

# eczema matters

RESEARCH, SUPPORT, AND EDUCATION FOR THOSE AFFECTED BY ECZEMA

FALL 2018

## HIGHLIGHTS FROM EXPO '18

Eczema Warriors convened in Chicago to learn, laugh, lament and let loose. **P.9**

## DECODING PRODUCT LABELS

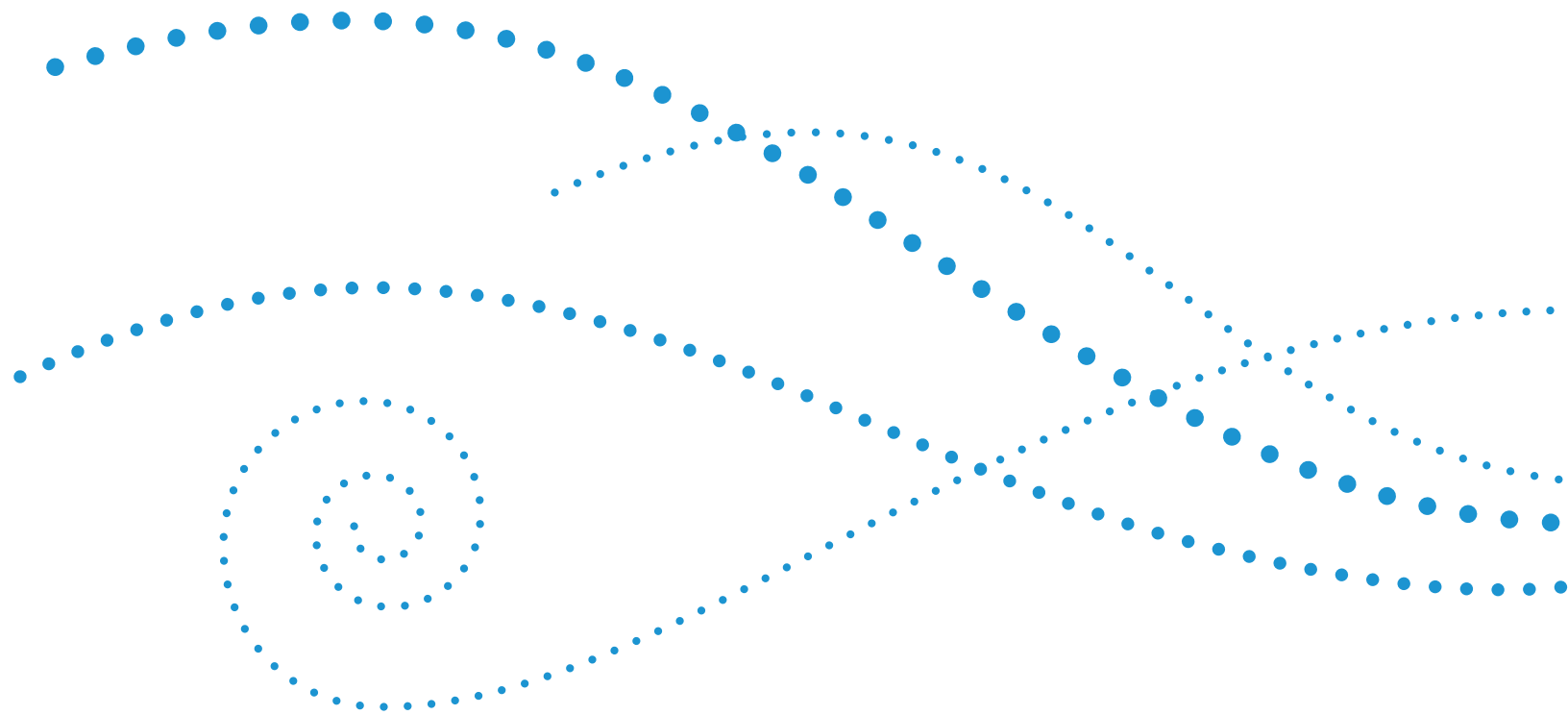
It's not easy to figure out which products actually are eczema-friendly. **P.4**

## LET'S UNHIDE ECZEMA

Learn what you can do to help NEA honor Eczema Awareness Month. **P.33**



NATIONAL  
**Eczema**  
ASSOCIATION



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# In This Issue

## Featured

### 04 Decoding Product Labels

Learn how to research the wording and ingredients on your personal and household product labels to make sure they're safe for eczema skin.

### 09 Eczema Expo '18

Hundreds of Eczema Warriors convened in Chicago over the summer to prove to the world (and themselves) that you really can "live your best life" with eczema.

### 26 Understanding Inflammation

Top dermatologists unravel complexities of the inflammatory response for people with eczema, in sickness and in health.

## Departments

**02 Letter from Julie:** Updates from NEA's President and CEO

**03 Scratch Pad:** Advice from the NEA community

**20 Community Spotlight:** Long Island's Steve Gawron

**23 Discovery Zone:** Exploring the latest in eczema research

**30 Ask A Doctor:** The impact of eczema on sleep

**33 NEA News:** What's happening at NEA

**36 My Journey:** Ashley Lora recaps Expo '18



**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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look forward to October every year—and not just for the reasons you might be thinking. Sure, I enjoy watching the leaves change colors and handing out candy to adorable trick-or-treaters. But the other reason why I love October so much is because it's ECZEMA AWARENESS MONTH!

During #eczemamonth, we invite people living with eczema from all over the world to gather as a community to raise public awareness and fight social stigma.

This year, we are continuing our work to #UnhideEczema and bring it out of the shadows. We began the campaign a little early with our summer billboard in Times Square (read more on page 34). After a simple request for photos for the billboard created a thunderous response, we knew how important this message is now. Throughout the month, we will have various calls on media and email encouraging you and your loved ones to #UnhideEczema together. Our annual virtual walk, Itching for a Cure, will also be happening throughout the month, so join us in raising awareness and funds for a cure!

If you weren't able to make it to Eczema Expo '18 in Chicago last June, you missed one heck of an event! Witnessing individuals and families who felt alone in their journeys have a chance to bond with other Eczema Warriors was a powerful and heartwarming experience. Hearing the sweet laughter coming out of our Kids' and Teens' Camp and watching new friendships unfold made all the time and effort we put into this event more than worthwhile. We are indebted to our esteemed speakers and presenters who shared all there is to know about living well with eczema, and have a newfound hope for the future.

We put together a fantastic issue of *Eczema Matters* for you that's full of riveting content to help you #liveyourbestlife with eczema. In our special section dedicated to all things Expo, we kick off a recap of the event on page 9, followed by our Superheroes of Expo profiles on page 14. There was one superhero at Expo in particular, Stephen Gawron, who earned special recognition in our Community Spotlight feature on page 20. And for a glimpse at what it was like to attend Expo firsthand, check out Ashley Lora's article on page 36.

In a world that can feel a bit divided these days, it's important to note that the eczema community is all-inclusive. It doesn't matter who you are, where you live, how you live or what you believe in, you are a part of the NEA family. Your voice matters. During Eczema Awareness Month, let's make sure our voices ring out loud and clear. It's time to #UnhideEczema.

Yours,  
Julie Block



## How do you make sure you #liveyourbestlife whether or not your eczema is flaring?



*Opening my window and listening to the peaceful sounds of nature.* – MICHELLE B.

*Painting on my skin (not on my patches) to make myself feel nice.* – CHELSEA B.

*Exercising or walking.* – JOANNA B.

*Weirdly, my therapy is helping others in the community.* – SUE M.

*Making sure to de-stress by playing my guitar every day or reading or riding my horse.* – REBECCA S.

*Music!* – ASHLEY B.

*Playing Xbox makes my hands busy and stops me from scratching.* – DANIEL

*Reading! A good book grabs hold of all my attention. My hands are too busy turning pages, and my brain is tuned into the story. #selfcare* – JESS



*Yoga and meditation* – @Byjustinema

*Exercising in the pool is great. I enjoy it, and it functions as a bleach bath as well.* – @Monkeyire

*Dancing and biking really help get my mind off it. Epsom salt baths are very awesome too!* – @Primephysiquenutrition

*Fortunately, I've always pointed towards natural, holistic solutions, and what used to feel restrictive is now an adventure.* – @Jenraydancinema

*Definitely wrapping up tightly with fuzzy blankets to avoid sleep itching.* – @Just\_an\_unknown\_poet

*Eczema is a part of my life and a part of who I am, so why not embrace it? Yes, people stare and that's OK because I'm a snack!* – @Noelletoliver

### CONNECT WITH US ONLINE!



@nationaleczema



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



# DECODING THE MYSTERY OF PRODUCT LABELS

Learn how to research the wording and ingredients on your personal and household product labels to make sure they're safe for eczema skin.

BY MARGARET W. CRANE

**E**ven if you're an educated consumer, and even if you routinely shop for products that are all-natural, organic and fragrance-free, a product's claims may not be all they're cracked up to be.

What's more, finding out what's really inside the tubes, bottles and boxes we buy can be surprisingly challenging.

