International Journal of Dermatology*, revealed that virgin coconut oil applied topically to the skin for eight weeks improved skin hydration for children with eczema.

### OK, BUT WILL COCONUT OIL HELP MY ECZEMA?

That's where the "*It depends*" answer comes into play. Scientists are making tremendous strides in their search for a cure, but they're only just beginning to decode the mysteries behind eczema and our immune system.

The good news is that you can play an active role in improving your eczema symptoms by making healthy lifestyle choices and sticking to your skincare routine, which of course means keeping the skin clean and moisturized!

It's important to remember that eczema is unique to every individual. Not everyone has the same triggers that provoke their flare-ups. And certain eczema treatments that seem like miracles to some patients may not work for all patients—coconut oil included.

In fact, some people with eczema might have an allergy to coconut oil, which could then exacerbate their symptoms instead of helping them. Always consult with your health care provider before trying a new product on your skin.



Will coconut oil cure your eczema? Unfortunately, no. Will it help? We're not sure, but we hope so. Please check with your doctor first. And stay tuned for future editions of "Get the Facts."\*

## A Passion for Science and a Commitment to Dermatology

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# DISCOVERY ZONE

The latest news, research and discoveries about eczema

BY KATHRYN JONES

## Dupixent shows positive results in adolescent clinical trial

Dupixent may soon be available to younger patients if the treatment continues its trajectory in adolescent clinical trials. The news was announced at the annual meeting of the European Academy of Dermatology and Venereology (EADV) in September 2018.

EADV is a nonprofit membership organization consisting of medical professionals from around the world whose mission is to advance clinical care, research, education and training in the fields of dermatology and venereology. They convene yearly to present clinical trial results and other scientific advancements.

At the 2018 annual meeting held in Paris, researchers shared the results of a stage 3 clinical trial on Dupixent (dupilumab) for adolescents with moderate to severe atopic dermatitis (AD). The treatment is co-produced by pharmaceutical giants Sanofi Genzyme and Regeneron.

Dupixent is the first biologic for adults with moderate to severe AD. Its active ingredient is an antibody (dupilumab) that binds to a protein called interleukin-4, which causes inflammation. By binding to this protein, Dupixent inhibits the inflammatory response that plays a role in AD flares.

The safety and efficacy of Dupixent was established in three placebo-controlled clinical trials with a total of 2,119 adult

participants. After the medication was approved by the FDA and brought to market, researchers embarked on another clinical trial to determine whether the drug is safe and effective for adolescents between the ages of 12 and 17.

The study recruited 251 adolescents with AD ranging from 12 to 17 years old. Patients were randomized into one of three treatment groups for the controlled period of 16 weeks.

The first group was treated with Dupixent subcutaneous injection 200 mg or 300 mg every two weeks, based on weight (with an initial dose of 400 mg or 600 mg, respectively). The second group was treated with 300 mg Dupixent every four weeks (with an initial dose of 600 mg), and the third group was treated with a placebo every two weeks.

According to Dr. Eric Simpson, professor of dermatology at the Oregon Health and Science University in Portland and principal investigator on both studies, said the adolescent clinical trial saw better Eczema Area and Severity Index (EASI) scores than the adult clinical trial.

“Dupilumab treatment showed clinically meaningful and statistically significant improvements in atopic dermatitis signs and symptoms and quality of life in adolescents,” he said. \*





## Biologics may show greater risk for infection than systemics

Off-label use of biologic treatments for AD may double the risk for serious infection compared to systemic treatments, according to results from an analysis that were revealed at the 2018 EADV meeting. The biologics analyzed did not include Dupixent (dupilumab), the only biologic currently approved by the FDA for treating adults with moderate to severe AD.

Data on nearly 400,000 AD patients showed that treatment with a biologic agent doubled the risk of hospitalization for a serious bacterial or opportunistic infection compared to topical steroids and systemics. Infection risk also varied substantially among nonbiologic systemic agents, with cyclosporine posing the lowest risk and azathioprine and mycophenolate the greatest risk.

Investigators undertook an analysis of a commercial insurance claims database encompassing 2003-2016 and 180 million patients. They used diagnostic codes to identify its group of adults being treated for AD.

The study consisted of two cohort analyses. The first cohort involved patients who initiated treatment with a low-potency topical corticosteroid that failed, and their treatment was then escalated to high-potency topical corticosteroids, biologics

and nonbiologic systemic therapies including methotrexate, cyclosporine and prednisone.

The second cohort comprised patients who started treatment with any type of topical corticosteroid and subsequently had treatment escalation to a biologic or systemic nonbiologic agent.

