

# eczema matters

RESEARCH, SUPPORT AND EDUCATION FOR THOSE AFFECTED BY ECZEMA | WINTER 2020



**NATIONAL**  
**Eczema**  
ASSOCIATION

*SKIN OF COLOR* p.14

*GET THE FACTS* p.23

*ADVOCACY* p.28

# Natralia Happy Little Bodies Eczema Care Regimen for Kids

Born in Australia, and now available worldwide, Natralia grew from a father's desire to help his young son, who faced the day-to-day challenges of eczema. Understanding the side-effects of long-term hydrocortisone use and knowing that eczema is a chronic condition that often results in extensive rashes, he was uncomfortable having his young son use steroid-based creams on a long-term basis. He knew there had to be a better option. He worked alongside experienced pharmacists to develop **Natralia Eczema & Psoriasis Cream**, free from petro-chemicals, parabens and hydro-cortisone.



Since that time, Natralia has grown to include a variety of skin care solutions, from eczema and psoriasis care, to dry skin and restorative treatments. As Natralia has grown, we have maintained our commitment to developing products that are safe and highly effective.

That is our promise.

Natralia offers eczema care products for both adults and children and we understand that eczema requires more than just a rash cream; it requires a regimen of care. Both our adult line of eczema products and our children's line include:

- A hydrocortisone-free, **flare control cream** to help relieve rash, irritation, itching and redness. Formulated with a unique blend of botanicals and essential oils, the adult product features licorice root, known for its effective anti-inflammatory properties and the children's flare cream contains colloidal oatmeal, known for its ability to gently soothe itchy skin.
- A soap and sulfate free **body wash and shampoo** to help prevent moisture loss while bathing.
- A **daily moisturizer**, containing colloidal oatmeal, clinically proven to restore moisture and hydrate the skin for up to 24 hours.

Natralia's **Happy Little Bodies** products contain colloidal oatmeal to help soothe itchy, eczema rashes and restore moisture.

The line is pH balanced for children's skin.

The Natralia brand is the result of in-depth, focused product development. Each product that carries the Natralia name has been specifically developed to deliver superior efficacy through an innovative and exhaustive research process.

Lacorium Health, the owners of the Natralia brand, are renowned for their innovative approach and global knowledge and have more than 20 years of experience.

For more information about Natralia, visit [www.natralia.com](http://www.natralia.com).



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### 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.



Hello, and Happy New Year! 2020 promises to be a transformative year for the eczema community. I've called it the Golden Era of Eczema, as we expect a surge in cutting-edge treatments making their way through the development pipeline toward FDA approval in the months and years to come.

While scientists work diligently to bring us safe and effective treatment options, NEA is working at the state and federal levels to improve access to treatments and care — bringing us closer to the day when eczema families will no longer have to contend with the mental, physical and financial burdens that impact their quality of life.

We can't do it without your help. One way to get involved is to share your experience — whether as an adult with eczema or parent of a child with eczema — with lawmakers. These personal stories go a long way in ensuring the passing of legislation that can improve millions of lives. Talking

to your elected officials about the realities of eczema can be rewarding on many levels. You can turn your eczema pain and frustration into action, as you'll learn from eczema warriors Cara Ellis and Amber Jewett on page 28.

I can tell you firsthand that your thoughts, feelings and experiences are important, and with NEA as your bullhorn, your voices are heard. We're constantly seeking input from our community members about the issues that matter to you and highlighting the real eczema to researchers, care providers and policymakers. Your feedback also helps us identify missing gaps in information and resources you need to enjoy happier, healthier lives.

Together, we've learned about how eczema can sometimes appear, and even behave, differently across the skin tone spectrum, leading to diagnostic challenges and a greater burden of disease for people of color. Our cover story on page 14 highlights the personal experiences of eczema patients of color and draws on the expertise of dermatologists who specialize in treating the disease across a broad range of ethnicities.

You wanted the facts on wet wraps? We've got it on page 23. You wished to learn more about alternative treatments and complementary therapies? Your wish is our command! Turn to page 9 to read about Traditional Chinese Medicine and how it's been used to treat eczema symptoms for thousands of years.

A new year means new possibilities and new opportunities to bring the community together for positive change. Here's to a magical 2020! And speaking of magical, it's never too early to plan for Eczema Expo '20. We look forward to seeing you June 25-28, 2020, in Orlando, Florida!

Yours,

Julie Block  
President and CEO

## Theraplex AIM Anti-Itch Moisturizing Cream soothes and protects dry, itchy, and damaged skin

Theraplex is proud to introduce its newest product, **Theraplex AIM Anti-Itch Moisturizing Cream**, which was developed in conjunction with board-certified dermatologist **Dr. Peter Lio**. Theraplex AIM joins the Theraplex family of products, which have been recommended by dermatologists for over 25 years.

AIM combines the unique moisturizing system of Theraplex with targeted, researched ingredients that soothe and protect dry, itchy, damaged skin to provide relief of itchy rashes associated with the flare-ups of eczema. AIM delivers a three-prong approach of enhanced moisturization, decreased inflammation, and balanced skin flora.

AIM uses the signature Theraplex moisturizer base which contains a special fractionated petrolatum, eliminating 80% of the greasiness associated with petrolatum, while still maintaining its superior moisturizing and skin protectant properties. Cyclomethicone serves as a unique delivery system to protect and support the skin's natural barrier. This virtually greaseless, durable micro-protective barrier provides hours of deep moisturization.

*A unique delivery system  
to protect and support  
the skin's natural barrier*



Hydrocortisone, colloidal oatmeal, and ferulic acid were added to the formula to combat the scratching and subsequent inflammation associated with eczema. Hydrocortisone 1% is the strongest anti-itch ingredient available without a prescription. Colloidal oatmeal offers a wide range of dermatological benefits in addition to naturally moisturizing and soothing skin. Finally, natural coconut oil offers superior moisturizing properties that improve skin's barrier protection and along with the antioxidant ferulic acid create a hostile environment for bacteria and improve the skin flora.

These carefully selected ingredients based in the latest research in atopic dermatitis combine to create a highly effective product that remains hypoallergenic and free from fragrance, parabens, preservatives, gluten, and lanolin. Targeting dry skin, itching, and compromised skin barrier function in a single product makes AIM a novel approach to eczema (atopic dermatitis) treatment and the perfect addition to the Theraplex family of moisturizers as an "all-in-one" product.

Theraplex AIM is available at [Theraplex.com](http://Theraplex.com), [Pharmapacks.com](http://Pharmapacks.com), Amazon (from Pharmapacks) and from dispensing physicians.



theraplex®

## What do you do when your eczema flares in public?



*“Grin and bear it. I often feel the need to mention it to those around me so they understand why I may seem distracted. I hate it when people ask, ‘What happened to your face?’ I’d rather just help educate everyone before that question comes up.” ~ Laura L.*

*“Generally, if eczema flares in public, I drink some water as a cooling technique and semidistract, or I excuse myself from the gathering to scratch in the bathroom.” ~ Rebecca V.*

*“Pop antihistamines and try not to scratch, then go home to smother myself in ointment as soon as possible. My friends understand.” ~ Elizabeth S.*

*“Just sit and be miserable like I am now.” ~ Sharie S.*

*“I can usually tell by how it feels if I need to go home and take it easy, or if I can grin and bear it. I always have Aquaphor and Benadryl on me everywhere I go.” ~ Elizabeth K.*

*“I just sit there and let my face weep, and if anyone points it out, I start crying. I mean, there is not much I can do about it.” ~ Gabriella A.*

*“I try really hard not to itch it. It kind of helps that it’s on my chest and ankle, which are both awkward places to itch in public, lol.” ~ Charlie Anna H.*

*“I’d itch! Sometimes I bring cotton gloves (it’s on my hands) and wear them. I know it’s awkward.” ~ Alem M.*

*“Eh, I just scratch or rub. I don’t hide it anymore. If people don’t like it, they can look the other way or make themselves out to be a jerk for drawing attention to someone who is obviously in pain.” ~ Emily B.*



*“Wear flip flops so that rubbing feet and ankles together is easier and more effective. For hands, sticking them in pockets and rubbing them on the rough inside and/or excusing oneself for a full-on scratch fest outside.” ~ allergykid2006*

*“When my eczema flares in public, I stay quiet and as calm as possible — otherwise I know it will get worse.” ~ iharrydo*

*“Having a bad flare of dyshidrotic eczema on both hands at the moment. When I see people staring at my hands, I try to let them know that it’s eczema and I’m not contagious. Sometimes I don’t even make it that far because some people walk away in order to avoid me.” ~ anabrathwaite*

*“How about when people want to shake your hand, and you’re like ‘Nooo!’?” ~ aj\_is\_awesome*

*“I keep hyaluronic acid with me. If my face itches or burns, I find a bathroom to rinse my face off really, really well ... then use the acid.” ~ missxiuni*

*“Applying a cold flannel or napkin to the area to limit itchiness and scratching!” ~ amberwhiteford.physiotherapist*

### CONNECT WITH US ONLINE!



@nationaleczema



## Leading medical experts answer your most pressing questions about eczema

### Eyelid Eczema

#### Q: Which treatments are safe for eyelid eczema?

When we have eczema around the eye or on the eyelid, it's somewhat difficult to treat because we have special considerations. The skin around the eye is thinner and more delicate and some treatments could actually cause issues with the eye itself if they are too strong or overused.