## LEARN TO DECODE "LABEL-ESE"

Labels aren't as transparent as we'd like them to be, mainly because the U.S. Food and Drug Administration (FDA) wields limited authority over cosmetics and personal care products. The FDA requires ingredients to be listed on package labels, but very few labels list the specific ingredients within general categories, such as "fragrance," "flavor" and "inactive ingredients."

Let's consider "fragrance," a common ingredient that appears on many personal product labels. People with eczema are often allergic to fragrance, yet it's almost impossible to find out which fragrance-related chemical is the culprit. By listing this seemingly simple category on a label, the manufacturer can mask hundreds of potentially harmful chemicals. ►







Descriptive language on product labels can also be deceptive. Watch out for questionable terms, such as:

**HYPOALLERGENIC** – According to the FDA, this term means anything a manufacturer wants it to mean. Consumers may be led to believe that hypoallergenic products will be gentler to their skin than non-hypoallergenic ones, but dermatologists say it has very little meaning.

**FRAGRANCE-FREE** – A product advertising this claim may legally contain fragrance chemicals as long as they are used for a purpose other than fragrance itself.

**UNSCENTED** – This one doesn't mean that a product is truly fragrance-free. The term can be listed on products that use fragrance chemicals to mask strong smells. A product may have no discernable scent, but it isn't necessarily free from chemical irritants.

**GREEN** – There is no set definition or standards for this term. It is frequently used as code for sustainable, environmentally friendly, and possibly manufactured with recycled materials.

**ORGANIC** – This popular term implies that a product is made from plants grown without chemical fertilizers or pesticides. But unless you see the U.S. Department of Agriculture's "USDA Organic" logo on the product label, the word can be inaccurate or even meaningless. However, small farms and businesses that sell less than \$5,000 in organic products per year don't require USDA certification, and you should always read the label completely.

**ALL-NATURAL** – This term typically refers to a product that is made of minimally processed ingredients and does not contain artificial ingredients or preservatives. This is not an official label with set standards, however, and even a product that contains one or more natural ingredients—aloe or lavender, for example—may contain potentially harmful preservatives or other additives.

Household product labels can be even harder to decode than those on personal products. As with cosmetics and skincare products, the household products we use all the time typically contain dozens of unregulated chemicals.

The Consumer Products Safety Commission regulates labeling for a wide range of household products, including cleaning products, car wax, battery acid and drain openers, among others. All such products are required to list their main ingredients, including those known to be hazardous.

They also need to list instructions on how to use a product, and how not to use it, along with first-aid information. But household product manufacturers suffer no legal or regulatory consequences when they fail to provide a complete list of ingredients.

If all this sounds grim, don't despair. There may be no foolproof way to see "what's in there" in every case, but there's a lot you can do to become label-literate and protect your skin and your health in the process. ►



## RESOURCES AND GUIDELINES

The Environmental Working Group's Skin Deep database is a good place to start exploring the world of cosmetics and personal care products, and the Cosmetic Ingredient Review and Cosmetics Info websites are highly informative as well. Use these resources to look up a product or ingredient and see if it has known toxic effects.

And in the real world, there's a lot you can do to make sure you're buying the gentlest, most skin-friendly personal care products on the market to keep allergic reactions at bay. Just pay attention to the following guidelines:

- Keep it simple! Buy products with fewer ingredients.
- When reading a product label, look for your known triggers, and if you see any of them, cross that product off your list.
- Test a small amount of a new product on a clear patch of skin. The inside of your wrist or the crook of your elbow are often good spots.
- Read and follow the directions on the product's label.
- Avoid trying new products when your skin is irritated or inflamed.

And you can also become a label-savvy consumer when it comes to household products:

- Get to know the National Library of Medicine's Household Products Database, where you can look up products and ingredients to check for toxicity.
- When shopping for "green" cleaners, read product labels carefully to make sure the ingredients are truly environmentally friendly.
- Choose products that advertise themselves as "non-toxic," "biodegradable" and "petroleum-free," and for products that list all their ingredients.
- Beware of catch-all categories such as "inactive ingredients" or "fragrance." Try to find out what's really in there.

Finally, check out NEA's Product Directory at [EczemaProducts.org](http://EczemaProducts.org). Our directory includes an extensive list of personal and household products that have earned the NEA Seal of Acceptance™.

NEA's Seal of Acceptance™ Review Panel awards the seal to products created for people with eczema and other skin sensitivities that meet the Seal of Acceptance™ criteria. The panel has also flagged ingredients that should be avoided.

*Note: NEA's acceptance of a specific product isn't an outright endorsement of that product. Everyone reacts differently to personal care and household products, so trial and error remains your best strategy for identifying and eliminating triggers, wherever they may lurk. \**



**DON'T LET UNCONTROLLED  
MODERATE-TO-SEVERE ECZEMA HOLD YOU BACK**

**DUPIXENT<sup>®</sup>**   
(dupilumab) Injection 300mg

## DUPIXENT can help heal your skin from within

The flare-ups you see and feel on your skin can be caused by inflammation happening beneath the surface. So help heal your skin from within with DUPIXENT.

### SEE AND FEEL THE CHANGE

An injection you may administer yourself, DUPIXENT is the first treatment of its kind that helps you continuously manage your eczema over time, even between flares when your skin may look clear. DUPIXENT is for adults and is not a steroid.

#### In Clinical Trials at Week 16:

- More than 1 in 3 patients saw clear or almost clear skin
- Almost half of patients saw significant skin improvement
- Patients experienced a significant reduction in itch
- Most Common Side Effects were injection site reactions, eye and eyelid inflammation, including redness, swelling and itching and cold sores in your mouth or on your lips.

**So stay ahead of your eczema symptoms with DUPIXENT.**

**Talk to your doctor and call 1-844-DUPIXENT (1-844-387-4936) or visit [DUPIXENT.com](http://DUPIXENT.com) for more information.**

### 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.**

SANOFI GENZYME  **REGENERON**

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**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.
- 

**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.
- 

**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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# WHY ECZEMA EXPO '18 WAS THE BEST EVER

**Hundreds of Eczema Warriors convened in Chicago over the summer to prove to the world (and themselves) that you really can “live your best life” with eczema.**

By Kathryn Jones

If you weren't able to make it to Eczema Expo '18, we understand. Things come up. Priorities shift. Life has a funny way of throwing wrenches into your plans. You'll come next year. We totally get it. But we must apologize in advance if you wind up with a bad case of FOMO (fear of missing out). After all, this was no ordinary eczema conference. For many of the 400+ people who attended, it was a life-changing event.

For those who didn't get the chance to attend this year, here are four things you missed.

## **1. Having the chance to meet world-renowned “eczeperts” in person.**

The who's who of eczema research and care came prepared to share everything they know about the latest treatments, research and alternative therapies, and to offer their best tips on skincare, sleep, mental health and more.

**Dr. Elaine Siegfried**, professor of pediatrics and dermatology at the Saint Louis University School of Medicine, brought us back to the basics with everything we need to know about living with eczema. She discussed the causes and triggers of eczema,

as well as new treatments on the horizon. She said never to trust “Dr. Google,” because “the internet is like a flea market. Trying to sort out the trash from treasure is really hard. What you read about on the internet is usually geared toward selling you something. It's best to find a trusted professional to talk things through with.”

**Susan Tofte, RN, MS, FNP**, who is a dermatologist nurse practitioner at the Oregon Health and Sciences University's Department of Dermatology and co-founder of the National Eczema Association, pulled out her best tools from her “eczema toolbox” with regard to bathing and moisturizing, reducing inflammation, and the correct way to apply topicals and take medications.

**Dr. Jonathan Silverberg**, assistant professor of dermatology, medical social sciences and preventative medicine at Northwestern University Feinberg School of Medicine, who specializes in eczema comorbidities and quality of life, walked us through the genetics of atopic dermatitis along with environmental factors that contribute to flares. His presentation broke down in layman's terms how new treatments, such as JAK inhibitors and biologics, treat eczema from the inside-out. ►



Affectionately known as “The Godfather of Itch,” **Dr. Gil Yosipovitch**, professor of dermatology and director of the Miami Itch Center at the University of Miami, shared cutting-edge research on the neuroanatomy and neurophysiology of itch, discussed new therapies that target the neural system, and offered his best remedies to help lessen the intensity of eczema itch. The trick, he said, is to keep skin moisturized and stress levels down.

**Jennifer Moyer Darr**, licensed clinical social worker at National Jewish Health’s Division of Pediatric Behavioral Health, captivated the audience with her presentation on eczema and the toll it can take on our mental health. Later that day, she led a soothing relaxation session that gave attendees new coping mechanisms to gain control over depression, anxiety and stress. Here’s a hint: it’s all about self-care.

Sleep doesn’t come easy when you have eczema or a child living with the disease, and sleep deprivation can lead to a host of emotional and physical ailments. Thankfully, **Dr. Lisa Meltzer**, director of the Pediatric Behavioral Sleep Clinic at National Jewish Health, was on hand to explain the science behind sleep and what we can do to ensure a restful slumber.