Because the analysis was launched before Dupixent was approved by the FDA, the analysis did not include patients treated with dupilumab or any other biologic agents specific to AD. Instead, it focused on older biologics that were developed to treat other inflammatory conditions, such as psoriasis and rheumatoid arthritis, that were prescribed off-label to AD patients.

When compared to systemics, steroids and other AD treatments, investigators found that the off-label biologics led to twice the amount of infection-related hospitalizations than their non-biologic counterparts.

The investigators added that they intend to update the analysis with new data that includes Dupixent—along with additional AD-targeted biologics coming onstream—and weigh them against the long-term outcomes of all AD treatment types. \*

## AD topical cream Jakafi moving on to phase 3 clinical trial

A new, nonsteroidal topical cream for AD called Jakafi (ruxolitinib) may soon hit pharmacy shelves if the treatment continues to show favorable results in clinical trials. Drug manufacturer Incyte Corp. announced the latest clinical study findings for its blockbuster janus kinase (JAK) pathway inhibitor at the 2018 EADV meeting.

JAK inhibitors, or jakinibs, are a type of medication that inhibits the activity of one or more of the Janus kinase family of enzymes. They are used in the treatment of cancer and inflammatory diseases such as rheumatoid arthritis.

Results from the study indicated that ruxolitinib cream, when administered twice daily, significantly improved patients' EASI scores in a phase 2 clinical trial, according to Dr. Steven Stein, chief medical officer at Incyte.

"We look forward to further advancing the True-AD clinical trial program for ruxolitinib cream and initiating phase 3 trials in this indication to further explore the potential of JAK inhibition to modulate inflammation and itch, and therefore provide much-needed relief to patients with this disease," Stein said. \*



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## New biomarkers identified for pediatric AD

Does the disease mechanisms of AD function differently on people with darker or lighter skin tones? Are there certain skin tones that have a higher risk of experiencing AD symptoms, such as pain, itch or discoloration, than other skin tones?

In medicine, a biomarker is a measurable indicator of the severity or presence of some disease state. When it comes to AD, researchers in The Netherlands say they've identified new biomarkers in pediatric patients relating to skin tone and its impact on disease mechanisms.

Scientists at the University of Amsterdam set out to determine whether the pathophysiologic mechanisms of AD differ among patients based on their skin type or tone. Pathology is the medical discipline that describes conditions typically observed during a disease state, whereas physiology is the discipline that describes processes or mechanisms operating within an organism.

The researchers used a “minimally invasive procedure” to collect small strips of skin from the forearms of 53 children with AD who had active lesions and 50 children with AD who didn't have any lesions.

When using a high-powered microscope to study these various skin samples, particularly the outermost layer of skin, or stratum corneum, that contains the “skin barrier,” scientists were able to gain valuable insight on the mechanisms or behaviors of AD.

The skin samples with AD lesions had a higher presence of certain interleukins and demonstrated a significant association with the Scoring Atopic Dermatitis (SCORAD) score. The scientists also observed a gradual decline in natural moisturizing factors (NMF) from healthy skin with no AD, to non-lesional AD skin, to lesional AD skin.

This gradual decrease in NMF levels was evident in a group they dubbed “skin type II” but not the group they called “skin type IV.” In fact, higher NMF levels were observed in both lesional and non-lesional AD skin in patients with skin type IV compared to those with skin type II.

The investigators concluded that based on the differences reported in NMF levels between children with AD with skin type II and those with AD with skin type IV, some pathophysiologic mechanisms may differ in children with AD who have lighter skin types compared to those with darker skin types.

Findings from their analysis were published in the July 2018 edition of the *British Journal of Dermatology* and reported at the 2018 EADV meeting. The scientists included a disclaimer with their study noting the major limitations of their research, including the small sample size of just over 100 participants and the fact that not all skin types were represented in their analysis. \*

### THERE'S MORE TO DISCOVER ONLINE!

Scientists are making tremendous strides in conducting groundbreaking research needed to bring us better treatments and a cure. For the latest on eczema-related research, visit

**[nationaleczema.org  
/category/discoveries](https://nationaleczema.org/category/discoveries)**





# THE UNSTOPPABLE MOM

Cara Ellis' frustration with struggling to find non-toxic skincare products for her son led to a new job and an opportunity to advocate for NEA.

BY KATHRYN JONES

When Cara Ellis' son, Walker, was born with eczema in 2012, nothing seemed to help her baby's itchy, painful rash.

"We tried everything in the world we could get our hands on from over-the-counter creams and lotions to prescription steroid ointments," she said. "I purchased all sorts of crazy things on the internet—companies claiming to have that one product that's supposed to cure everything. But nothing seemed to help."

Ellis began to wonder if the ingredients in her son's personal care products were exacerbating his eczema symptoms instead of helping them. In her spare time, she started researching ingredients. "I used to be a school teacher, so I'm a nerd, a researcher by heart," she said.