This said, the principles are generally the same. We want to use a topical corticosteroid to cool things down briefly, and then switch to a noncorticosteroid-based cream as soon as we can. We don't want to use super strong topical steroids in the area around the eye ever, so we'll start with either a mild or moderate steroid. Once things are better, we can stop the steroid. If the case is mild enough, we might be able to avoid topical steroids altogether and just use one of our noncortisones.

#### Q: What are some long-term side effects that I should be aware of?

With prolonged eczema flaring around the eye, the skin in this area can become damaged and thinned. It can actually get a stretchmark-type of appearance. If people are rubbing a lot, you can also see a chronic thickening of skin around the eye that we call lichenification. If we've overused topical steroids in this area, there can be a higher risk of cataracts and glaucoma. And these are two things we definitely want to avoid.



*Peter A. Lio, MD, assistant professor of clinical dermatology and pediatrics dermatology at Northwestern University Feinberg School of Medicine*

## Eczema and the Microbiome

### Q: What do we know about the relationship between the skin microbiome and eczema?

We continue to learn more at what seems like an ever-increasing pace, with numerous studies, publications and products rapidly appearing. In recent history, I would say that the thinking was that *Staphylococcus aureus* (staph) was a colonizer and an opportunist; it found the open, oozing skin of atopic dermatitis an apt home.

However, we are learning that staph may actually be a primary driver of skin disease for some patients, and this is altering our therapeutic approach, at least on the cutting edge. Dr. Heidi Kong at the National Institutes of Health wrote a bold and impressive paper in 2012 that outlined the relationship between the microbiome and atopic dermatitis AD flares.

In short, it suggested that as staph became more dominant, the microbiome diversity decreased and this led to a flare. For recovery, the diversity increased again with staph correspondingly reduced, and then skin symptoms improved. There is a bit of a chicken-and-egg problem here, but I am convinced that, in some instances, staph overgrowth (and loss of the erstwhile microbial diversity) can be a true cause of disease flares. ►

### Q: Are there good guys and bad guys when it comes to bacteria?

I feel very confident in saying that *Staphylococcus aureus* is the bad guy here. It dominates, makes a multitude of toxins and seems to have a verifiable effect on driving AD. The good bacteria are a lot more complex. I think the most timeless answer, perhaps, would be to say that a strong diversity seems to reflect a healthy microbiome, and this may well be the priority over identifying one or several species as culprits.

### Q: Is this something that may be altered in the skin's microbiome early on that paves the way for newborn eczema?

I don't think we really know for sure, but it certainly seems reasonable and likely. We know that gut microbial diversity in the first week of life is a strong predictive factor for developing AD and decreased diversity correlates with increased AD risk.

We also know that skin barrier dysfunction is an important independent risk factor for developing AD, such as filaggrin mutation and consequential filaggrin deficiency. Thus, it follows that there are very likely to be microbiome abnormalities in newborn eczema, and, perhaps, if righted early enough, the disease could be halted.

### Q: What questions remain about the relationship between the skin microbiome and eczema?

There are many questions that need to be answered including the role of birth and home environment on the microbiome, and better understanding of the differences in different body areas, and will also help with stacking better understanding of prebiotics and postbiotics beyond just the organisms present. I would say we are at the very beginning here and far from being able to understand how to manipulate the skin's microbiome for therapeutic purposes.

### Q: What probiotics are effective for AD?

Even today, I'm not comfortable saying that any are reliably effective, but there are some studies that suggest oral *Lactobacillus* GG can have both a protective effect against developing AD and may have a slight (and variable) effect on existing AD.

There are several promising topical probiotics on the market, but I don't feel we have seen enough data yet to routinely recommend them beyond personal explorations. A so-called "microbiome transplant" with *Roseomonas* was recently published and seemed relatively convincing for an effect on AD severity, but, again, much more work needs to be done before we can confidently recommend such an approach.

**A portion of this Q&A with Peter Lio, MD, originally appeared in Practical Dermatology® magazine. Visit PracticalDermatology.com to read more from Dr. Lio, including a discussion of gut health and the skin. \***

Do you have a question for our ecz-perts?  
Email them to [editor@nationaleczema.org](mailto:editor@nationaleczema.org).

# ECZEMA: UNDER CONTROL. SO ROLL UP THOSE SLEEVES.

DUPIXENT is an innovation in the treatment of uncontrolled moderate-to-severe eczema (atopic dermatitis) for people 12 and up.

**RHONDA, REAL PATIENT.**  
Individual results may vary.

HELP  
HEAL  
YOUR  
SKIN  
FROM  
WITHIN

DUPIXENT is not a cream or steroid. It's a biologic that continuously treats eczema over time—even between flare-ups when skin looks clear. See and feel the difference with:

## Clearer skin • Significantly less itch

- In clinical trials at 16 weeks, 37% of adults and 24% of teens (ages 12-17) saw clear or almost clear skin vs 9% and 2% not on DUPIXENT.
- And 38% of adults and 37% of teens (ages 12-17) had significantly less itch vs 11% and 5% not on DUPIXENT.

**DUPIXENT**<sup>®</sup>  
(dupilumab) Injection  
200mg • 300mg

— TALK TO YOUR ECZEMA SPECIALIST AND VISIT [DUPIXENT.COM](http://DUPIXENT.COM) OR CALL 1-844-DUPIXENT (1-844-387-4936) —

### INDICATION

DUPIXENT is a prescription medicine used to treat people 12 years of age and older 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 with atopic dermatitis under 12 years of age.

### 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; are taking oral, topical, or inhaled corticosteroid medicines. **Do not** stop taking your corticosteroid medicines unless

instructed by your healthcare provider. This may cause other symptoms that were controlled by the corticosteroid medicine to come back; 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 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 (hypersensitivity), including a severe reaction known as anaphylaxis.** Stop using DUPIXENT

and tell your healthcare provider or get emergency help right away if you get any of the following symptoms: breathing problems, fever, general ill feeling, swollen lymph nodes, swelling of the face, mouth and tongue, hives, itching, fainting, dizziness, feeling lightheaded (low blood pressure), 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 in patients with atopic dermatitis 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. DUPIXENT is an injection given under the skin (subcutaneous injection). If your healthcare provider decides that you or a caregiver can give DUPIXENT injections, you or your caregivers 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. In children 12 years of age and older, it is recommended that DUPIXENT be administered by or under supervision of an adult.

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

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# Brief Summary of Important Patient Information about DUPIXENT® (dupilumab) Rx Only (DU-pix'-ent) injection, for subcutaneous use

## What is DUPIXENT?

- DUPIXENT is a prescription medicine used:
  - to treat people aged 12 years and older 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.
- DUPIXENT works by blocking two proteins that contribute to a type of inflammation that plays a major role in atopic dermatitis.
- It is not known if DUPIXENT is safe and effective in children with atopic dermatitis under 12 years of age.

## 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.

## 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
- are taking oral, topical, or inhaled corticosteroid medicines. **Do not** stop taking your corticosteroid medicines unless instructed by your healthcare provider. This may cause other symptoms that were controlled by the corticosteroid medicine to come back.
- 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.

**Pregnancy Registry.** There is a pregnancy registry for women who take DUPIXENT during pregnancy. The purpose of this registry is to collect information about your health and your baby's health. You can talk to your healthcare provider or contact 1-877-311-8972 or go to <https://mothertobaby.org/ongoing-study/dupixent/> to enroll in this registry or get more information.

- 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.

## 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. In children 12 years of age and older, it is recommended that DUPIXENT be administered by or under supervision of an adult.
- 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 medicines to use with DUPIXENT. Use the other prescribed 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 (hypersensitivity), including a severe reaction known as anaphylaxis.** Stop using DUPIXENT and tell your healthcare provider or get emergency help right away if you get any of the following symptoms: breathing problems, fever, general ill feeling, swollen lymph nodes, swelling of the face, mouth and tongue, hives, itching, fainting, dizziness, feeling lightheaded (low blood pressure), 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, and cold sores in your mouth or on your lips. Eye and eyelid inflammation, including redness, swelling and itching have been seen in patients who have atopic dermatitis. 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.

Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

## 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 for this use. 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)

## 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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# TRADITIONAL CHINESE MEDICINE

## AN ANCIENT ECZEMA TREATMENT

Traditional Chinese Medicine (TCM), has been used to treat eczema symptoms for thousands of years. We spoke with a TCM practitioner (who is also an eczema patient) to learn more.

By Brooke Bilyj

**O**livia Hsu Friedman grew up battling eczema, asthma and a multitude of allergies. Although she tried all kinds of ointments and medications to manage her condition, she still suffered severe allergic reactions that regularly landed her in the hospital.