Internationally renowned dermatologist, and fan favorite, **Dr. Richard Aron** flew in from South Africa to present on the Aron Regimen, stunning audience members with his before and after pictures of patients treated with compounded antibacterial, steroid and moisturizer (CASM). Aron shared the stage with **Dr. Peter Lio**, clinical assistant professor of dermatology and pediatrics at Northwestern University Feinberg School of Medicine, who discussed other patient-

powered therapies from elimination diets to cannabis.

Melissa Thomson traveled from the land down under to meet Dr. Aron in person. “That first hug with Dr. Aron is up there with the best moment of my life and a very emotional one,” she said. “Only an eczema parent whose child has been healed would understand how significant this moment is. Dr. Lio was another highlight for me, as I follow his research closely from across the world. The motivation and inspiration I have taken from this event, I believe, will assist me to help Australians move forward with eczema care.”

## 2. Getting pampered with spa-like wellness experiences the whole weekend.

What can we say, we love to spoil our friends in the eczema community! This wasn’t your average expo—it was more like a wellness retreat exclusively for Eczema Warriors and their biggest fans. NEA took great pains to ensure guests felt as pampered as possible from the choice of location (a four-star hotel situated on Chicago’s scenic river walk), to the bleach bath and wet wrap kits awaiting them at the front desk, to the “Yes, I’ve tried coconut oil” T-shirts that made folks giggle out loud.

Each morning, guests had the option to take an “eczercise” class that offered “no sweat” workout alternatives crafted by a certified personal trainer. Alternatively, they could take a soothing yoga class modified for yogis of all levels by Chicago-based certified yoga instructors Eunice Yu, a former educator and therapist, and Jennifer Jenkins, an Eczema Warrior also known as “The Allergista.” Or they could attend a guided mindful meditation session led by Yu or pediatric occupational therapist Jaclyn Stillmaker, who specializes in yoga for children and teens. ►



In between seminars and breakout sessions, guests could visit with exhibitors and try samples of the latest products and therapies to help them live their best lives with eczema. If their skin was feeling parched, they could slather on lotions and ointments at various “moisturization stations” featuring products from Expo sponsor Theraplex. Chicago-based certified acupuncturist David Kato was also on site to offer complimentary 20-minute acupuncture treatments.

For those who needed to rest, reflect or recharge, there was a serene space called “The Living Room” stocked with eczema-themed coloring books and crafts. Another popular space was the photo booth with a green screen where guests could incorporate silly props and make funny faces in front of the Chicago skyline. There was even a video confessional set up in a private setting where people could share their stories or speak candidly about their concerns, ideas and experiences.

A wellness retreat wouldn't be a wellness retreat without delicious health food to nosh on. Eczema Warrior and whole food enthusiast Tara Tom collaborated with Chris Rolewicz, executive chef at Westin Chicago River North, to create an allergy-friendly, nutrient-dense menu that made adults and kids alike return for second helpings. The menu even got a seal

of approval from The Allergista herself. “The food was great, and I love how the ingredients were listed next to everything,” Jenkins said. “It's all in the details!”

### 3. Making the adults jealous over how much fun was had at Kids' & Teens' Camp.

If you think a summer camp for kids and teens with eczema sounds boring or lame, you couldn't be more wrong! Our carefully planned, superhero-themed Kids' Camp (for kiddos aged 5 to 12) and Teens' Camp (for teens up to 17 years old) was chock-full of entertaining activities in a bully-free zone. From creative projects and action-packed outings to age-appropriate educational sessions, every aspect of this three-day adventure was designed to boost self-esteem and leave our junior Eczema Warriors feeling empowered to live their best lives.

Day one was all about being a silly superhero, with a photo booth set up for the kids to take funny pictures with props, and the chance to get to know each other over superhero-themed games and crafts. Camp coach Ashley Lora, who grew up with severe atopic dermatitis, led the kids and teens in an all-ages vision board exercise to help them picture their best lives. After lunch, the group ventured out to 10Pin Bowling ►







Follow us on Facebook, Instagram and Twitter, and sign up for our e-news to be the first to hear the date and location of Eczema Expo '19. [@nationaleczema](#)

Lounge for healthy snacks and unlimited rounds. Later that day, Stillmaker discussed the importance of fitness for both body and mind, and led the group in a flare-conscious, stress-reducing yoga session.

On day two, our campers hit the town again for a customized scavenger hunt in Chicago's scenic River North neighborhood. Yu led the group in an exploration of eczema and self-identity to help kids and teens identify alternative methods to manage stress and anxiety. After more superhero-themed crafts and games, the kids settled in for an allergy-friendly dinner and movie night, while their parents let loose and danced the night away upstairs at the NEA Ecz-travaganza cocktail reception.

Day three of camp kicked things off with an hour-long skincare demonstration that showed kids and teens how to care for their skin at school, at home and on the road. After more superhero-themed games, crafts and photo opps, the group exchanged contact info with their new besties and

closed out the weekend with a special presentation that left adult attendees nothing short of impressed.

"My favorite part about teen camp was meeting new people and not feeling like I was being looked at all time," said 16-year-old camper Kyle Bruner, who traveled from Sarnia, Ontario, Canada, with mom Jenn Johnson and older brother Tyler. "I loved learning new ways to work out and getting to see the Chicago sights on the scavenger hunt. Best of all, my brother understands my pain a bit more and learned different ways to help me with my eczema."

"Our 11-year-old daughter, Genevieve, has grown up not knowing any other children affected by atopic dermatitis," said Lisa Thomas of Baraboo, Wisconsin. "She had so much fun at camp (she says her favorite part was the crafts), and now feels much less alone and 'different.' We are also noticing an increase in her self-confidence. She proudly wears her official Eczema Expo backpack and buttons wherever she goes and is more comfortable speaking with others about her condition." ►





Photos courtesy of  
Tori Soper Photography



#### 4. Feeling supported from professionals and peers at our breakout sessions.

Each day at Expo, there were three 30-minute breakout sessions covering any and every topic related to eczema, and guests had unlimited choices as to which breakout sessions they wished to attend.

There were professional and peer-led support groups designed to address all aspects of life with eczema from infancy through the golden years, including how it affects our relationships and body image as a male or female; what it's like to parent kids and teens with eczema; and how life is affected when eczema strikes key parts of the body such as your hands or face.

There were hands-on trainings in skincare, storytelling and fitness from the eczema experts.

There were idea exchanges on hot-button topics, such as allergy-friendly eating; biologics for kids and adults; complementary and alternative treatments; how to participate in a clinical trial or research; tips for navigating the insurance marketplace; hair, makeup and other grooming challenges; and how easy it is to become a grassroots eczema activist who can help influence legislators and shape policies that will improve the lives of all people living with eczema, not just a privileged few.

"My biggest surprise was how emotional some of the sessions made me," said Thomas. "Seeing photos and hearing the stories of other children and adults doing battle with the disease often reduced me to tears. It made me realize that my husband and I were also extremely isolated. Being with others who 'get it' helped me work through a lot of feelings, and I returned home feeling lighter and more empowered."

"My favorite part about Eczema Expo was being around a community of people that got what we were going through," said Lauren Swallow of Quincy, Michigan. "Our son is 3-and-a-half, so for the past three years, my husband and I have felt totally isolated dealing with this disease. Until Expo, we had never met another family whose child has eczema or just a person in general with it. It was almost a culture shock (in the best way possible!) when we first arrived. But, we began feeling a sense of belonging, support and bonding with the families there. To be able to complain, cry, laugh and support each other was everything to us."

Has that FOMO kicked in yet? See? We warned you! NEA would like to give a special shout-out to all of our Eczema Warriors who attended Expo '18. It wouldn't have been the same without you! Are you ready to read about our Superheroes of Expo? Turn the page to see if you recognize some familiar faces. \*



# SUPERHEROES OF EXPO

**We might not have been able to fit ALL 400 OF YOU in this issue, but Expo attendees, you left an imprint on our hearts. Thanks for joining us at Expo '18!**

BY MARGARET W. CRANE AND KATHRYN JONES

Look up at the sky. Is it a bird? No. Is it a plane? No. How about a drone? Those are popular these days. No, it's you! Sure, you may not be wearing a cape or be able to shoot laser beams out of your eyes. But we see you. You are the millions of people around the world who are living with eczema. To us, you are superheroes.

We know how difficult it is to fight symptoms of this disease, but every day you come out stronger and wiser than the day before. Individually, you might worry that you're the only person who understands what it's like to have eczema. But when we join forces as a community, we have superpowers.

That's what Eczema Expo '18 was all about: connecting with others around the world who share one dry, red, itchy, irritating thing in common. Whether you were a patient, parent, sibling, spouse, friend, doctor, researcher or caregiver, you brought your own eczema journey to Chicago and left with a renewed sense of community.