What Ellis discovered astonished her. "The United States has not passed a major federal law to regulate the safety of personal care ingredients since 1938. Consumers have no idea that it's been that long since a major health protective law has been passed," she said.

"We assume the personal care industry is regulated like the food industry, but it couldn't be further from the truth. I was spending so much money on products making these claims that they were all-natural, preservative-free and dermatologist recommended. And I was trusting what they said. It infuriated me as a mother." This led Ellis to a new job as executive director at Beautycounter, a company that aims to spread public

awareness about harmful chemicals in personal care products through The Never List™.

The list bans more than 1,500 questionable or harmful chemicals—1,400 of which, Ellis added, were banned or restricted by the European Union, whereas the U.S. has only partially banned 30 to date.

"Through this, I've learned that consumers need to be their own advocates," Ellis said. "Not only do we need to be advocating for our own health and wellness, but we also have to hold others accountable. This will help increase transparency between manufacturers and consumers."

## NEA's latest advocate lays down the law

Since Walker's eczema is what ignited Ellis' passion for advocacy and safer personal care products, it's no surprise that she and NEA were destined to connect. "It was serendipity," Ellis said.

Tim Smith, vice president of advocacy and access for NEA, knew of the advocacy work Ellis had done for Beautycounter and reached out to see if she'd be interested in advocating for NEA. The answer was a resounding, "Yes!"

First, Smith asked Ellis if she'd be willing to approach her elected officials and ask for a resolution declaring October 2018 Eczema Awareness Month in her home state of Tennessee. "I was familiar with the process and said, 'Just give me the verbiage, and I will make it happen,'" she said. ►



## ***"All you need is your story and the passion to share it to truly make a difference."***

Ellis, who happens to live in Nashville, her state's capital city, requested an in-person meeting with her representative and senator, which she was granted. She said she was delighted by how receptive her elected officials were.

"They want to hear our stories," Ellis said. "They want to know the things that drive their constituents. I told them that eczema is an illness that affects every demographic, no matter the age, race or gender. All of these people are your voters.

"I said that we need to take the time to bring more public awareness around eczema to break the stigma," Ellis continued. The lawmakers agreed. "They were willing to present a bipartisan resolution, and I found out that our governor, Bill Haslam, signed the resolution on April 12, 2018."

In early May 2008, Smith asked Ellis if she'd be interested in being one of three NEA advocates to attend a Derma Care Access Network (DCAN) meeting in Washington, D.C., and share her eczema story with policymakers.

"We were part of a panel to address the access-to-treatment issues that we've had with Walker," Ellis said. "I spoke about step therapy, which is what happened when our insurance company required us to try a treatment out for a six-month period of time, even though our pediatrician knew this medicine was not going to work for us.

"I also spoke about the emotional and financial effects eczema has had on our family," she continued. "It's important to keep driving home the point that these experiences eczema families are having don't always make it all the way to the key players that really should be hearing our stories."

Ellis learned that she didn't need prior experience in advocacy to make an impact on legislators or policymakers.

"I don't have a law degree, and until I was thrown into it, I thought you needed those things to make a difference in that arena," she said. "In hindsight, I learned that all you need is your story and the passion to share it to truly make a difference." \*



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# SQUAD GOALS:

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TREATING THE SYMPTOMS AND SIDE EFFECTS OF ATOPIC DERMATITIS SHOULD NOT BE DONE SOLO. LEARN HOW TO PUT TOGETHER A WHOLE CREW OF MEDICAL PROFESSIONALS TO HELP YOU FEEL YOUR BEST.

BY KATHRYN JONES

**W**ant to know the best way to take charge of your eczema and be a self-empowered advocate for your health and well-being? Create your own eczema care team consisting of licensed, specialized medical professionals you can trust, and keep those lines of communication open.

That's right—we said team. Putting the fate of your disease and quality of life in the hands of just one doctor would be like hanging up an original Picasso painting using only one nail. It can be done, but yikes! Wouldn't you want to ensure that masterpiece is carefully preserved? After all, just like you, it is a priceless work of art.

Atopic dermatitis (AD)—the most common, difficult to treat form of eczema—is a chronic, relapsing inflammatory disease that causes the skin to become dry, discolored, itchy, scaly, oozy, painful and more susceptible to staph infections. It also comes with its fair share of comorbidities including asthma, allergic rhinitis or hay fever, food allergies, depression and sleep troubles.

“This is so much more than an itchy, trivial rash,” said Dr. Mark Boguniewicz, professor, division of allergy-immunology, department of pediatrics at National Jewish Health and University of Colorado School of Medicine.