Eventually, Friedman began looking into alternative treatment options and decided to see a Traditional Chinese Medicine (TCM) practitioner. Within six months, she experienced “a pretty profound transformation” as her skin cleared up, her asthma improved and most of her allergies alleviated. Friedman’s own experience inspired her to study – and ultimately become a practitioner of – TCM in order to bring the natural solutions to other patients.

“There are a lot of medications out there that are pretty good at managing symptoms, but not necessarily at alleviating the actual condition,” said Friedman, who earned a doctorate in acupuncture and Chinese medicine, as well as a diploma in TCM Dermatology. “A lot of people get to the point where they’re looking for a deeper solution, and they eventually come to TCM.”

Now, Friedman operates Amethyst Holistic Skin Solutions in Chicago, where she uses Chinese herbal medicine to treat dermatology patients. She sat down with NEA recently to explain how TCM can help treat eczema. ►

# WHAT IS TCM?

TCM is an ancient approach to promoting health by bringing the body's systems into balance. Where Western medicine focuses on treating specific symptoms, TCM looks at overall wellness.

“What’s different with Chinese medicine is that we’re looking at the root cause of the condition and trying to rebuild those systems so they can function normally,” Friedman said.

TCM employs several modalities, including acupuncture, which refers to the insertion of fine needles into strategic points on the body. Although Friedman is a licensed acupuncturist and serves on the board of the American Society of Acupuncturists, her practice is entirely focused on herbal medicine.

Chinese herbs can take the form of liquid extracts, capsules, powders or topicals. “In dermatology, the ideal way is to take them in liquid form,” Friedman said, because the extraction method maximizes the strength and efficacy of the herbs.

However, she often recommends topical herbs along with liquids, “to treat the skin from the inside and the outside as well.” ▶



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# CUSTOMIZED APPROACH

One of the greatest advantages that Friedman sees in Chinese herbal medicine is how the formulas can be customized for each patient.

“You can customize the ingredients and dosage of each formula based on that particular person’s condition, as well as other contributing factors that are making their eczema worse,” she said. “It’s a very individualized medicine.”

Friedman said TCM’s herbal arsenal includes more than 10,000 herbs, which are mainly found in the leaves, stems and roots of certain plants. Each formula may include anywhere from 10 to 30 different herbs — some of which have antibiotic, antibacterial or anti-inflammatory properties — which can be adjusted as each patient’s eczema evolves.

“In TCM, we recognize that as the condition progresses, eczema touches a lot of other systems,” Friedman said, “so we can really customize the formula to treat you based on where you’re at.”



# RESEARCH RESULTS

While there have been some scientific studies of herbal medicine, Friedman said the research falls short because TCM doesn’t easily fit into randomized control trials (RCTs).

“RCTs are set up to focus on one chemical and how it reacts on one mechanism, and then we study it on hundreds of people and give them the exact same thing over time,” she said. “But the problem with Chinese medicine in terms of research is that there are thousands of bioconstituents in each herbal formula. It’s very difficult to say that they’re only reacting on one mechanism, and because the medicine is so individualized, there is no one way to look at this medicine that fits the RCT.”

A few small studies suggest the therapeutic potential of TCM for eczema. In the early 1990s, trials in the U.K. found promising results: About half of the children and 70% of adults in one study saw 90% improvement in their eczema after 12 months of herbal treatment.

A more recent 2008 study combined Chinese herbal medicine with acupuncture to treat patients with atopic dermatitis for 12 weeks, and 100% of them reported reduced severity of their eczema.

Although medical professionals call for larger scale studies to confirm the efficacy of alternative therapies, there’s no shortage of anecdotal evidence from patients who have found relief through TCM.

“Chinese medicine has existed for thousands of years; there must be something to it,” Friedman said. “If there are enough people actually seeing results, that’s a testament that this medicine does work. We just have to be more open-minded in how we’re going to look at it in terms of research.” ►

## WHAT YOU NEED TO KNOW

Since eczema impacts each person so uniquely, Friedman cautioned that no single medicine will fix everyone's AD issues and all treatments take time to work.

"A lot of people are looking for a quick fix, but I liken it to exercise in that you can't just go to the gym and do a few sit-ups and have a six-pack of abs. Herbs take time, so I always caution people that it's not an overnight fix," she said. "I usually tell my patients to give themselves three months, and you should see changes all along the way."

Even if you are a good candidate for herbal medicine, treatments can get expensive because TCM is not covered by most insurance companies. Some insurers might allow health spending accounts or flexible spending accounts to be used for appointments and herbs, but others may not.

"Because people have to pay out of pocket, it's not the easiest solution, and it can be financially hard for some," Friedman said.

Accredited TCM dermatologists like Friedman are a relatively small (but growing) specialty, which can make it difficult to find a licensed practitioner. That's why Friedman offers telemedicine or video conferencing — to see patients across the country who don't have access to a local provider.

"I feel strongly that this medicine can offer help and hope to a lot of different people," she said, "so my hope is that we can make this medicine more accessible." \*

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*Dr. Olivia Hsu Friedman, DACM, LAc, Dipl. OM, owns Amethyst Holistic Skin Solutions in Chicago where she treats dermatology patients with Chinese herbal medicine. She serves on the board of directors of the American Society of Acupuncturists, the advisory board of LearnSkin, and the faculty of the Chicago Integrative Eczema Support Group.*



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# Eczema in skin of color

photos on  
pages 14 and 15  
by Tori Soper

**Eczema can appear and behave differently across the skin tone spectrum. This can lead to diagnostic challenges for doctors, and a greater burden of disease for patients of color.**

**By Emily Delzell**

**H**arry Do, a 23-year-old from Gainesville, Georgia, has been living with eczema since he was a few months old. It was mild in his early years, but as he entered his teens, he began having flares of severe atopic dermatitis (AD) that took away the natural confidence he'd had as a child.

“As soon as I started high school, I became more aware of my skin, more self-conscious and more insecure,” Do said. “Living with it, answering questions about why my skin looked ‘sunburned,’ started to become much more emotionally draining. Depression came and went like waves.”

Potent topical corticosteroids were his main treatment. Do, who is of Vietnamese ancestry, says he felt that, at times, he was under- or over-treated because the dermatologists he was seeing weren't used to the way AD looked in his Asian American skin.

“I felt that they weren't able to judge how flared I was due to hyperpigmentation on my face and being less familiar with how that looks in darker skin,” Do said.

Although treatment for eczema doesn't vary with ethnicity — medications have similar efficacy and safety across ethnic groups — the skin condition often looks quite different in more richly pigmented skin, that can make it harder to diagnose, according to Andrew F. Alexis, MD, MPH, professor of dermatology at the Icahn School of Medicine at Mount Sinai in New York City and director of its Skin of Color Center.

“The color of areas of eczema involvement are typically pink or red in people with lightly pigmented skin of European ancestry,” said Alexis. “In more darkly pigmented skin, the redness might be masked, and areas of involvement might be red-brown, purplish-gray or a deep brown with hints of red.

“In other words, there's a broader palette of color in eczema in darker skin, and redness and inflammation may not be as easily discernable to health care providers.” ►

## Eczema can vary by ethnic background

Alexis says that the 20-year-old Skin of Color Center, the first of its kind, was created to address distinctions in skin type that can change how dermatological conditions are diagnosed and treated.

In dermatology, “skin of color” means the skin of anyone with non-white ancestry. It’s important because, historically, white skin was the default used to teach medical students how to recognize and treat skin conditions, Alexis said.

“That means the language and the images in textbooks have historically had a Eurocentric approach,” he said.

“We’ve now recognized that there are a number of educational, research and therapeutic gaps when it comes to skin conditions that affect patients of color. Our center has worked to close these gaps by raising awareness of the diagnostic and treatment nuances that can exist among people of different ethnicities.”

How eczema appears on skin of color isn’t the only clinically meaningful feature of the disease that can vary with ethnic background, said Mamta Jhaveri, MD, MS, a board-certified dermatologist and assistant professor of dermatology at the Johns Hopkins University School of Medicine in Baltimore, Maryland.

“Melanin, the pigment that gives skin its color and that varies in amount and type among people of different ethnicities,



is very sensitive to inflammation,” she explained. “That means that people of color are more likely to develop hypo or hyperpigmentation — lightened or darkened areas of skin where the eczema has been and remain after it has gone.

“People with darker skin types also seem more likely to have papular eczema [small bumps on the torso, arms and legs] and to develop follicular prominence or bumps around hair follicles.”

In addition, she said, African American skin is often drier than other skin types, which makes the moisturization that helps keep symptoms in check even more crucial.

Eczema is also more common in people with particular ethnic backgrounds. African Americans are more likely than white people to be affected and both groups are more likely to have eczema than Asians. ►

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## Skincare tips for people of color

Understanding the unique qualities of your skin type – and how it's affected by eczema – can help you identify the best treatments.