Here's a handful of the folks who made Expo '18 go down in history as one of the best Eczema Expos ever. For additional Superhero profiles, visit our online magazine at [EczemaMatters.org](http://EczemaMatters.org). ►



## KELLY BARTA

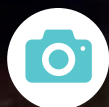
For 26 years, Atlanta-based Kelly Barta managed her condition with topical steroids. She decided to wean herself off topical steroids after a round of online research advising against their long-term use. But soon after, she was assailed by violent burning, itching and red skin. For well over a year, she was bedridden, saddled with “burning, oozing and bone-deep itch.” She lived between her bed and bathroom, and sleep was a scarce commodity.

She found her way to the International Topical Steroid Addiction Network (ITSAN), a nonprofit that raises awareness about a condition called red skin syndrome, also known as topical steroid withdrawal syndrome. She has since become president of ITSAN, allowing her to advocate for herself and others who have experienced the effects of topical steroid withdrawal.

“Not everyone reacts this way to steroid use,” she said, “but even most doctors don’t recommend using them long-term. Steroids have amazing properties, and they can really help people. What we need is a balanced view of how to use them based on solid research.”

One of Barta’s “overarching takeaways” from this year’s expo was “the sense of community and family. It was amazing to see parents with little kids who had full-body eczema. I know the stress and the emotional toll that can take.

“And I see the kids thinking, ‘How are other people going to perceive me?’ But by the end of the weekend, their whole expression had changed. Some of them trickled into the adult dance party on Saturday night and danced like crazy. It was as if they were living out their joy!” ►



Photos courtesy of  
Tori Soper Photography



## JENNIFER JENKINS AKA "THE ALLERGISTA"

You've probably heard the expression "turning lemons into lemonade." That's precisely what Jennifer Jenkins did when she found out she had eczema and severe allergies. After a year-long rollercoaster ride of medical appointments, Jenkins was diagnosed with allergic contact dermatitis and atopic eczema in 2010.

A routine patch test had led to the discovery of nearly two dozen allergies, forcing Jenkins to make significant lifestyle changes to better fight her disease. "In the beginning, I really wished I had someone who could tell me how to get around touching doorknobs, how to deal with only being able to wear cotton clothing (I love fashion) and the zillion other situations I come across," she said.

So, Jenkins did what any smart, savvy Millennial would do. She made it her business to motivate and inspire others to live happier, healthier lives with eczema. She dubbed herself "The Allergista" and launched a lifestyle brand offering tips to better cope with eczema and allergies. After gaining a loyal following, The Allergista reached "social media influencer" status and now vlogs (video blogs) about new eczema products.

Jenkins played a fundamental role at Expo '18, leading yoga and meditation classes and hosting breakout sessions at the event. "Hands down, my favorite part about the expo was the breakout sessions. I led a couple including dealing with eczema in your 20s and 30s, and one about beauty and grooming tips," she said.

"The way that people opened up was incredibly touching. Tears were shed, and while that was happening, other people showed their support in such a genuine way that if I had any doubts about humanity, they were erased right then and there. On top of the breakout sessions, the speakers were incredibly informative and the Ecz-travaganza at the end was amazing!" ►



## RENEE DANTZLER

Wife, mother and eczema advocate Renee Dantzler has been to nearly every Eczema Expo since the event started back in 2005. This year, the Dantzler family—Renee, husband Anthony (Tony for short) and 18-year-old daughter Jasmine—traveled from Clinton, Maryland, to Chicago together. All three agreed that this was the best Expo yet.

Mainly, said Dantzler, "there was more of everything: more Millennials, more people generally, more presentations, more to learn and more to enjoy." And, she added, "NEA paid more attention than ever to the things that make a big difference: a photo booth, moisturizing stations and workshops on every topic under the sun."

The Dantzlars benefited greatly from the session on sleep disruption, a major bugaboo that every eczema family has had to face at one time or another. The Dantzlars faced sleep deprivation big time when Jasmine was a little girl, especially during the period spanning age 4 to 11.

Jasmine Dantzler, a talented singer, actress and all-around effervescent young woman, hit her stride at this year's expo as well. "All these years, she was a camper at the Kids' Camp, but this time around she worked as a counselor," her mother said. "She has come a long way! My daughter has a lot to give, and NEA has helped her find ways to give it."



## DR. PETER LIO

We've all heard the stereotypes about doctors. From their impossible-to-read handwriting to the clinical, almost business-like nature of their bedside manner, we've come to love and respect society's no-nonsense lifesavers. While we can't speak for his handwriting per se, there's something about Dr. Peter Lio that sets him apart from the pack.

The Harvard Medical School grad and faculty member returned to his native Chicago in 2008 to put worried parents at ease at Lurie Children's Hospital and to serve as clinical assistant professor of dermatology and pediatrics at Northwestern University. In addition to being the founding director of the Chicago Integrative Eczema Center, he also serves on NEA's Board of Directors and Scientific Advisory Committee.

Unlike most MDs, Lio incorporates his fascination with Eastern medicine into the Western medical

field. He received formal training in acupuncture while at Harvard and openly integrates alternative and complementary medicines into his dermatology practice. His seminars and breakout sessions were the highlight of Expo '18 for many attendees.

Plus, he's just so darn likeable! Lio's friendly demeanor and patient-centric approach to health care has made him a fan favorite in the eczema community. What were some of his favorite things about Expo? "I loved visiting the Kids' and Teens' Camp and spending some time with them talking about moisturizers and watching them work on cool projects and play together," Lio said.

"I really loved the group sessions where we had deep discussions about some of the bigger questions. I got lots of input from many people, especially those who have been through a lot. I loved the positive energy that suffused the entire weekend. Everybody was there to support each other, learn and connect." ►



*Photos courtesy of  
Tori Soper Photography*



## FRAN HUNTER

Fran Hunter, a first-time expo participant, has been a registered nurse for 51 years. She started out as a helicopter nurse, helping to transport patients from smaller hospitals to larger ones equipped to deal with emergencies and traumatic injuries. Nowadays, she's a school nurse.

"I never had kids of my own, but I consider the 600 kids at my school 'my' kids," she said. "Fifty of my kids have eczema. They cry, they bleed, they have crises. That's why I asked my school to send me to Eczema Expo this year. I needed to find out more about the skin condition that makes my kids cry."

Hunter met a lot of parents in Chicago this June. She already had some idea of how busy families can get as they strive to help their children deal with their eczema, from wet wraps to moisturizing to frequent medical appointments and sleep issues. "Now I understand why parents are so caught up in their kids' struggle with eczema," Hunter said.

From her experience at Expo, Hunter gathered lots of extra ways to help her kids back in St. Louis. She loved Dr. Gil Yosipovitch's presentation, which clarified the seriousness of itch for her. "I'm hoping my school will empower me to do more for our eczema kids and their families," she said. ►



Photos courtesy of  
Tori Soper Photography







## RAELLE BROWN

Raelle Brown, another Expo first-timer, has had AD her whole life. She also developed severe seborrheic dermatitis—the type of eczema that targets the scalp—when she was in high school. “My hair fell out,” she shared. “And it has fallen out a couple of times since then, including recently. This time, though, instead of wearing a wig, I just cut it all off and let it grow back naturally.”

“I thought I knew everything there was to know about eczema, having dealt with it my whole life,” she added, “but I learned a whole lot more at Expo '18.”

The highlight for Brown? “The reassurance that I’m not the crazy one—that I’m not alone. I’ve been through it all—the effects of eczema on my emotional, neurological and physical health, and on the health and well-being of my family. I learned that all these things have been studied.”

The presentations from Dr. Richard Aron and Dr. Peter Lio, in particular, “blew my mind,” she said. “It was an out-of-body experience to hear them speak and see their slideshows, which showed exactly what I’ve been experiencing for so many years. They’ve been doing the research that will help me heal.”

“When I asked a question during one of Dr. Lio’s sessions, I started crying,” Brown added. “I’m not usually a crier, but just saying it out loud caused all kinds of emotions to come out of me, seemingly out of nowhere. And then, most of the room started crying with me!”



## LAINIE SEELINGER

“This was my first Expo but it won’t be my last,” said 25-year-old Lainie Seelinger, who came to the event from Detroit, where she works for an oral surgeon. She arrived with her mother and her fiancé, Jon—and all three had important roles to play at the conference.

“My mother went off on her own,” she said. “She was in a group for supporters and advocates, which allowed her to share what she has learned about raising a child with eczema. She did good! And Jon joined the sessions for caregivers. He shared what he knows—especially, the little things a caregiver can do that mean so much. His contributions made me feel so proud, loved and supported.”

Seelinger, who has had eczema since childhood, spoke about her favorite thing about Expo: the opportunity to “sit down and listen to the doctors talk about all the effects of eczema: physical, emotional and psychological. Dr. Lio was huge! He’s so knowledgeable! I could listen to him all day!”

In December 2017, Seelinger started on the first biologic approved for treating atopic dermatitis, and the results have been, in her words, “miraculous. I was in a major flare for about four years, starting in 2014, from head to toe. Now my skin is about 99 percent clear.”