“Having a disease like AD—with significant pruritus (itch), painful skin, ongoing sleep disturbance, uncertainty

about triggers, and concerns or misunderstandings about medications—requires more than just making a quick diagnosis and handing out a prescription,” he said.

“Clinicians often do not have adequate time to spend with patients or caregivers to properly educate them about the nature of this disease, triggers, testing (and limitations of tests), or treatment risks vs. benefits. In many ways, our current approach to medicine in general is not conducive for caring for patients with chronic, relapsing disease. And our health care system really doesn't make it easy to facilitate a team approach. That's the sad reality.”

Dr. Vivian Shi, director of the eczema and skin barrier clinic at University of Arizona College of Medicine in Tucson—and longtime eczema warrior herself—agreed. “Since there is no universal electronic medical record system, it is often difficult for multiple out-of-network providers to gain access to a patient's medical record. In my opinion, this is an intrinsic impediment to patient care,” she said.

“Certain specialists also may not be familiar with diagnosing and managing all aspects of AD, as it is a very multi-factorial and heterogeneous condition. Additionally, a multidisciplinary team is often challenging to assemble within the same health care network, partly due to institutional constraints and insurance reimbursement issues. Thus, most multidisciplinary AD specialty centers are within tertiary teaching medical centers and are few in number.” ►



## TWO EXAMPLES OF ECZEMA CARE TEAMS IN ACTION

Boguniewicz is a pioneer when it comes to taking a team approach to treating AD. He runs the Day Treatment Program at National Jewish Health in Denver, where pediatric patients and their families often stay on or near campus for days at a time. Here, young patients with AD are evaluated by a medical team that includes physicians, nurse educators, behavioral clinicians, dieticians and others.

Patients undergo intensive skincare routines, including wet wrap therapy, for the first four to five days. Then they step down to a more achievable maintenance regime while the team continues to evaluate triggers and address scratching behaviors and other issues. Before leaving the program, patients are given a home management plan and referred to physicians who specialize in AD in their hometowns.

“What is so striking is that, for the majority of patients coming to our program, no matter how severe their eczema is, or what prior treatment they have been on, or how infected their skin may be, they tend to get dramatically better when our nurses take over initial skincare with the assistance of behavioral health clinicians, child life specialists and other members of our team,” Boguniewicz said.

The Atopic Dermatitis Center at Boston Children’s Hospital also takes a team approach to treating pediatric AD cases. Crew members include an allergist or allergy nurse practitioner who completes a medical assessment and provides educational resources to the patient and their family, and a psychologist who counsels the patient on distraction techniques and coping mechanisms to minimize scratching.



## HOW TO FIND AND BUILD YOUR OWN ECZEMA CARE TEAM

Think of your eczema care team as if they were specialized contractors hired to perform fine repair work on your home. You wouldn’t hire a plumber to install the windows. You don’t expect the roofers to handle the electrical wiring. You want to hire the person who specializes in that particular field of work so that the job will be done correctly. The same principle applies in the medical world.

“Patients must be empowered to manage their disease because their illness has daily challenges that can last a lifetime. These challenges may be far more frequent than can be dealt with in the relatively few clinic visits they may have per year,” said Dr. Donald Leung, head of the allergy/immunology division in the department of pediatrics at National Jewish Health.

“Although the patient may require multiple medical providers, it is important that the patient has one health care provider who can orchestrate the various subspecialists to treat these complex cases. The multi-disciplinary team led by the patient’s primary health care provider is most effective in optimizing care for the patient with moderate to severe eczema.”

It’s important to feel comfortable with the experts you’re relying on, Shi added. In addition to evaluating your symptoms and providing answers to your questions, your eczema care team should take the time to listen to any concerns you might have about skincare, triggers, treatments or quality of life.

“Patients/caregivers are often the catalyst and glue for their own care team,” said Shi. “It is tremendously helpful to identify specialists that are committed to working with the patient/caregiver, as well as other AD specialists, though it may take some effort and time to assemble the ‘right’ team of doctors.”

NEA’s Eczema Provider Finder is a good place to start. Our online directory allows you to search for medical providers who specialize in treating eczema. All you have to do is plug in your zip code. The directory pulls up vital information including their contact info, medical specialty, types of treatments they provide, and whether they are covered by Medicare/Medicaid or private insurance. Visit [\*\*EczemaProviderFinder.org\*\*](https://www.eczema.org/provider-finder) for more. ►

# TYPES OF DOCTORS TO CONSIDER FOR YOUR TEAM



## General practitioner/primary care physician

Meet your new BFF! These doctors treat acute and chronic illnesses and provide preventive care and health education to patients. Since they possess the ability to refer you to specialized providers, they play a key role on your eczema care team. Remember, you can see a nurse practitioner or physician's assistant too!