Dermatologists Mamta Jhaveri and Andrew Alexis offer the following advice:

- Commit to regular moisturization. Some people of color, particularly African Americans, may have a drier skin type, making moisturization even more important. Start with a moisturizing cleanser (not soap, which strips skin of its natural oils), and follow with a thick emollient moisturizer.
- Carefully follow instructions for using topical corticosteroids. Overusing topical steroids can cause unwanted side effects, including thinning or lightening of skin.
- Use sun protection. Apply sunscreen often and wear hats and sun-protective clothes to block ultraviolet radiation in sunlight, which makes areas of hyperpigmentation even darker.
- Ask your dermatologist about your vitamin D status. Because melanin protects against the effects of vitamin D-producing sunlight, people with darker skin types often have lower-than-optimal levels of this vitamin that may play a role in eczema severity. If your levels are low, your doctor may prescribe vitamin D supplements. ▶



**“I think, just like anybody, I have days when I wish I had perfect skin. Then I reflect on where I used to be and how my skin was, and I’m grateful for where it is now.”**

**~ Mercedes Matz**

## Pigment changes affect quality of life

People of color often have more severe courses of AD, including more intense itching that can lead to chronic scratching and scarring, said Jhaveri.

Alexis noted that studies show African Americans with AD use more health care services for the skin condition, indicating a greater burden of disease.

The reason isn't completely understood, but Alexis thinks hypo and hyperpigmentation may be contributing factors. The pigment changes are often more noticeable — and therefore more disfiguring — in skin of color.

"Pigment changes can affect quality of life," he said. "If they involve arms or legs, patients may not feel comfortable exposing those areas, for example. This can mean they skip social events or aren't comfortable with certain activities like swimming because of unevenness of skin tone."

Mercedes Matz, diagnosed with eczema at 6 months old, doesn't remember a life without severe AD. She has hyperpigmentation and scarring from the years she struggled to bring deep itching, that caused "hours of scratching with no relief" and other symptoms, under control.

"My skin is 1,000% better than it used to be. With the help of my dermatologist and an interleukin blocker [a biologic medication first approved for eczema in 2017], I don't get flares as frequently as before, and if I do, they're fairly mild," said Matz, 25, who is African American.

"I think, just like anybody, I have days when I wish I had perfect skin. Then I reflect on where I used to be and how my skin was, and I'm grateful for where it is now."

Once eczema is resolved, both hypo and hyperpigmentation eventually fade on their own (usually in six months to a year), and there are some medications that can help lighten darker areas.

Matz has tried lightening creams, but because she still has eczema in the hyperpigmented areas, they haven't had much of an impact.

"I've learned to deal with hyperpigmentation, though I sometimes use makeup to conceal it on my face," said Matz, who recently moved to New Jersey from her hometown of Chicago to begin a career as an underwriter.

Early and ongoing treatment can help prevent pigment changes and scarring, according to Alexis and Jhaveri. "The earlier we treat eczema, the less pigment alteration patients will have," Jhaveri said.

Alexis emphasized the importance of keeping up eczema care even when skin isn't flared. "There's a need for continuous control of this chronic condition, including appropriate skincare, moisturization and bathing practices," he said.

"With these practices, along with the appropriate medication for the individual patient, we can control the condition effectively over the long term. When we do that, we can minimize the development of pigmentary changes and allow for the resolution of those changes."

## Lean on NEA for support

Perhaps most important is healing from the emotional scars of eczema. Both Matz and Do have found that connecting with others through the National Eczema Association (NEA) has helped them build confidence and self-acceptance.

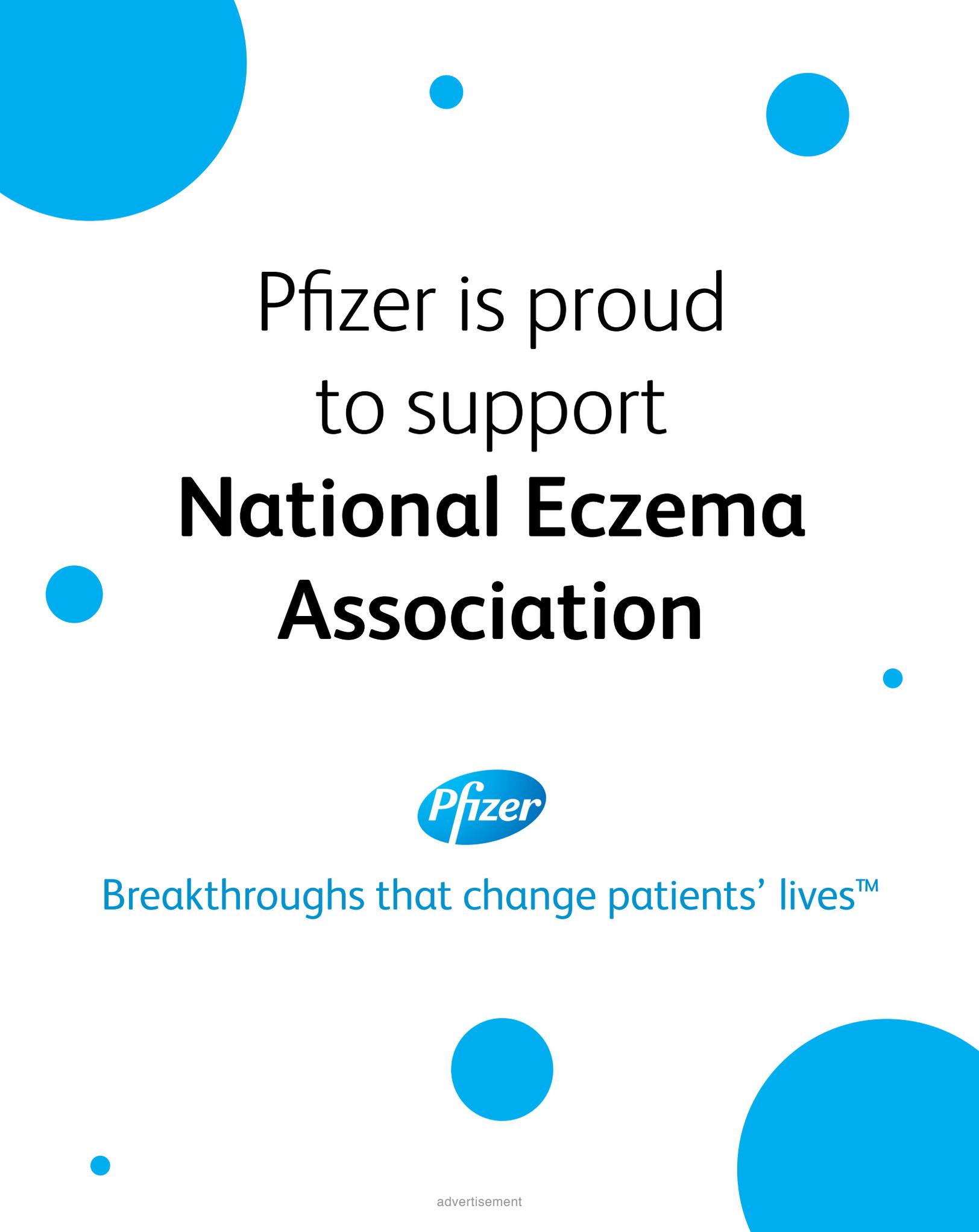
"I've learned through my eczema peers that telling other people about the condition is therapeutic," said Do, whose retail job allows him to share his love of fashion — especially sneakers, which he collects.

"Through NEA, I've met people with the same condition as me and we just start talking," said Matz. "Although my skin was still the same, I no longer felt isolated. Just having someone who 'gets it' was life changing for me."

Matz and Do also recommend finding a dermatologist who is committed to working toward your goals for your skin and your overall health. Together, they have seen dozens of dermatologists, and both have struggled to find an eczema specialist who "gets" them and their skin.

Matz found a dermatologist who inspired her trust just three years ago, and the results have been lifechanging. Do is still looking, but he isn't giving up until he finds the right therapeutic fit.

**To find a healthcare provider near you with experience treating eczema, check out NEA's Provider Finder at [nationaleczema.org/eczema-doctors-near-me/](https://nationaleczema.org/eczema-doctors-near-me/).**\*



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# peer INTO THE FUTURE

Your #1 source for the latest news, research and discoveries about eczema

BY KATHRYN JONES

## AD in older adults is common but hard to treat

*Researchers are starting to identify distinct characteristics of atopic dermatitis in elderly patients along with special considerations required for diagnosing and treating them.*

There was once a time when atopic dermatitis was primarily considered a pediatric condition. However, new and robust data have shown that AD is now almost as common in adults over 60 as it is in children under 18.

In fact, aging alone may result in pathophysiologic changes that could trigger or worsen AD, according to a British Journal of Dermatology review published March 21, 2019.

Dr. Anna De Benedetto, assistant professor of dermatology at the University of Florida College of Medicine in Gainesville and her colleagues who conducted the review, noted that many age-related changes seem to overlap with key hallmarks observed in AD.

These include pruritis (itch), xerosis (dry skin), a decline in skin barrier function, dysregulation of the immune system and an increased risk of *Staphylococcus aureus* (staph) infection.

Evidence suggests environmental triggers, combined with a defective, aged epidermal barrier, might contribute to the development or worsening of AD in elderly patients.