Seelinger attended sessions for women and for people in their 20s. She was excited to be able to share her own success story with her peers. However, “I may be doing well on the surface, but I’m still the same person in my own head,” she admitted. “Old thoughts, fears and memories don’t go away just because my skin has cleared. I still need support. At Expo, I found the support I needed.” \*

# 'REGULAR JOE SCHMO' MAKES A MIRACULOUS RECOVERY

Steve Gawron of Long Island, New York, is getting used to his clear skin after battling severe atopic dermatitis for almost five decades.

BY KATHRYN JONES

**A** When NEA asked 49-year-old Stephen Gawron to share his eczema journey with hundreds of people attending Eczema Expo '18, the Long Island, New Yorker couldn't say no. And while those who know him wouldn't describe him as a shy person, "I was never one to do any public speaking," Gawron admitted.

"Did I want to be in the spotlight? No. But I did it to show other people that they aren't alone, especially the moms and dads with kids who will go through what I did with the bullying and the trial and error of allergy shots, food elimination diets, and always having to go back to the drawing board."

Audience members may recall that the man speaking on stage at Expo '18 had almost clear skin, with only 3 to 5 percent eczema left on his body. But less than two years ago, in January 2017, Gawron was hospitalized with one of the worst flare-ups of his life.

He had a staph infection so severe, "it looked like I was dipped in a vat of boiling acid." It took six weeks' worth of biweekly dermatologist visits to get Gawron's staph infection under control. At that point, he was already maxed out on immunosuppressants and oral steroids, and constantly slathering himself with topical creams and antibacterial ointments. "I was like a walking pharmaceutical sample, and nothing was working," he said.

"Believe it or not, I started researching all the hotels on Long Island to see who had an indoor salt pool. I would book a hotel room, leave work, drive to the hotel, go in the room that I rented, change my clothes and go jump in the pool so nobody could see my condition, swim around for like an hour, get out and go back up to room, slather on all my garbage and drive home at 10 p.m. every night. I can't tell you how costly and tiring it was." ►



*Photo courtesy of  
Tori Soper Photography*



## Severe Eczema Club

If there was such a thing as a “Severe Eczema Club,” Gawron would be an honorary member. He’s had atopic dermatitis (AD) since infancy with flare-ups so severe he’d have to soak his feet in order to remove his socks. And yet no matter how physically painful AD can be, nothing compares to the toll it takes on your self-esteem.

“Even my wife, Christine, when we were dating—and she was always 100 percent accepting of it—it would still be on my mind. I’d get up in the morning, look in the mirror and ask myself, ‘How can I go out today? I look like a tomato.’ It’s the perception that people are going to think you’re some freak of nature, when in reality, they probably don’t even give it a second thought. That fear stems all the way back from your childhood.”

One of his earliest memories was being led to the nurse’s office scratching and bleeding, feeling hurt, angry and embarrassed by the schoolyard bullying. “I was called every name you can think of,” Gawron said. “Scaly, alligator, cooties—that kind of garbage. Here I am at almost 50 years old and I can still hear the voices of the kids who called me names. It sticks with you for life. To think about what the kids are going through these days with the cyber bullying, I can’t even imagine it.” ►

*“DON’T LET ECZEMA DEFINE WHO YOU ARE. BE STRONGER THAN IT.”*

— Steve Gawron



## At Long Last, Relief

You know your eczema is bad when you're on a first name basis with your dermatologist. That's been the case for Gawron, who recalled an extra bad flare-up eight years ago that led him to miss a week's worth of work. He knew it was time to go back to the drawing board.

"My derm says, 'Alright, Steve, we're running out of tools in the toolbox.' He started me on a mild dosage of methotrexate, and ever so slowly, it got larger until we maxed out. I was on the stuff for a good six years. I'd be like, 'Ron, listen, I've been on this methotrexate. I want to cut back,' he said.

When Dupixent (dupilumab), the first biologic for AD, was approved by the U.S. Food and Drug Administration in March 2017, Gawron finally had a new tool in the toolbox. "I ran to my doctor and said, 'OK, buddy, let's do this!' Within 48 hours, I noticed a definite decrease in itchiness. By the end of the first month, I saw a remarkable improvement," he said. "There were days when I forgot to put on moisturizer because my skin was so clear. It's like a miracle."

That's why Gawron agreed to give his speech at Eczema Expo—to give others hope. "I just wanted to get up there as a regular



Joe Schmo and say, 'Hey folks, here's my story. I'm not going to sugar coat anything. I'll tell you how it is. This is what I went through. Here's where I am today. Don't let eczema define who you are. Be stronger than it.'

"We know many people with eczema exist, but meeting them is few and far between," Gawron added. "That's why events like Eczema Expo are so important. It's common, but it's never talked about. You never know if the person next to you has it." \*

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# DISCOVERY ZONE

The latest news, research and discoveries about eczema

BY MARGARET W. CRANE

## Can probiotics help children with AD?

For years, researchers have been looking at probiotics as a possible treatment for atopic dermatitis (AD) in children and adults, but their results have been less than convincing—until now. 2018 may go down in history as the year when the evidence started to come in—evidence showing that probiotics are effective in treating babies and small children with AD.

The authors of a study published in June found that *Lactobacillus*-containing probiotic strains reduced disease severity in infants and children less than 3 years old.

The researchers reviewed seven clinical trials comparing probiotics vs. placebo in a total of 609 infants and children under age 3. They found a significant decrease in the Scoring Atopic Dermatitis (SCORAD) index among those who received probiotics.

The SCORAD index is the most common method of measuring of AD severity. However, the SCORAD decrease was only seen in the children given *Lactobacillus*-containing strains, while other probiotic strains, such as Bifidobacterium, were shown to be of little benefit.

Additionally, the study's authors reported that infants and small children with moderate to severe AD showed a greater response to probiotic treatment than did those with milder disease.

The researchers conceded that these results, while promising, are just the beginning. Before probiotics receive approval as a preventive treatment or intervention for infantile AD, further studies will be needed to answer the following questions:

How should they be administered? What's the optimal dosing regimen? At what precise age is treatment with probiotics most effective? What is the optimal duration of treatment—one month, three months, a year or longer? And finally, should the use of probiotics be personalized, and if so, how?

The new study may have its limitations, but its findings spell a hopeful message for families who want nothing more than to see their children heal from AD, and for the physicians waiting for evidence supporting the use of probiotics in their youngest patients. \*





### Topical microbiome-based treatment for AD shows potential

In an early-phase clinical trial at the National Institutes of Health (NIH), topical treatment with a common skin bacterium called *Roseomonas mucosa* was seen to reduce AD severity in a small group of adults and children with the disease.

This approach—introducing microbes from healthy volunteers to patients with a variety of diseases and conditions—is an emerging part of personalized medicine. It's called microbiome-based research.

With the successful mapping of the human genome, scientists are now engaged in the much larger enterprise of mapping the human microbiome. The microbiome is estimated to contain the genomes of all the bacteria, viruses and other microbes that live inside and on the surface of our bodies. Each person's microbiome is unique.

Our skin is home to billions of microbes. Most of the time, they get along just fine—as long as they stay balanced. But in AD, the “bad guys” tend to take over, especially *Staphylococcus aureus*, leading to frequent staph infections in AD skin.

That's where applied microbiome research comes in. In their case study, the NIH team aimed to restore the microbial balance of AD skin by transplanting a “good guy” into the mix—and the results were encouraging.

The researchers enrolled 10 adults and five children in the study and treated them with topical *R. mucosa* twice a week for six weeks. They instructed the participants to apply the

mixture to the crook of their elbow and another body surface of their choosing. Every two to six weeks, they'd need to apply a slightly stronger mixture. At the six-week mark, they'd stop using the treatment and begin a four-week “washout” phase.

At 10 weeks, the adults showed a reduction in disease severity of 59.8 percent, while the pediatric patients experienced an even greater decrease of 70.3 percent. The enrollees' itch reduction was even more impressive—at 78.5 percent and 78.8 percent, respectively.

Four of the adult patients didn't respond to the treatment, owing possibly to their complex medical histories. However, the adults who showed a favorable response have continued to report improvement in their AD symptoms. The five children and teens enrolled in the study are still being evaluated as of this writing.

The authors of the study reported that, overall, the treatment reduced the patients' rash and itch. Plus, it reduced the amount of topical steroids they felt they needed to keep their AD under control.

The NIH team have observed no problems or complications since the study's conclusion. In light of the treatment's positive safety profile and its promising impact on AD severity in this small group of patients, the researchers intend to proceed with larger studies of topical *R. mucosa*-based therapy. Their hope is to lay the foundation for placebo-controlled trials that will be necessary to validate this promising approach to AD treatment. \*



## Mounting evidence sheds light on the burden of AD

In a report, titled “The Burden of Atopic Dermatitis,” a group of researchers reviewed the literature on the impact of AD from multiple perspectives. A summary of the report was published in the *Journal of Investigative Dermatology* in January 2017.