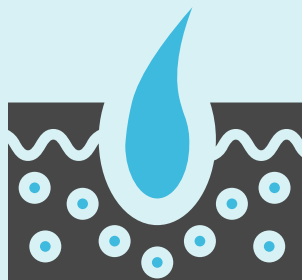
## Pediatrician

Pediatricians are medical doctors who specialize in the treatment of infants, children and adolescents. If you are a parent or guardian of a child living with eczema, look for a pediatrician who specializes in treating eczema. Many pediatric nurse practitioners and physician assistant's specialize in eczema too.



## Allergist/Immunologist

An allergist/immunologist is a physician trained to diagnose, treat and manage allergies, asthma and immunologic disorders including immune deficiencies. They can perform tests to help identify eczema triggers.



## Dermatologist

A dermatologist specializes in the treatment of skin cancers, melanomas, moles and other abnormalities of the skin, along with atopic dermatitis and other inflammatory skin disorders. Find a dermatologist you trust who specializes in eczema and keep those lines of communication open.





### Naturopathic doctor

Naturopaths understand the value of Western medicine as well as herbal remedies, supplementation, diet and natural health techniques to help you heal. They lean more toward natural therapies to promote the body's innate ability to heal itself as opposed to scientific evidence-based medicine.



### Acupuncturist

Acupuncture has its roots in ancient China and involves the insertion of fine needles along strategic points of the body. It works on some people, but not others. Acupuncture may (or may not) help with a variety of ailments, including stress management and pain relief.



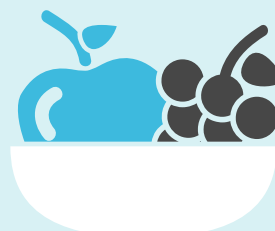
### Functional medicine practitioner

A functional medicine practitioner understands genetics and the environmental and lifestyle factors that can affect health and disease. The doctor looks at the root causes of your illness, including nutrition, exercise and stress levels, before determining a treatment plan.



### Mental health provider

People with eczema face certain emotional struggles that come with living with a chronic illness, such as stress, depression, anxiety or low self-esteem. Find a mental health provider you trust and feel comfortable sharing your innermost feelings with.



### Dietitian/nutritionist

Dietitians and nutritionists advise people on what to eat in order to lead a healthy lifestyle, manage a disease or achieve a specific health-related goal. Your best bet is to find a registered dietitian, who is a regulated healthcare professional licensed to assess, diagnose and treat nutritional problems.





# MANAGING YOUR ECZEMA CARE TEAM



Being proactive in your trigger tracking and following your doctors' orders when it comes to skincare and treatment are a big part of successfully managing your eczema care team. Patients should come to medical appointments equipped with photos, notes and other evidence demonstrating the progress (or lack thereof) of that person's current skincare and treatment regimen.

"Important elements that patients and caregivers can provide for the doctors during office visits should include disease severity trends, such as itch, redness, sleep loss; trigger tracking diaries and medication use logs," Shi said. "Without this information, it is more challenging for the doctor to fully understand whether or not one's AD is adequately controlled on the current regimen and how to modify the management plan moving forward.

"An emerging solution for this practice gap is called shared decision-making (SDM)," Shi continued. "It's a process in which the patients/caregivers and providers collaboratively make disease management decisions based on available clinical evidence in order to improve treatment outcomes. SDM tools have been implemented in a number of medical specialties outside of dermatology."

But not for long. NEA is forging new and innovative paths in patient care by bringing the SDM model to dermatologists and other medical providers serving the eczema community.

This year, we will launch a beta model of our SDM platform, a custom e-tool or website that will help eczema patients and their caregivers track and monitor symptoms and triggers on their computers. Serving two research grants to start, NEA is working directly with patients and providers to place this tool in active use at clinics with the ultimate goal to provide this important resource to our entire community.

The SDM platform also equips patients with pre-appointment checklists, action plans, decision aids and more. Since patients will be able to share these items with their health care providers, their medical team will be able to gain more complete insight into how the patient's disease is progressing in between medical appointments.

Becoming empowered is one of the most important steps Eczema Warriors can take in their journey to wellness. Learn everything there is to know about this disease and find medical professionals who are determined to get to the bottom of your symptoms. Remember, you are a priceless work of art, and you deserve an eczema care team that will nourish and support all aspects of your health. \*



## 6 STEPS TO BECOME AN EMPOWERED ECZEMA PATIENT

**ONE** Go to any and all medical appointments. A medical professional's time is valuable, and so is yours. Don't deny yourself the opportunity to receive professional care or advice about your eczema.

**TWO** Be candid with your health care team. Discuss any symptoms you are experiencing, regardless of how minor they might seem.