Specifically, seniors with AD tend to be more allergic to pollens and dust mites, and they often are hypersensitive to fragrance mixes and metals, such as nickel and cobalt.

Meanwhile, the reduction in the skin barrier function associated with getting older could exacerbate AD since aging skin has a harder time repairing itself compared to younger skin, the researchers pointed out.

In addition, the multiple changes that occur in an aging immune system can lead to a decreased ability to defend against pathogens, which would make older adults more vulnerable to severe and chronic infections.

As researchers do not yet fully understand the contributions of these immune system changes to AD onset or progression in the elderly, this may create challenges in treating elderly patients. Further, the use of available AD treatment options can be impacted by the frequent presence of other age-related comorbid conditions in older patients, such as high blood pressure, diabetes or osteoporosis.

The bottom line? More research is needed to address diagnostic concerns and treatment needs for senior AD patients as there are few clinical trials, research studies and care guidelines that focus specifically on adults over the age of 60.

The authors of the British Journal of Dermatology review concluded that understanding the distinct characteristics and needs of senior AD patients will be necessary as the worldwide elderly population continues to expand along with the rising number of AD cases.





## NEA to fill missing research gap

Thanks to a NEA-funded grant, a team of researchers led by Dr. Katrina Abuabara, assistant professor of dermatology at the University of California San Francisco, are conducting an investigation to better understand eczema heterogeneity in older adults.

First, they hope to pinpoint potential drug triggers of AD to help clinicians identify which treatments should be discontinued among older adults with new-onset eczema or avoided by elderly patients with a history of eczema.

Secondly, they intend to conduct a pilot phenotyping study that would potentially recruit 25 adults over the age of 60, including 10 with a history of eczema since childhood, 10 newly diagnosed with eczema, and five controls who don't have a history of skin disease.

Using state-of-the-art technology, the researchers would then collect blood samples and skin biopsies and perform detailed clinical assessments on these participants to gain a better understanding of the variability in underlying genetic, immune system and clinical profiles of eczema among older adults.

Knowledge gained from this pilot study would then support additional investigations, including future clinical trials, allowing researchers to develop and test treatments better suited to the unique needs of elderly patients.

“Our ultimate goals are to improve the diagnosis and treatment of eczema among older adults and to design prevention strategies to combat this growing epidemic,” Abuabara said. \*

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## Apple cider may not improve skin barrier, pilot study shows

*Researchers are starting to identify distinct characteristics of atopic dermatitis in elderly patients along with special considerations required for diagnosing and treating them.*

Apple cider vinegar (ACV), or fermented apple juice, has been a popular eczema treatment alternative for decades. People have turned to ACV based on the understanding that skin affected with eczema can have higher pH levels. Since ACV is a mild acid, soaking in ACV or applying ACV topically may help restore the skin's natural pH levels, thereby improving the skin barrier.

However, dilute apple cider vinegar soaks did not seem to improve skin barrier integrity in patients with atopic dermatitis, according to a Pediatric Dermatology study published July 22, 2019. If anything, apple cider vinegar soaks were associated with mild skin irritation, the authors reported.

Researchers at the University of Virginia recruited 11 patients with AD and 11 healthy controls, aged 12 years or older, to participate in the study.

All 22 participants soaked one forearm in a selected brand of dilute apple cider vinegar (0.5% acetic acid) and the other forearm in tap water for 10 minutes daily for 14 days. The apple cider vinegar soak concentration was determined based on prior research demonstrating its safety and tolerability.

Transepidermal water loss (TEWL) and skin pH were recorded at 0, 15, 30, and 60 minutes after the first soak, and 24 hours after completion of the 14-day treatment course. Patient-graded skin discomfort levels were then reported.

In both study groups, TEWL was increased immediately following the apple cider vinegar soak compared with baseline. However, among atopic dermatitis patients, TEWL returned to

baseline after 30 minutes, the researchers reported.

Compared with baseline levels, the skin pH was decreased at immediately following the apple cider vinegar soak in all participants. Skin pH remained decreased 15 minutes post soak in patients with AD and 60 minutes post soak in the control group. Among patients with AD, the effect of 14 days of apple cider vinegar soaks on TEWL and pH was comparable with soaking in water alone.

Additionally, 73% of participants reported mild discomfort from apple cider vinegar soaks, which improved after discontinued use.

“Results showed that soaking in dilute acetic acid yielded no benefit as measured by changes in skin TEWL and pH, yet caused substantial adverse effects,” the authors wrote.

“Therefore, although epidermal acidification would theoretically be beneficial in treating AD, our study shows that acidification by way of topical bathing in a 0.5% ACV solution as performed in this study is not useful in AD treatment.”

Limitations to this study include the small study size and the use of only one brand of apple cider vinegar product with the same dilution and application location on each participant.

The study authors concluded that “future studies are needed to explore whether lower concentrations of acetic acid soaks or other applications such as a leave on acidic ointment would be more effective in acidifying the skin and improving skin barrier integrity in a safe, nonirritating way.” \*

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## PEER online for more discoveries!

Scientists are making tremendous strides in conducting the groundbreaking research needed to bring us better treatments and a cure. For the latest on eczema-related research, visit [nationaleczema.org/category/discoveries](https://nationaleczema.org/category/discoveries).

## Born to be wildling

*A new kind of lab mouse might someday help scientists better understand the role microbiota play in eczema and the human immune response.*

A laboratory rat, or lab rat, is a rat species that is bred and kept for scientific research. It is believed that the first lab rats were brought into laboratories as early as 1828 for physiological studies on fasting.

While scientific studies have certainly evolved over the past two centuries, the lab rat and its smaller, more commonly used counterpart, the lab mouse, have remained unchanged — until recently.

Researchers at the National Institutes of Health (NIH) have developed a new mouse model that could improve the translation of research in mice into advances in human health.

The mouse model, which the scientists called “wildling,” acquired the microbes and pathogens of wild mice, while maintaining the laboratory mice’s genes that make them more useful in research. The result? Lab mice that maintain their useful genetic characteristics while incorporating real-world qualities of mice in the wild.

Unlike squeaky-clean lab mice raised in artificial settings, wildling mice are bred to have natural microbiota that better model human immune system responses. Microbiota are the trillions of tiny microbes (including bacteria, fungi and viruses) that live in and on the bodies of humans and animals.

Only in recent years have scientists gained a better understanding of the critical role that microbiota play in keeping our immune systems healthy. People with eczema and allergies, for instance, have overreactive immune systems that trigger inflammation

in the body whenever they come into contact with otherwise harmless substances such as pollen or mold.

Scientists rationalize the immune responses and microbiota of wild mice and humans are likely shaped in a similar way — through contact with diverse microbes out in the real world. Therefore, the more human-like wildlings are bred to be, the greater the chances that scientific research conducted on them can be applied toward improved human health.

In two preclinical studies, wildlings mirrored human immune responses, while lab mice failed to do so. Led by scientists at the NIH’s National Institute of Diabetes and Digestive and Kidney Diseases, the study was published online Aug. 1, 2019, in the journal *Science*.

“While animal models of human disease are invaluable for research discovery — these models often lack a ‘real-world’ element, as the animals are kept in controlled environmental settings,” said NEA Director of Research Wendy Smith Begolka.

“This study highlights the development of new ‘wildling’ mice that are bringing the outside into the lab, with the goal to better understand the connections and contributions of the immune system and the microbial environment to health, disease and drug response.

“As we understand more about the microbiome in eczema, this type of animal model may help future research make more informed links between the lab bench and clinical care.” \*

# GET THE FACTS: WET WRAPS

What are wet wraps, and do they really help soothe symptoms of eczema? Spoiler Alert: Yes!

BY KATHRYN JONES

If you or your child have ever been to a dermatologist's office with a severe eczema flare-up, there's a good chance you've heard of "wet wraps" before. If not, don't worry — you've come to the right place!

During particularly intense eczema flares with severe itch or pain, wet wrap therapy can work wonders to rehydrate and calm the skin and help topical medications work better.

Wet wraps are dressings — often made from articles of clothing — that have been soaked in warm water with a dry layer applied on top. Face wraps are done by nurses trained in the procedure using gauze and surgical netting.

Wet wraps are a common skincare technique used in the pediatric eczema program at Denver-based National Jewish Health, a leading research and health care institution for treating atopic dermatitis in the U.S. The hospital uses a variety of inpatient and outpatient programs that teach how to identify triggers and manage symptoms of eczema.

According to Dr. Mark Boguniewicz, a pediatric allergist and immunologist at National Jewish Health, applying and maintaining wet wraps should be done with care and, when necessary, under the supervision of a medical professional skilled in wet wrap treatment.

"The wraps help keep skin moist and improve effectiveness of topical medicine. They also have a cooling, anti-itch effect. Rewet or take the wraps off when they start to dry out. This should be done under medical supervision for short periods of time and only [on] more severe eczema, and the patient should be observed for signs of skin infection," Boguniewicz said.

Boguniewicz co-authored a study published in the *Journal of Allergy and Clinical Immunology: In Practice* July 2014 issue highlighting the profound effects of wet wrap therapy on children with severe eczema. The 72 children who took part in the inpatient study saw an average 71% reduction in symptoms and maintained healthy skin a month after returning home.