The researchers emerged with a clearer-than-ever picture of the burden of the disease on patients’ quality of life, along with its social, economic, academic and occupational repercussions.

In the United States, the financial impact of the disease is conservatively estimated at \$5.3 billion per year as of 2015, two years before the biologic Dupixent (dupilumab) received FDA approval. Health economists say that the annual costs of AD have likely gone up significantly since then.

Hospital costs associated with AD have continued to climb as well. The cost of emergency room visits nearly doubled between 2006 and 2012. Researchers speculate that rising ER costs are being driven by health care disparities, including inadequate or no insurance, low income and a lack of access to outpatient care during the summer months and on weekends.

Then, there are the indirect costs of AD. These mostly have to do with lost productivity. Absenteeism—missed days at work—and presenteeism—reduced productivity at work—are costly to patients and families in the form of lost income and to society as lost taxes and contributions to gross domestic product (GDP).

Beyond the financial burden of AD, experts have long since developed ways to measure the physical and psychological burden of AD through testing and clinical evaluation. But, as it turns out, the patients themselves have a great deal to say on the subject. A patient survey published in the July 2018 issue of *JAMA Dermatology* further clarified and quantified the burden of disease as patients experience it.

The researchers administered a questionnaire to 1,519 adult patients with AD being treated at clinical practices associated with six academic medical centers. They found that, on average, patients with moderate to severe disease experienced itchy skin 5.7 days a week, with 22.8 percent reporting itch lasting more than half a day. By contrast, patients with mild disease had itchy skin for 2.7 days a week, with only 2.9 percent of them experiencing itch lasting more than a half day.

Poor disease control played a major role in the disease burden reported by the patients with moderate to severe AD. That burden included severe pain and itch, disrupted sleep, anxiety, depression and impaired quality of life.

However, with more and more patients doing well on Dupixent—and with many more AD drugs in the pipeline—the burden of the disease should ease significantly over time. \*

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

# UNDERSTANDING INFLAMMATION'S ROLE IN ATOPIC DERMATITIS

TOP DERMATOLOGISTS UNRAVEL COMPLEXITIES OF THE INFLAMMATORY RESPONSE FOR PEOPLE WITH ECZEMA, IN SICKNESS AND IN HEALTH.

BY MARGARET W. CRANE

**W**hen you're in the middle of an eczema flare, do you ever feel like your skin is on fire? The ancient Romans would sympathize. After all, they coined the word *inflammare*—the Latin root of the English word inflammation—meaning “to set on fire.”

In the first century A.D., a Roman physician named Cornelius Celsus documented the four signs of inflammation: redness, swelling, heat and pain. These are still considered the hallmarks of inflammation today, even as advances in molecular biology are deepening our understanding of a process that is as common as it is biologically diverse.

But inflammation certainly isn't all bad. More often than not, it's a normal and even healthy phenomenon. That's what

makes it so tricky for doctors to deal with when it turns chronic and destructive.

On the one hand, said Dr. Eric Simpson (pictured below), professor of dermatology at Oregon Health Sciences University (OHSU), “inflammation is the immune system's normal response to infection or injury. It's the body's way of protecting us from disease-causing viruses, bacteria, fungi and other potentially harmful invaders, along with cuts, sprains and injuries of all kinds.

“However,” he continued, “there are times when the body mounts an inflammatory response even when no invader is present.”

For a complex tangle of reasons, the immune system can get stuck in the “on” position. That's exactly what happens in atopic dermatitis (AD), allergies, asthma and other inflammatory conditions.

Chronic inflammation can lead to destructive changes in the skin and in other organs and tissues. Its precise form and its severity depend on the molecular pathways along which the inflammatory response begins, travels and intensifies.

## Digging deeper into skin inflammation

It's easier to understand the “what” of inflammation—its signs and symptoms—than the “why” and “how,” said Simpson, who served as co-chair of the National Eczema Association's 2017 Scientific Advisory Committee and is a leading researcher in the field of chronic skin disease prevention and treatment.

“At a molecular level, inflammation is extremely complex,” added Dr. Lawrence Eichenfield, chief of pediatric and adolescent dermatology at Rady Children's Hospital in San Diego. “For example, the immune cells implicated in psoriasis are different from those ▶







As for the “how” of AD, Eichenfield stressed the interplay of genetic and environmental factors.

“Some people are born with a genetic tendency to have compromised skin function,” he said. “They’re missing a little protein that would normally allow their skin to hold on to water. That tiny missing molecule leaves their skin dry and vulnerable to allergy-like reactions.”

Underlying, genetically determined inflammation shows up in the skin as sensitization—hyper-reactivity to environmental irritants, he explained. Skin sensitization can worsen with repeated exposure to the substance, including certain metals, foods, fabrics, perfumes or chemical additives in personal care or household products.

“We may not have a cure for AD just yet,” said Eichenfield, “but patients can reasonably aim to manage and minimize the impact of the disease. Here, tackling inflammation is key. Treatments range in strength from over-the-counter topicals all the way to biologic agents that target the cytokines at play in moderate to severe AD.”

seen in AD. These cells secrete different inflammatory molecules, called cytokines, that are specific to the disease in question.

“That’s why biologic drugs that block TNF-alpha—a cytokine associated with psoriasis—don’t work for patients with AD,” he continued. By contrast, “Dupilumab (Dupixent) is effective precisely because it targets IL-4 and IL-13, two cytokines known to drive the inflammatory response in AD.”

Then, there’s the outside-inside question: Is inflammation in the skin the dominant issue in AD, or is systemic inflammation the main offender? Eichenfield said the answer is that the two are intricately interconnected.

“In moderate to severe AD, you can find inflammatory cells in both inflamed and unaffected skin, as well as in the blood,” he explained. In other words, it’s impossible to answer the outside-inside question with certainty.

## The many faces of inflammation and eczema

Jill Harris, a 28-year-old from Greenville, North Carolina, said she can tell when her eczema is about to flare when her skin starts to “tingle.”

She associates that sensation with inflammation, and the minute she starts to feel it, she applies a small amount of topical steroid to the affected area. Sometimes, that’s enough to calm her skin, at least for a while.

Harris had eczema as a child, but she outgrew it—or so she thought, until the birth of her daughter, Meredith, in October 2015. Shortly after giving birth, her eczema erupted so violently that she could barely function.

She spent the next two years under the care of a trusted dermatologist, and her eczema has been under control since the start of 2018. ►



## The link between inflammation and emotional health

Dr. Charles Raison, professor of psychiatry at the University of Wisconsin-Madison School of Medicine and Public Health, points to sufficient sleep as essential to good health. If you have a chronic skin disease, he said, your sleep may be interrupted by pain and itch but also by anxiety—yet another example of the complex nature of human biology.

“When people are stressed, they experience higher levels of inflammation,” Raison explained. “Conversely, people with inflammatory conditions like AD show higher rates of depression, anxiety and other mental health disorders.

“Just having AD alone can increase a patient’s risk for depression,” he continued. “But our biological processes are round robins. They flow in both directions. Inflamed skin ‘talks’ to the brain, fostering anxiety and depression.

“On the other hand, many people with AD report feelings of shame and self-consciousness, and these emotions can fuel anxiety, depression and other mental health disorders,” he explained. “Once a mental health disorder sets in, it can activate inflammatory pathways”—and around and around we go, from inflammation to emotion and back again.

### Putting your life together piece by piece

People with eczema like Harris have harnessed the power of mindfulness to interrupt the stress-inflammation circuit. Her experience, Raison noted, is consistent with recent evidence supporting the ability of mindfulness and other meditation practices to “quell inflammatory responses in the body.”

Meditation is an excellent, low-impact anti-depressant, he said, but some patients on biologics also find that when their skin clears, their mood improves.

Does their emotional state improve due to the anti-inflammatory effects of the medication? Or do they become less depressed as they lose the shame and stigma associated with inflamed skin? Probably both, in Raison’s view.

The next stop on the lifestyle train is diet. Doctors across every specialty encourage their patients to move away from processed foods toward sound nutrition.

“What you eat can change the level of inflammation in your body,” Dr. Simpson said. “Many of my patients do well on the Mediterranean diet, but so far, there isn’t enough ►

“I started with a low dose of a topical steroid cream, and my doctor gradually upped the dose until it had the desired effect,” she said. “I’d take antihistamines at night and during the day. I used plenty of coconut oil and dermatologist-tested skincare products. I was basically dealing with my eczema around the clock.”

Harris also underwent allergy testing to identify her potential triggers. Most of these turned out to be fairly common among people with eczema and allergies, but one was surprising. She’s allergic to sulfites—a substance present in red wine and tofu.

“On a special date night with my husband, Lee, last year, I had just one glass of wine, and my eyes got inflamed and swelled up. I don’t mind giving up tofu, but red wine!” Harris lamented.

The young mother is also a full-time employee at East Carolina University and the owner-manager of an all-natural cleaning service. With her 24/7 schedule, Harris says she can easily get stressed out.