**THREE** List all medicines you're taking, including over-the-counter medications, vitamins and alternative therapies.

**FOUR** Discuss any emotional symptoms you are having. If you are feeling anxious or having trouble sleeping, let them know. These are common side effects of eczema.

**FIVE** You have the right to get a second opinion—from a medical provider, that is. Your friends, family and coworkers mean well, but you need a professional's input.

**SIX** Talk to your doctor before trying any new treatment. Once you agree to a treatment plan, follow through with it. If the treatment is not what you expected, talk to your doctor before stopping the treatment.

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*dyshidrotic eczema*

## Beyond AD: Exploring the other eczemas

*Eczema is an umbrella term for a group of skin conditions that share similar symptoms. Atopic dermatitis is the most common type of eczema, but what about the others, including dyshidrotic, seborrheic, stasis and prurigo nodularis? We asked Dr. Peter Lio to walk us through the different types of eczema and the best ways to treat them. Please note that portions of this Q&A have been edited for clarity and brevity.*

### **My 2-year-old daughter's eczema presents differently depending on where on the body it is. Is it possible to have different types of eczema at the same time?**

Absolutely. You can have different presentations on the same patient over time, or you can have different presentations on the same patient at the same time. It makes it so weird and so interesting to me because you have to be flexible to diagnose it. It can be very confusing to see different types of eczema in the same patient because there may be one type of eczema that triggers another type, or it could be the same type of eczema that just looks different on a separate part of the body.

### **What are your moisturizing cream or lotion recommendations for people with AD plus another type of eczema, such as dyshidrotic or asteatotic?**

It's really the same. For those who know me, they know I am a moisturizer nerd. I can talk about it all day. There are so many

good brands out there that are all awesome. In general, you can look at brands like CeraVe, Cetaphil, Aveeno, Gold Bond, Theraplex, Aquaphor or Eucerin. You can do the fancy French brands like La Roche-Posay and Avene. Just find one that you really like.

For the day, I'll often pick something lighter weight—not a lotion though. You don't want lotions because those are too watery. You want something cream-based but non-greasy. Then at night, you might pick something heavier, more protective that will seal everything in. Some patients like the greasy, heavy ones all the time. Other patients think the heavier ones feel too hot or uncomfortable. You want to listen to your skin and find something that feels good. That said, there are some moisturizers that are off limits completely. You don't want anything with fragrances, preservatives or a ton of ingredients because then you might end up irritating your skin and making things worse. ►



### How dangerous is it to use cortisone cream on my eyelids?

It's not that dangerous when used correctly for short intervals under supervision. It would be dangerous if you used a high-potency one or even a medium- to low-potency one for a long time without checking in with anybody. The eyelid skin is really thin and more absorbent than other parts of the body. The big issue with absorption in that area is that it could damage the skin. That's bad, and we don't want that to happen. But what's much worse is because the eye is nearby, you'll have an increased risk of cataracts or glaucoma.

Ideally, you want to stick to low- to medium- potency at most around the eyes. And you want to do it for a couple of days, get it better and then put it away. You can then switch to a nonsteroidal or, ideally, if you don't need another medicine, a good moisturizer. Something heavy, thick and protective would be awesome to help protect those lids. What if it's chronic? Then I might be suspicious it's contact dermatitis. We'd need to do patch testing to figure out what's driving this so that we can remove it from your environment and stop it from happening again.

### What can you tell us about perioral dermatitis?

Perioral dermatitis is another tough one that affects mostly adult women and kids. You get these micro papules that tend to be around the nose, mouth or eye. It can look almost like irritation. If you're not paying close enough attention to it, people will say, 'Oh it's a little irritation. Here's some steroid.' No way, Jose. You do not want to put steroid on it. Why? Because it gets better at first. It looks like it's gone. And then when you stop, it goes crazy. It turns out that the steroids are feeding it. We definitely do not want to use steroids on this condition at all costs. \*



*seborrheic dermatitis*



## WANT MORE?

NEA Webinar Wednesdays feature world-class medical experts discussing the latest in disease management, research, treatments and related information you need to live well with eczema. Each webinar is an hour and includes time for Q&A from the audience. Watch the full "Other eczema's" webinar and more at <https://nationaleczema.org/resources/webinar-wednesday-archives/>



*Dr. Peter Lio is clinical assistant of dermatology and pediatrics at Northwestern University Feinberg School of Medicine. He also is a member of NEA's Scientific Advisory Committee and Board of Directors.*

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# WHAT'S HAPPENING AT THE NATIONAL ECZEMA ASSOCIATION

BY KAREY GAUTHIER, MS

## Together, we can #unhideECZEMA

This past October, we celebrated Eczema Awareness Month as we do every year. The theme for 2018 was #unhideECZEMA, and our community did just that.