"We took a step-up, step-down sort of approach to managing their symptoms in this study," said Boguniewicz. "We would apply the wet wraps to the affected areas two to three times a day, depending on the severity of the case, then we would taper the therapy down. Over roughly four days, we saw dramatic improvements."

## How to do wet wraps at home

Wet wraps can be done at home or when traveling, but only after consultation and approval from your health care provider.

"You first want to familiarize yourself with the concept and talk to a specialist about it [to] determine if this is the right approach for your child," Boguniewicz cautioned. "Overuse can do more harm than good."

Once you get the go-ahead from your doctor, you'll want to start with clean, preferably white, cotton clothing or gauze from a roll for the wet layer, and pajamas or a sweat suit on top as a dry layer. If the eczema is on the feet and/or hands, you can use cotton gloves or socks for the wet layer with vinyl gloves or food-grade plastic wrap as the dry layer.

First, moisten the clothing or gauze in warm water until they are slightly damp. Next, wrap the moist dressing around the affected area. Then, gently wrap the dry layer over the wet one. Lastly, carefully put on nighttime clothing so as not to disturb the dressing. Leave wet wraps on for several hours or overnight, being sure not to let them dry out.

Do wet wraps work for treating the itch and pain associated with eczema? Yes! But you should always consult with a health care provider prior to starting wet wrap therapy.

**For more information on wet wrap therapy, visit [nationaljewish.org/conditions/eczema-atopic-dermatitis/eczema-treatment/wet-wrap-therapyandnationaleczema.org/eczema/treatment/wet-wrap-therapy/](http://nationaljewish.org/conditions/eczema-atopic-dermatitis/eczema-treatment/wet-wrap-therapyandnationaleczema.org/eczema/treatment/wet-wrap-therapy/) \***



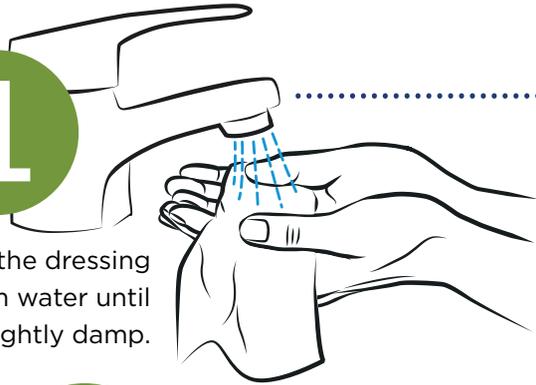
# Wet Wrap Step-By-Step

During particularly intense eczema flare-ups with severe itch or pain, wet wrap therapy can work wonders to rehydrate and calm the skin and help topical medications work better.

Wet wraps are best done in the evening after bathing, moisturizing and applying medication. You can use clean, cotton clothing as a dressing and pajamas or a onesie on top if the eczema is widespread; cotton gloves or socks if it is not.

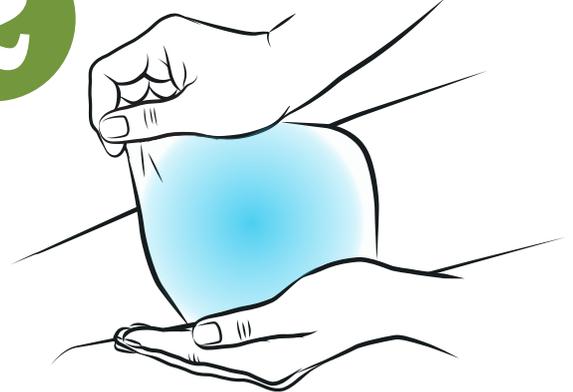
1

Moisten the dressing in warm water until it is slightly damp.



2

Wrap the moist dressing around the affected area.



3

Wrap a dry dressing over the wet one.



4

Carefully put on nighttime clothing so as not to disturb the bandages.



5

Leave bandages on for several hours or overnight.



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# Her Platform is a Throne



Thanks to the ingenuity of recent college grad and pageant queen Morgan Brunson, trick-or-treaters received healthy treats and Eczema Awareness Month materials on Halloween.

BY MARGARET W. CRANE

**T**alk about problem-solving! Eczema warrior Morgan Brunson scored a win when she conceived a way to combine several unrelated goals.

It all started when she snagged the title of “City Queen,” making her a finalist in the National All-American Miss pageant. The competition was held in Anaheim, California during Thanksgiving week.

But there’s another, less rosy side to Brunson’s story. The 22-year-old from Tinton Falls, New Jersey, was diagnosed with psoriasis at 18 and with eczema a year later.

She’s one of a relatively small group of people who has both skin diseases, including not one, but two types of eczema: atopic dermatitis and seborrheic dermatitis, which affects her scalp. Add psoriasis into the mix, and Brunson has a heavier burden to carry than most of her peers can imagine.

With no family history of either condition, Brunson was taken by surprise when her skin erupted during her teens. Since then, she has been educating herself about eczema and psoriasis and finding her way toward a self-care regimen that works.

And she finally found one: tacrolimus ointment, along with positive changes in her diet, exercise routine and sleep habits, has been keeping Brunson’s flare-ups under control.

Brunson graduated from Ithaca College in May 2019 with a

major in sociology and a minor in theater. Like many college grads, she finds herself at a crossroads, asking questions like, “What should I do next? Where is my life heading? How can I use my education to make a difference in the world?”

## And then opportunity knocks

When Eczema Awareness Month rolled around in October, Brunson decided the time was right to step up her eczema warrior game. Her first task was to come up with an idea for a community service project focused on eczema education for children and families.

“In the fall, community interaction is usually at its highest on Halloween,” she said. “I decided to create and fill 100 trick-or-treat bags with eczema awareness materials, including brochures, stickers, wristbands and NEA business cards. And, of course, I tossed in plenty of allergen-free candy to sweeten the deal!”

“I never saw anything about eczema when I was a kid,” she continued. “Halloween gave me the opportunity I needed to provide people in the community with eczema information and spread the word about a disease that is still under-recognized.”

Eczema Awareness Month also prompted Brunson to create an Instagram account, [@Miss\\_Invisible\\_Illness](#), where she’ll continue her public education efforts. ►

## Bringing it all together

The National All-American Miss Pageant is part of a larger group of competitions under the rubric of National American Miss, Inc., which aims to empower girls and young women.

Unlike the typical beauty pageant, National All-American Miss doesn't have a swimsuit competition, nor does it focus on "beauty" unless you define it as "inner beauty," Brunson explained. "It's about who you are."

And there isn't just one winner. Multiple contestants are named as queens in several concurrent competitions. Those selected benefit from the program's scholarship and career development offerings, including help with the nuts and bolts of any job search nowadays: the all-important resume and cover letter.

Brunson earned distinction at the local level for what the judges saw as her leadership potential and the creativity of her community service project — bringing awareness to life with eczema and psoriasis, and using Halloween as a springboard for community education.

She also featured eczema awareness in a public speaking contest, held in Anaheim in November. "I entered that contest just for fun," she said.

If only all chronic diseases had such passionate and creative public awareness campaigners. We can't wait to see what Brunson does next. \*





## *HOW TO BE AN ADVOCATE FOR YOURSELF AND OTHERS*

Every year, eczema warriors gather on Capitol Hill to share their stories with legislators, pushing to fund national research and improve access to eczema treatments. Join the National Eczema Association's growing grassroots movement and learn how to speak with Members of Congress about the issues that matter to you.

*BY BROOKE BILYJ*

**A**s a teacher and mother in Nashville, Tennessee, Cara Ellis never imagined herself meeting with legislators in Washington, D.C. But when her son, Walker, was born with eczema in 2012 — and then her older daughter, Callan, was diagnosed several years later — Ellis suddenly became “an accidental lobbyist” for eczema, speaking out about the challenges her family endured.

When countless over-the-counter treatments failed to calm her son's skin, Walker's pediatrician prescribed a steroid ointment. But when Ellis arrived at the pharmacy, she learned that her insurance would not cover his medication.

Instead, the insurer required Walker to wade through step therapy, trying — and failing — several cheaper medications before granting coverage for his prescription. Step therapy, or fail first, is a health insurance protocol that requires patients to try and fail on one or more medications before approving coverage for the treatment originally prescribed by their physician.

“We had to start all over and then work our way up to the right steroid ointment that our pediatrician prescribed. All the while, she

knew that the products in between were not going to work,” Ellis said. “It infuriated me.”

In 2019, Representatives Raul Ruiz (D-CA) and Brad Wenstrup (R-OH) introduced a bipartisan federal bill called the “Safe Step Act” to reform the use of step therapy.

“All too often, patients experience unnecessary discomfort or disease progression due to step therapy protocols that hinder patients from receiving the prescriptions their providers initially prescribed,” said Kelly Barta, senior manager of advocacy at NEA.

“That is why NEA is actively working at the federal and state levels to curb step therapy practices and put the power back into the hands of patients and providers.”