But “ever since I started taking yoga and Pilates, I have been coping better and making better use of my downtime.” She’s learning to be more mindful during the day—and that has made all the difference at night.



evidence to say just how strongly anti-inflammatory it is.”

The good news is that Mediterranean, Paleo, vegetarian, vegan and low-carbohydrate diets all have one thing in common: they lead to weight loss.

Reaching and maintaining a healthy weight is vital, Raison said, and not only for the sake of cardiovascular health and overall fitness.

“Belly fat is the largest source of inflammation in the body. If you’re overweight and have AD, you’re adding fuel to the fire.” Raison’s advice? Eat more healthfully. Eat less. And, of course, get regular exercise.

To recap, Raison proposes a six-point lifestyle program:

- Get enough sleep.
- Adopt a consistent meditation practice.
- Eat well but less.
- Stay active.
- Connect regularly and often with friends and family.

The importance of this last item—social support—can’t be overstated, he said. “Humans are astoundingly social animals. As a species, we need to have at least one person in our lives who really knows us and is on our side. Our social connections are a biological necessity.”

### Leading-edge research for atopic dermatitis

It’s an exciting time in AD research, Eichenfield said. “Two advanced treatments for AD—Dupixent and Eucrisa—were approved in 2017, and several other biologic drugs are in clinical trials right now.

“Researchers are also studying the influence of microbial factors in AD—the viruses, fungi and bacteria present in our bodies and our environment,” he added. “Probiotics also are under investigation as a treatment for babies and very young children with inflammatory skin conditions.”

Even with the range of treatments that are available right now, you may not need to work on managing your eczema 24/7 the way Harris did. But if you decide to try a mosaic of approaches to self-care, you may get a lot busier! In the meantime, no need to get stressed out. It’s all in how you put it together. \*



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## Eczhausted?

# The impact of eczema on sleep

*We all know a good night's sleep is key to our health and well-being. What happens when itching keeps us or our children up all night? We asked sleep expert Dr. Lisa Meltzer to discuss the impact eczema has on our sleep cycles and what we can do to get a better night's rest. Please note that portions of this Q&A have been edited for clarity and brevity. Watch the full webinar at [nationaleczema.org/resources/webinar-wednesday-archives/](http://nationaleczema.org/resources/webinar-wednesday-archives/)*

### What are some of your tips for improving sleep when you are experiencing an eczema flare?

It's all about finding what works best for you. For example, we use a lot of wet wraps at the institution where I work. Sometimes you have to wake up and do the wet wrap in the middle of the night to cool the skin and calm the child. Cooling is important because we see this increase in external body temperature that can lead to an increase in itching overnight. Doing whatever it is you're supposed to do during the day to treat your eczema is important, otherwise, it will catch up to you at night.

### If I've had eczema for my whole life and no longer have symptoms, will I still have issues sleeping?

Possibly. If you've had fragmented sleep your whole life, you may develop habits or behaviors that perpetuate poor sleep. When you lay down in bed, your body should think, "Ah, it's time for sleeping." But if you've had a long history of insomnia or sleeping, you get in bed and your body thinks, "Oh my gosh, am I going to get any sleep tonight?" That hyperarousal makes it very difficult for sleeping. I would figure out how much sleep you're actually getting and then consolidate how much time you spend in bed. Spending two or three hours in bed watching TV or reading a book is not the best idea when you have trouble sleeping because then your bed becomes a wonderful place for hanging out and not such a great place for sleeping. You need to retrain your body so that once it gets into bed, it automatically feels sleepy.

### Does a lack of sleep cause depression in patients with atopic dermatitis?

Yes. A lack of sleep causes depression, period. It impacts mood so quickly and so heavily. Lab-based studies where you keep people awake, after those 16 hours of wakefulness that most of us need to finally go to sleep, immediately one of the first things that goes away is your mood. You don't necessarily feel it quite so quickly,

but within three hours—so 19 hours of wakefulness—you can see mood rapidly deteriorating. Depression, in particular, that feeling of sadness, lack of control, anxiety—all of these things are exacerbated by lack of sleep. If you have any predisposition for these illnesses, lack of sleep is only going to make things worse.

### How can long-term lack of sleep impact the health of mothers of children with eczema?

It impacts every aspect of health. We see higher rates of depression and anxiety in mothers of children with chronic illnesses. Immune functioning is very helpful at night, and lack of sleep can make it more difficult for the body to fight off infections. I hate saying these things because I know if you're not sleeping, it's not by choice. That's why it's so important to manage your own eczema or your child's eczema. Getting as much sleep as possible is the goal, but you should also recognize that certain things are just beyond your control.

### How can I get involved in overnight sleep studies? Is that something a patient can ask for?

Overnight sleep studies are primarily done within the lab to screen for sleep apnea. If you have regular snoring, pauses in breathing, choking, gasping, etc., that is sleep apnea, and all children and adults should be screened for it. Frequent restlessness in moving, twitching or kicking during sleep should also be screened with an overnight sleep study.

### What about actigraphy—the small wristwatch-like device that can be worn on the wrist to monitor human rest and activity cycles? How can I get access to one?

Actigraphy is harder to come by. A lot of sleep centers do it, but it's hard to find sleep centers unless you live in a large city with a major university that has a sleep center built in. You can try to ►



find consumer wearables, but I will tell you that they are really inaccurate. If you turn over in your sleep, for instance, they'll assume you're awake when you're really not. So don't rely too heavily on those, and don't get too freaked out by the data that comes from them.

### Do you ever recommend using sleep medications for children or adults?

It's important to note that I'm a psychologist, so I don't prescribe, and that there is no FDA-approved sleep medication for kids. Everything used to treat sleep in kids is off-label. But clonidine, which is an anti-hypertension medication, when used in teeny-tiny doses, can help kids sleep. We do recommend short-term use only to get them through a difficult flare. We don't want them on it permanently. In adults, it's a different ballgame. There are a lot of medications that can help with sleep. And when you are able to sleep, it gives your skin a chance to heal, and it can help with mood and other effects. It's definitely something to be discussed with your health care provider to see whether it is the right choice for you. But yes, there's a little bit of evidence that 1 to 3 milligrams of melatonin taken about 30 minutes before bed might be useful.

### You mentioned melatonin might be helpful. What about magnesium?

There's not a ton of research on magnesium's effect on sleep. I know magnesium helps a whole bunch of other things, but the research literature associating magnesium and sleep is not very strong. The same thing goes for vitamin D, which is usually the next thing people ask me about. Melatonin seems to be the only one we truly know there's a strong association with.

### There's a lot of discussion around the use of antihistamines in the eczema population for their sedative effect. What are your thoughts?

The problem with antihistamines is that they don't work long-term. After three or four nights, you build up a tolerance to them. If it's something you believe works well for you, you might save it for the nights that you really need it. You have to be cautious using antihistamines for kids. Benadryl can sometimes have a paradoxical effect in young children and could make them quite hyper. In other words, don't give your child a Benadryl for the first time before they get on a plane. It may not be pretty.

### Is it true that people with eczema might have lower melatonin levels in their system?

There was a small study done in Germany that was conducted on 20 adults about 25 years ago. It found that adults with eczema actually had lower melatonin levels than adults without eczema. It was hypothesized that perhaps this was the reason that there is so much dysfunction with sleep. If your melatonin doesn't ever peak, then that's going to make it hard for your body to prepare for sleep. The mechanism behind all of that is unknown, and again, it was a very small study. There's a lot more research that is needed.

### Have there been studies done to identify low melatonin levels in children?

Melatonin is so heavily regulated by light and dark. The times where we see melatonin dysfunction in adolescents is when the timing of melatonin is delayed by about one to two hours, which is why they can't fall asleep and why they have a hard time waking up in the morning for early school start times. Another population where we've seen some melatonin dysfunction are children with autism where, again, we don't see that peak and we know they have trouble falling asleep. It's unclear why this happens, and again, I wouldn't want to base too much of it until additional research is done. \*



### JOIN US FOR WEBINAR WEDNESDAYS!

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. View archives of past webinars and register for upcoming events at [nationaleczema.org/nea-webcasts](http://nationaleczema.org/nea-webcasts).



*Dr. Lisa Meltzer is associate professor of pediatrics and director of the Pediatric Behavioral Sleep Clinic at National Jewish Health in Denver. She is board certified in behavior sleep medicine by the American Board of Sleep Medicine.*

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# WHAT'S HAPPENING AT THE NATIONAL ECZEMA ASSOCIATION

BY KAREY GAUTHIER, MS

## Finding the Beauty in Imperfection

**T**he Japanese tradition of kintsugi (or kintsukuroi) is the practice of repairing broken pottery with lacquer mixed with powdered gold, silver or platinum. It treats damage and repair as a part of the history of the item, something that adds to the object's beauty rather than something to disguise.

Founded in the Japanese aesthetic of wabi-sabi, which is a worldview centered on the acceptance of transience and imperfection, kintsugi demonstrates an appreciation for asymmetry, roughness and simplicity—much like the asymmetry, cracking and roughness that comes with eczema.