Our mission for EAM 2018 and #unhideECZEMA was to encourage people living with eczema and their supporters to unhide eczema with two primary purposes:

- *Raise awareness about the prevalence and burden of eczema to those who are outside our community; and*
- *Encourage our community to come out of the shadows and unhide their own eczema to their communities.*

Using the concept of kintsugi and wabi-sabi in the Japanese tradition, we spent the month sharing and even celebrating our perceived imperfections. When we tell our stories, show our cracks and roughness, we become empowered. We heal the invisible cracks in our hearts. And we do the same for the people watching.

Throughout the month our community showed up in droves to participate in EAM. Hundreds of people joined the conversation on social media using the hashtags #unhideECZEMA #EczemaAwarenessMonth and #EczemaWarrior – many sharing their life with eczema for the first time in such a public forum.

Three eczema warriors who have been sharing their stories through national and international forums like the Dove Dermaserie campaign, joined us for an evening of conversation around the importance of storytelling.

Alexis Smith (aka @EczemaLove), Mercedes Matz (aka @KeystotheCedes) and Ashley Ann Lora (aka @AshleyAnnLora) discussed why they chose to share their eczema experience so publicly, how their lives and relationship with their eczema changed after, and how the community can join them in un hiding eczema. If you missed it, you can view the webinar at [nationaleczema.org/resources/webinar-wednesday-archives/unhide-eczema-webinar/](http://nationaleczema.org/resources/webinar-wednesday-archives/unhide-eczema-webinar/) or on the NEA YouTube channel. ►







Thousands of community members responded to weekly surveys to help inform our understanding of the eczema experience for adults, children, caretakers and even health care providers. We asked questions about comorbidities and related conditions such as food allergies and anxiety/depression, experiences with access to care issues such as step therapy, and the impact eczema has on life such as career, dating and family.

One of the most striking results that came out of this survey series was that 71 percent of respondents indicated that they have experienced anxiety or depression. Compared to an estimated 18 percent of the general population, this number indicates a serious need for mental health screenings and support as a part of eczema's standard of care.

In addition to the phenomenal showing from our community of Eczema Warriors, our partner organizations stepped up to raise awareness too. The American College of Allergy, Asthma & Immunology, Dermatology Nurses Association and the National Association of School Nurses actively joined the #unhideECZEMA campaign alongside NEA.

Industry partners Sanofi Genzyme, Regeneron, Abbvie, Dermira, Pfizer, Aveeno, Dermavant and Leo also joined the movement as sponsors. Several companies held corporate town halls to educate their teams on life with eczema, and some held walks in support of NEA's virtual walk "Itching for a Cure." With over 41 fundraisers participating, Itching for a Cure 2018 raised over \$15,000, thanks to the incredibly hard work of the eczema community. Regional walks were held from Hawaii to Mississippi to New York, with individuals everywhere in between walking to show their support. Every T-shirt worn and donation given helped us #unhideECZEMA.

Once October ended, we quickly dove into the holiday season and are setting big goals for the new year. We think it's important to keep the momentum going from EAM and build on it. The more people who are willing to bring their eczema out of the shadows and shed some light on this common skin disease, the better our chances of fighting the stigma surrounding it.

We hope throughout 2019 and beyond that you will continue to #unhideSTRENGTH, #unhideBEAUTY, #unhideBRILLIANCE, #unhideLOVE and #unhideECZEMA. \*





## NEA turns 30 years old this year

Thirty years ago, in December 1988, a dermatologist, Jon M. Hanifin, MD; an individual with severe eczema, Irene Crosby; and a research nurse, Susan Tofte, RN, MS, FNP, came together to provide support and education for people living with eczema. This was the humble beginnings of the National Eczema Association.

At first, the group started with meetings around a table at the Oregon Health and Science University library in Portland, Oregon, where our three founders lived. Dr. Hanifin was serving on the board of the National Psoriasis Foundation and believed those with eczema should have an organization providing the same level of support.

Originally founded as the National Eczema Association for Science and Education (NEASE), the founders believed it was crucial to educate the world on how to care for eczema based on the scientific evidence available. They supported clinical trials and offered small support groups.

Although NEA later dropped the (SE) and relocated to California, our focus on education, support and research based on scientific evidence remains the same. From research grants, to grassroots advocacy, to educational materials, and in person events like Eczema Expo, our mission remains the same.

“NEA is on its way to becoming an amazing global organization,” shared founder Susan Tofte. “What I most appreciate about it is that it is very patient centered, and it always will be. The focus will always be on what we can do for our patients. We are not in the business of making money or trying to grow our organization in any way other than to benefit our patients. I hope in my lifetime to see a cure for this disease, and I’m happy to be a part of the cause.”