Walker eventually received the steroid ointment his pediatrician initially prescribed. The treatment helped to reduce his inflammation and relieve his itch. Although her child's eczema is now under control, the frustrating journey inspired Ellis to speak up. ►

She began advocating through NEA in 2018, first by asking her state officials to recognize October as Eczema Awareness Month – which they did. Then, Ellis attended two Derma Care Access Network (DCAN) meetings in Washington, D.C., where she shared her family’s eczema journey with policymakers.

More recently, Ellis joined hundreds of members of the Coalition of Skin Disease on Capitol Hill for the American Academy of Dermatology Association (AADA) Legislative Conference.

“Although eczema is incredibly common, our legislators don’t understand how difficult it is to take care of yourself or a loved one who has eczema,” she said. “The AADA Legislative Conference was an opportunity for me to share our struggles with step therapy and educate our lawmakers about the impact it’s having on their constituents.”

### *YOU DON'T HAVE TO BE AN EXPERT TO BE EFFECTIVE*

Ellis and participants from 36 states were present at the annual AADA Legislative Conference in Washington, D.C., this past September. Attendees at the three-day event included dermatologists, patient group leaders, practice administrators and political insiders, in addition to patient advocates like Ellis. The goal of the conference was to educate participants about

how health policy impacts dermatology patients and practices, while equipping them to advocate effectively.

Event coordinators emphasized attendees didn’t need to be experts in the legislative process. Throughout the conference, the AADA provided briefing materials and training workshops to help participants present their stories to legislators on the third day.

“We had workshops that helped form our story and make our messaging clear and concise,” Ellis said. “The training and resources really made us feel empowered to go into those meetings with confidence.”

### *PERSONAL EXPERIENCES MAKE THE BIGGEST IMPACT*

On the third day, conference participants met with officials at 157 U.S. House of Representatives offices and 71 Senate offices to address legislation that could impact rising pharmaceutical costs, access to medical treatments and other important issues. Of these 228 congressional meetings, 84 included direct encounters with elected officials.

For these meetings, participants were grouped with other advocates from their home states. Ellis’s group included four dermatologists, which made the experience seem even more ▶

*“No amount of education or experience will ever speak louder than your own story.”*

*– Cara Ellis, Nashville, Tennessee*



daunting. But through her advocacy experience, Ellis realized the power of her personal story could make a huge impact.

“What I have learned, and what I hope people take away from me sharing my experience, is that there is no amount of education or experience that will ever speak louder than your own story,” Ellis said.

“So many people discount their story because they don’t have a certain degree or clout behind their names, but I know how powerful my personal experience is, and that gives me the confidence to stand in front of these elected officials.”

### *PREPPING IN ADVANCE MAKES IT LESS INTIMIDATING*

Another first-time participant at the AADA Legislative Conference was Amber Jewett whose 4-year-old son, Jack, has had eczema since he was 4 months old. She said the conference helped her understand issues from her legislators’ perspective so she could shape her story to intersect with their priorities.

“It’s a little intimidating walking through those offices on [Capitol] Hill, but you are the expert in eczema for your child, so you have to help educate them,” Jewett said.

“They work for us, and they need to understand that this really does impact not only my son, but others. If we can get them the

treatments they need, that cuts health care costs for all of us. It means less time out of work for parents like me, so it has a ripple effect on the economy.”

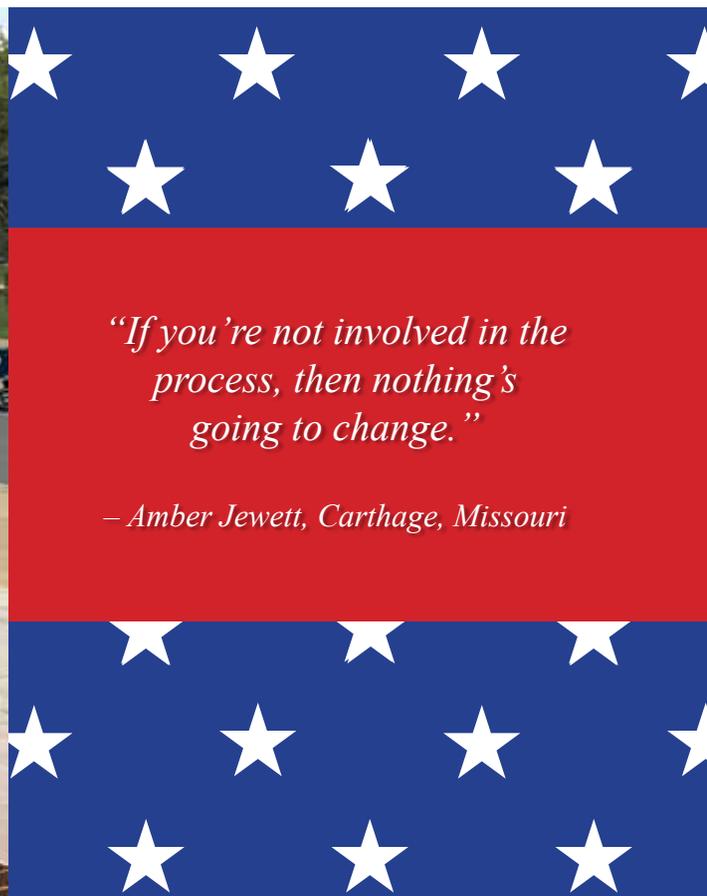
Jewett’s biggest concern heading into the congressional meetings was presenting her story without getting too emotional about the struggles she faced. To keep herself on track, she put together a one-page handout that showed pictures of Jack with rashes covering his face, legs and hands, along with statistics about eczema.

“Developing that one-pager helped hone my message,” Jewett said. “The pictures told the story, so I didn’t have to get emotional, and I could talk in terms of strengthening pharmaceutical access and affordability.”

### *THE IMPORTANCE OF GETTING INVOLVED*

Jewett remembers feeling hopeless leaving Jack’s doctor appointment after learning that he’d have to wait months to see a pediatric dermatologist. That’s when she decided to get involved because advocating offered an opportunity for her to take action.

“We can’t always control eczema, and as much as my son has improved, it’s just so frustrating because you don’t know how to help your child,” said Jewett, who lives in Carthage, Missouri. ▶



*“If you’re not involved in the process, then nothing’s going to change.”*

*– Amber Jewett, Carthage, Missouri*



“As a parent, you want to fix things, so this is the outlet for me to work on fixing it. If you’re not involved in the process, then nothing’s going to change.”

Jewett’s mission is to raise awareness about the challenges of dealing with eczema. “If people aren’t aware of the burden of it, I don’t think we’re going to get as much traction on the new drug development and therapies that we really need,” she said.

Ellis said the AADA Legislative Conference made her realize that most legislators don’t see how issues like step therapy impact simple treatments for conditions as common as eczema — until constituents speak up about it.

“As soon as I stop telling my story, that’s when the progress will stop,” Ellis said. “I can’t sit back and hope that lawmakers will wake up one day and decide step therapy isn’t appropriate anymore. I have to be a part of the work that goes behind making that a reality.”

That’s why Ellis encourages others to join the cause, creating a snowball effect of advocacy magnifying the impact of events like the AADA Legislative Conference.

“I would love to see more people get involved in this process,” Ellis said. “I feel like we’ve lost the understanding and the belief that our voices really do matter. Yes, it’s important that we vote, but it’s even more important that we continue to make our voices heard beyond election day.”

Ellis hopes to set an example for her children as they watch her in action. “I’m using my advocacy experience to empower them,” she said. “I’m driven to continue sharing our story because I want my son and daughter to see the importance of standing up and using their voices too.” ▶



## With atopic dermatitis, itching isn’t even the worst part.

From the embarrassing red blotches to the painful sores, atopic dermatitis requires the right treatment. The ADvocate 1 Study aims to see if an investigational medication may be safe and effective for moderate to severe atopic dermatitis patients. Adults and adolescents 12 years of age and older who have had atopic dermatitis for at least one year may qualify to participate. Talk to your or your child’s doctor and visit [ADvocatestudies.com](https://ADvocatestudies.com) to learn more.

**ADvocate**  
STUDIES

# TAKE ACTION!

*Here are seven easy steps to effectively communicate with elected officials about eczema:*

- 1) **Start small.** Having young children with eczema gives parents an opportunity to educate daycare providers and teachers about the disease. “Start small in your local community,” recommended Jewett, who hands out NEA brochures and the Tools for Schools publication to her children’s educators and school nurses.
- 2) **Promote awareness.** Some states like Georgia, Tennessee and Illinois officially recognize Eczema Awareness Month (EAM) in October. “If Eczema Awareness Month isn’t already set up in your state, that’s an easy one,” Jewett said. “You can send a quick email to your state representatives, and then do a follow-up call or email.” NEA will support these efforts with coaching and the EAM Resolution. You can look up contact information for your senators and representatives by searching the following links: <https://www.senate.gov/senators/contact> and <https://www.house.gov/>.
- 3) **Craft your ask.** “The first step is to identify your story,” Ellis said. “No one can tell your story better than you.” To make your personal experience more meaningful to legislators, tie your story into a current regulatory issue and ask them to take a stand. Learn about NEA’s legislative priorities and positions at [nationaleczema.org/advocacy-priorities/](http://nationaleczema.org/advocacy-priorities/).
- 4) **Pick up the phone.** When you call into your elected official’s office, you will speak to one of their aides. It’s important to be polite and concise. Give the office staff member your name and your zip code so they can verify that you are a constituent. Then, let them know why you’re calling and what you’re asking for.  
  