In both kintsugi and wabi-sabi, there is a belief that from (perceived) imperfection—cracks, pain, roughness—comes strength and beauty. It is in this belief that we ask our community to join NEA in our commitment to #UnhideEczema during Eczema Awareness Month in October.

We want to show the world what eczema really looks like. To us, it looks like the woman wearing a business suit to work, whose eczema can't be seen because it is only on her arms and legs, but it still kept her from sleeping the night before.

It looks like the 13-year-old boy who chooses video games over sports and books over bike riding. It's the same boy who never fails to impress you with his ability to articulate his experiences because he is wise beyond his years.

It looks like everyone's favorite uncle, whose facial eczema adds years to his appearance, even though he is the youngest at heart, who is always quick with a smile or joke and ready to play. It's the same man who chose not to have children of his own because he didn't want them to inherit his eczema.

It looks like the little girl who is bright red from head to toe and can't stop scratching her unbearably itchy skin. It's the same girl who receives fearful glances from strangers because they assume whatever she has is contagious, when the only contagious thing about her is her joy at riding the hotel elevator alone.

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.

Unhide beauty. Unhide strength. Unhide power. Unhide brilliance. Unhide joy. Unhide peace. #UnhideEczema ►





## Eczema Warriors #UnhideEczema in Times Square

In an exciting push for global awareness, the National Eczema Association was thrilled to launch a billboard in Times Square, New York City in late May. The billboard features several Eczema Warriors through its 10-second cycle along with simple facts to bring eczema awareness to the public eye.

*Did you know...*

It begins.

*Did you know, over 31 million Americans live with eczema.*

*Did you know, eczema is NOT contagious.*

*Empower yourself. #UnhideEczema*

*Text Cure to 501501 to donate \$10 to help find a cure.*

The billboard ran throughout the summer and set the foundation for an empowering Eczema Awareness Month in October.

With a call to our powerful community for photos of Eczema Warriors that wanted to represent NEA and the eczema community in Times Square, we were overwhelmed with hundreds of photos. We wish we could have used every single one to truly show the many faces of eczema. Since we couldn't, we created a slideshow of the courageous warriors who shared themselves with us.

Enjoy both videos at <https://nationaleczema.org/times-square/> and join us by tagging @nationaleczema on social media to #UnhideEczema. ►





## New Eczema Product Directory is Live

Have you ever needed a new product for your eczema but simply didn't know where to begin? We know the feeling.

As a service to our community, and to encourage/recognize product innovations that provide benefits and improve the quality of life for people with eczema and sensitive skin, in 2008, the National Eczema Association established the NEA Seal of Acceptance™ program.

The NEA Seal of Acceptance™ helps individuals recognize products that are suitable for care of eczema or sensitive-skin by including a seal on its packaging that's easily recognizable. Many people already have some awareness of the importance of avoiding certain ingredients, contents and formulations when they are purchasing personal care products, household products, fabrics and devices.

Products eligible for the NEA Seal of Acceptance™ are those that have been created or intended for use by people with eczema or severe sensitive skin conditions and that have

satisfied the NEA Seal of Acceptance™ criteria.

The NEA Seal of Acceptance™ criteria includes a list of ingredients and contents that should be avoided because they contain known irritants. Depending on the product, the NEA Seal of Acceptance™ Review Panel considers testing data on sensitivity, safety and toxicity as well as the ingredients, content and formulation data.

With more than 200 products now bearing the Seal of Acceptance™, the directory offers many options from moisturizers and sunscreens to shampoos and laundry detergents. New products are being added regularly.

The redesign of the product directory creates a mobile friendly, searchable database. You can limit your search to a particular category such as lotion, or a particular brand, or even by excluding ingredients that you are sensitive to.

Check it out at **[EczemaProducts.org](http://EczemaProducts.org)**!



*Acceptance of a specific product does not represent an endorsement of that product. Acceptance of a product means that the product has been evaluated to determine that it does not contain ingredients or contents that are known to be unsuitable for use by persons with eczema or sensitive skin conditions. NEA makes no representation or warranty regarding any of the accepted products; including without limitation any implied warranties of merchantability or fitness for any particular purpose.*

# WE ARE FAMILY

*Eczema Expo '18 reminded me of a fun family reunion with lots of food, laughter, dancing and breakout sessions...?? OK, maybe not that part.*

BY ASHLEY LORA

Ever been to a family reunion where you didn't know majority of the people there, but you knew everyone was related somehow? That's what attending Eczema Expo '18 felt like!

It was like reuniting with long-lost cousins, aunties and uncles, and still feeling connected despite not knowing much about them or their journey. We each had one major thing in common: eczema.

Whether some were patients, parents of patients, caregivers, dermatologists, or researchers—we were there because our lives have, in some way, been touched by eczema. We also shared the hunger for more knowledge about eczema—for instance, how it impacts those around us, the different ways of managing it, and new medical advancements and solutions.

Expo '18 wasn't just any ordinary family reunion. Let me tell you why...

## THE TEAM WAS BEYOND NURTURING

The NEA team created value before Expo '18 even began. They were nurturing, thoughtful and in constant communication with me to ensure I understood all details of the event and what to expect. They also supported me financially with The Carolyn and Tom Reese Scholarship Fund to cover some of my travel expenses.

I was completely taken aback by the amount of thought and care NEA and its sponsors put into ensuring that participants were comfortable and had all the essentials needed to get through the weekend flare- and stress-free.

For example, upon checking into the Westin Chicago River North, myself and the other attendees received a "Welcome Bag" full of goodies. Mine contained products such as Honest shampoo and body wash, Dove's Derma Series Eczema relief body lotion, Zego's vegan chocolate bars and more. It was as if they'd been reading my mind and knew just what I needed!

## IT WAS KID FRIENDLY

NEA created an environment similar to that of the movie "Big Momma's House." They hosted the family under one roof and had staff caring for the young ones, while the adults went on to another area and learned about everything they would gain from the expo.

The Kids' & Teens' Camp was filled with activities to build connection, relationships, self-esteem and empowerment. I had the honor of doing a "Visualize Your Super Life" vision board workshop with the kids and teens.

This was an incredibly powerful experience for me because growing up with eczema, I thought I was the only kid who had it and never felt like others could relate to me. It was endearing to witness kids of all ages come together, have fun and forget about their eczema momentarily.

## IT WAS EDUCATIONAL AND INFORMATIVE

Did you know that 83 percent of children with eczema have sleeping issues? Were you aware of how Cognitive Behavioral Therapy (CBT) and reframing your thoughts can support you or a loved one in managing your eczema? Did you know that cannabis is being researched as a potential treatment for atopic dermatitis? Me neither!

I was fascinated by the amount of research being done behind the scenes. All of the topics we discussed at the Expo were filled with juicy information backed up by scientific research. Let's put it this way: no Google search could have amounted to all the knowledge we were exposed to at Expo '18.

Additionally, NEA had some of the best doctors and researchers in our industry attend this event. From Dr. Richard Aron to Dr. Peter Lio to Dr. Lisa Meltzer and more, these doctors are game changers and have contributed significantly to the eczema community. ►





## IT WAS EMPOWERING

My favorite part of Expo were the breakout sessions. They were designated times that gave small groups and moderators a chance to intimately connect with the other attendees, participants and professionals. It was a great opportunity to learn from different Eczema Warriors and caregivers, share our experiences and learn from one another.

With each passing breakout session, I was more empowered and courageous to share my story. In doing so, I realized how similar all of our stories were and our undeniable resilience to overcome eczema together.

## IT WAS FUN

OK, OK, OK! I must admit that my other favorite part was NEA's Ecz-travaganza cocktail party. It was a pivotal moment for me because it was the first time I got to express myself authentically without the topic of eczema being the center of attention.

It also gave me a glimpse of what other people's lives may look like outside of them suffering from eczema—plenty of dancing, laughing and simply being happy. I secretly wondered if this is

how expressive and liberating they would feel if eczema wasn't a factor in their life.

Regardless, it was beautiful and euphoric! NEA President and CEO Julie Block and her entire team even joined in dancing with us. It felt like a true family reunion, and everyone knows it's not a REAL family reunion if there's no one getting down on the dance floor!

## IT WAS HISTORICAL

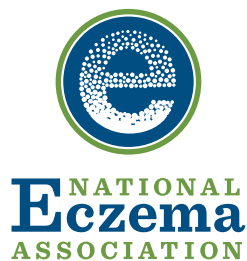
Until this Expo, it was unheard of to gather more than 400 people in one room who were directly or indirectly affected by eczema. Well, we did it; we made history together!

Leaving Expo '18, I felt a greater sense of purpose than what I'd first arrived with. And I'm more confident than ever that we are closing the gap between eczema and a cure. I'm ready to make history again at Expo '19. Are you? \*

*Ashley Ann Lora is an Eczema Warrior and founder of VisionHery, a conscious movement dedicated to empowering others to take action towards living a fulfilling life, utilizing vision boards to heal one's mind, body and spirit. Follow her on social media @visionhery.*







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# October is Eczema Awareness Month



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