Throughout the year, we will be celebrating our 30-year history, showcasing the work that has been done to improve the health and quality of life for individuals living with eczema. Keep your eyes out for celebratory publications, events and fundraisers. \*

## Are you prepared?

It may be the news, it may be climate change, it may just be the forces of mother nature doing her thing. Regardless of the cause, it feels like there has been one natural disaster after another in recent times. From hurricanes to floods to blizzards and forest fires, communities around the world have been deeply impacted by these dramatic shows of nature.

While everyone should have emergency plans in place to ensure they have food, water and safety, individuals with a chronic illness have additional concerns to manage, such as:

- *What do I do if I don't have time to get my prescription medications?*
- *Who can I call for help to replace supplies left behind?*
- *Does my insurance cover replacement medications, or will I have to pay full price?*

Every disaster is slightly different, and available resources rely on the impacted community. However, there are some consistent options, and we at NEA will do our best to remain a resource for those living with eczema, especially in times of crisis.

That's why we created our Emergency and Disaster Preparedness resource page (<https://nationaleczema.org/emergency-prep/>). Here, you will find lists to help you prepare for emergencies and what to do if a disaster hits your community. In addition to the information listed on these pages, NEA is always available to answer questions or find specific resources in times of crisis.

We are here because you are here. \*



# From sufferer to survivor

***How a particularly painful flare-up of atopic dermatitis gave me a new sense of purpose and a more positive outlook on life.***

BY DEBBIE BYRNES

Everyone with atopic dermatitis (AD) has a story to tell. Mine is no longer about suffering with AD. It's about the peace, joy and friendships I have found because I have this dreadful disease.

If people had told me 10 years ago that someday I would be happy because of my atopic dermatitis, I never would've believed them, but it's true. The reason is that I learned how to manage my AD, which, for too long, had a devastating effect on my life. My story is about how this disease has changed me for the better. I'm more confident, positive and outgoing.

Nearly a decade ago, I was in a new city enjoying the challenges of a career change. My three children were independent young adults preparing to leave the nest for college. My husband and I looked forward to that next phase of life — empty-nesting.

This is about the time when my life turned upside down. My childhood disease, atopic dermatitis, returned with a vengeance. I thought I could control it like I had done before, but this became something much worse. I didn't know then that it would change my life in ways I never imagined. ►







## *A new purpose*

It seems strange to think that something so horrific could be a blessing, but that's how it turned out. It wasn't all about the sleepless nights, constant itching, painful and burning skin from head-to-toe. It was about taking control of this disease and owning it.

When I finally accepted the fact that it was going to be a fight like no other, I put every ounce of strength into beating this disease and focusing on all the good that came from it.

Finding people who understood atopic dermatitis became my mission. It was not an easy task considering I did not know one person in San Antonio, Texas, who had AD, nor anyone in the world for that matter.

After months of research, I found the National Eczema Association. It was like finding a pot of gold. I attended NEA's "Itching for a Cure" fundraising walks, patient conferences and forums.

I surrounded myself with people who were just like me. Instantly, I formed a bond with those people that brought a sense of relief to me. Those newfound friendships gave me peace and happiness and began to fill a void in my life.

I mastered the skill of "networking" by cultivating those friendships and working hard to build new ones. I volunteered to speak about the disease, write about it and promote public awareness.

One thing led to the next, and before long, I realized I had friends all over the world who were connected to this disease one way or another. I accepted every opportunity I got to travel and spread the word about AD. On a recent vacation through Europe with my husband, I connected with people there whom I had met at a NEA event years ago.

## *A new me*

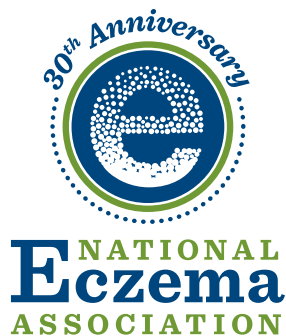
My dark and lonely days with this disease have faded. I've learned how to manage my AD and feel a sense of pride for how I've handled it. My life has taken on a new dimension. It warms my heart when I go to AD events and bump into people I've met before at conferences or forums. I've discovered that I'm part of one big family — all of us passionate about helping others who suffer from this.

I never realized until I became involved with NEA and started speaking in public about this disease how much I was actually keeping to myself. I thought I was doing a good job over the years of telling my family and friends what I was going through. When they hear me talk about it now, they say I never really shared with them how much I was suffering.

The opposite is true now. I enjoy telling my story because I want to be an inspiration to others fighting this disease. I will continue to do my part to increase public understanding of AD and the need to find a cure. \*

*Debbie Byrnes is an atopic dermatitis advocate living in San Antonio, Texas.*





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