Ellis started her advocacy efforts by making phone calls to state legislators addressing issues impacting eczema care. “That gave me a little practice before getting face-to-face with elected officials,” she said. “When we make phone calls, those are documented, and once enough calls or emails have been received on a particular issue, then our legislators are required to do something – whether it’s to begin researching it or to return that call.”
- 5) **Request a meeting.** “Having some sort of face-to-face communication with your elected official or their staff adds more power to your story,” Ellis said. “It’s very easy to request and secure a meeting with your state officials, and then you can work up to your federal officials.” The AADA recommends sending a formal invitation to your lawmaker’s scheduler at least three to four weeks before your proposed meeting.
- 6) **Make a connection.** “Any personal tie-ins are good,” Jewett said. For example, some of her friends had campaigned for her district’s U.S. Representative. Jewett made sure to mention their names when she met with him on Capitol Hill. “That helped build a personal connection,” she said.
- 7) **Don’t give up!** Keep reaching out to your representatives. “So many times, my phone calls have gone unreturned,” Ellis said. “But I will not allow that to deter me from continuing to share my story, because if we stay silent, nothing will change.” \*

# WHAT'S HAPPENING AT THE NATIONAL ECZEMA ASSOCIATION

BY KATHRYN JONES

## NEA takes a stand against step therapy

On Oct. 28, 2019, eczema warrior and patient advocate Raelle Brown stood beside NEA Senior Manager of Advocacy Kelly Barta during a press conference at the Pennsylvania State Capitol, representing NEA's support of the recently introduced legislation.

Step therapy, or fail first, is a health insurance protocol that requires patients to try and fail on one or more medications before approving coverage for the treatment originally prescribed by their physician. This legislation would help safeguard patients from potentially harmful step therapy practices.

"In late October, both the House and Senate of Pennsylvania have introduced a bill that will help create better access to innovative medicines and put treatment decisions back into the hands of physicians and their patients," Barta said.

In April 2019, representatives Raul Ruiz (D-CA) and Brad Wenstrup (R-OH) introduced a bipartisan federal bill called the "Safe Step Act" to reform the use of step therapy.

"The step therapy amendment is one of the most important issues that NEA is currently working on at the federal and state levels. This legislation ensures patient safety, recognizes the importance of the physician-patient relationship, and increases transparency for both patients and health care providers," Barta said.

To learn more about step therapy and how it effects eczema patients, visit <https://nationaleczema.org/advocacy-priorities/>.



## Are you ready to step up your game?

Join NEA in our fight against harmful step therapy practices. Ask your House and Senate representatives to support the bipartisan "Safe Step Act" bill, which will help bring about step therapy reform.

All you have to do is open your web browser, plug in the following link, fill in your information and click the "Take Action" button. This will let them know that you care about the rights of eczema patients. <https://nationaleczema.salsalabs.org/federalsteptherapy2019/index.html>

## Itching for a Cure 2019: NOW THAT'S TEAMWORK!

If you're looking for ways to raise eczema awareness and funds for eczema research and support at the same time, look no further than Itching for a Cure (IFAC). NEA's annual fundraising campaign consists of fundraising events that take place during Eczema Awareness Month (EAM) in October.

Participants have the option of hosting in-person events such as walkathons, bake sales and craft fairs; teaming up to run an online fundraising campaign like our friends the #ItchyBees did this year; or supporting an existing fundraiser by making a donation.

This year, our top fundraisers were two courageous eczema warriors, Ella Kate and Kristen Mohan, who each raised more than \$2,500 in their online fundraising campaigns.

We also want to give a special shout-out to long-time NEA supporter Tracy Zultko and her coworker, Alex Mueck, who ran a successful campaign during EAM in honor of Tracy's son, Christopher, called "Christopher's Itch Warriors." Mueck led a hike, and they both raised money from friends, family and colleagues at Wells Fargo.

Lastly, we want to extend our warmest gratitude to the individuals who donated to NEA this year. Thanks to your support, NEA will continue to build awareness, advance research and improve patient care year after year until a cure is found. Every dollar makes a difference and has a direct impact on the millions of people affected by eczema, so please continue to make a donation at <https://nationaleczema.org/donate>.



# Thank you! Thank you! Thank you!

*Thank you to our 2019 IFAC participants who helped us raise more than \$8,000 for eczema research, resources and support. We couldn't have done it without you!*

- Ella Kate
- Tracy Zultko
- Alex Mueck
- Kristen Mohan
- Amy Chnelich
- Airisel Nickson
- Brenda Chavez
- Jen Parvin
- Brooklyn Cashman
- Jakiya Harris
- Kathy Sage
- Veyann Henry
- Shannon Steinmann
- Kyle Bruner
- Kristin Boelter
- Harry Do
- Sam Bittner
- Lindsay Swire Jones
- Alexis Smith
- Christy Cox
- Angela Fox
- Stephen Gawron

## Join us in congratulating this year's top teams!

- #ItchyBees
- Nick's Itch Squad
- Gavyn's Gang
- Christopher's Itch Warriors

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\*Data on file

# FROM LOBSTER BOY TO FINALLY LOVING MYSELF

After a serious medical scare, I ditched steroids for good. My decision may not be the right choice for everyone, but it helped me understand that we have to advocate for ourselves, even if it means going against the grain.

BY BAILEY LOSA

I don't remember not having eczema. It's always been part of my life. I know firsthand the difficulties and frustrations that come with coping with a chronic disease.

Millions of Americans (and millions more worldwide) suffer with atopic dermatitis, mostly in silence. The experience ranges from milder cases to more severe. I happen to be one of the severe cases – 90% of my body has been affected by eczema over the years.

## WE JUST WANT OUR VOICES TO BE HEARD

It can feel like those of us with the most serious condition are heard the least. The mainstream medical community simply does not have the answers that we desperately need.

And that's not a knock directed toward doctors – it's just the simple fact that eczema is underrepresented and misunderstood by the majority of the population.

It isn't easy to talk about what we go through, but it's extremely important to tell the world our story. The time has come for a bigger push for answers, a bigger push to give us the lives that we deserve.

The goal of telling my story is to give some insight and understanding to those who don't know and those who are willing to learn about this disease. This is the life many of us live, and this is the story of my struggles and what I believe we can do to turn the tide in the right direction.

## STEROIDS LED TO A SERIOUS MEDICAL SCARE

I won't go into my entire medical history, but I will say that I've seen countless doctors in my time (dermatologists, allergists, chiropractors, etc.) and have tried every medication known to man.

Spoiler alert, my eczema never went away. Topical and oral steroids were a normal part of my life for years and years. I never questioned the medical "care" that I had been receiving my whole life. Unfortunately, that ignorance led to the formation of a tumor in one of my adrenal glands.

It was freshman year of high school, and the tumor caused my skin and overall health to go completely insane. I was made fun of for the way my skin looked, it was red and inflamed 24/7. "Lobster boy," "frostbite face," and "lizard" were common jabs I'd get from fellow students (clearly ignorant of my situation).

A trip to my pediatrician led me to an appointment with an oncologist, who diagnosed me with the tumor and eventually took steps in order to remove the adrenal gland completely. For a while my life went back to normal, or as "normal" as a life with eczema can be.

You'd think that after this health scare someone would've linked the tumor with the ungodly amount of steroids I'd been given my entire life. Nobody did though, and I continued down the dreaded path of doctors' appointments and steroid use.

Fast forward to a year ago, and my symptoms began to escalate month by month. As my condition worsened, the steroids became more plentiful and increasingly strong. It got to the point where I was forced into urgent care about once every other week. ►

My life had fallen apart. Relationships dwindled, my mood was perpetually down, and I couldn't even show up to my job on a consistent basis. I felt helpless.

## TAKING THE NATURAL ROUTE WAS THE RIGHT CHOICE FOR ME

I decided to take a stand for myself and completely ditch the endless loop of toxic medication. The withdrawal symptoms from these heavy pharmaceuticals were intense. My body had become addicted to the very drugs that were hurting me.

I'm still on the path to recovery, but my life has changed for the better. I'm completely off all medications and creams. I decided

to take a more natural route to my ailments. My skin is slowly getting stronger, and I have cleared about 30% of the disease already.

I truly believe that the way to heal is not by masking the symptoms, but rather eradicating the disease at its source. This is not to tell you that you need to follow in my footsteps, but I implore anybody dealing with the disease to really take a step back and rethink the way you've been told to treat eczema.

I'm fortunate enough to be able to share my story, and I believe my future is bright. My advice is to be your biggest advocate, do what's best for you, and above all, stay strong.

*Bailey Losa is a 20-year-old eczema warrior living in Miami, Florida. \**



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