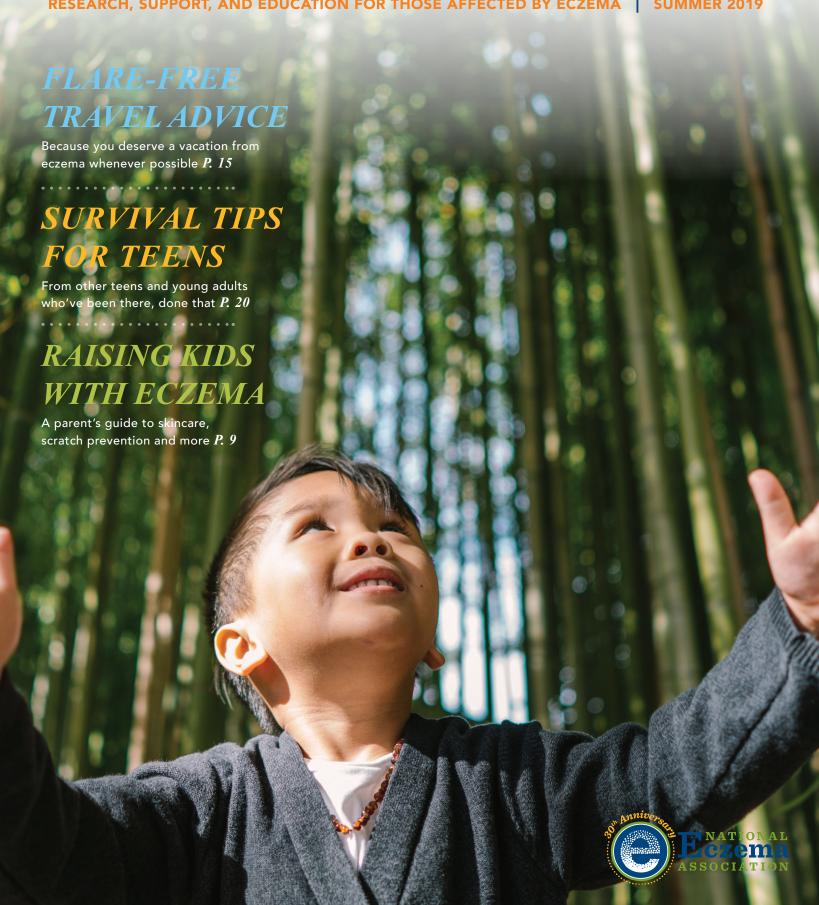
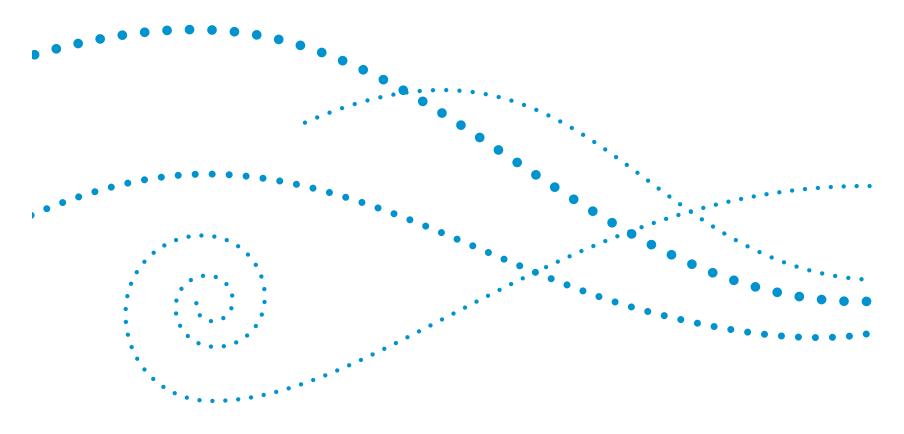
## eczema matters

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





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#### eczema matters

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#### In This Issue

#### **Featured**

#### 09 The Struggle Is Real

Parents and doctors offer their best advice for raising kids with eczema.

#### 15 Bon Voyage, Eczema

Want to travel without triggering a flare? It can be done.

#### 20 It Does Get Easier

Millennials dole out practical tips for surviving those awkward teen years.

#### 27 Get Fit Without Flaring

Excersing is essential, but those with eczema should Exercisingautions.

#### **Departments**

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

03 Scratch Pad: Advice from the NEA community

04 Ask An Eczpert: You ask — we find answers

18 Get the Facts: Acupuncture

24 PEER: Your #1 source for eczema research

30 Community Spotlight: Teen Steering Committee

34 NEA News: Tools for School

**36** My Journey: 24 hours of eczema



#### **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.



f there's one thing I've learned from serving the eczema community all these years, it's that you can't — you won't — and you don't let eczema stop you from living your best life.

Our annual Eczema Expo is certainly proof of that. Nothing warms my heart more than watching all those hugs and happy tears whenever our community gets together. It's like a family reunion, but instead of being blood-related, we're connected by a common, and oh so complex skin condition that takes courage and dedication (not to mention a diligent skincare routine) to manage.

Eczema is more than a chronic disease. It's a lifestyle that permeates nearly every facet of our day-to-day lives. And it doesn't just impact the person diagnosed with eczema — it affects the whole family. That's why we decided to make this issue all about family and embracing the eczema lifestyle.

We know that many of our eczema families travel from afar to attend Expo each year and that traveling with eczema is no easy feat. For travel tips from community members and medical experts alike, turn to pages 3 and 15, respectively.

If you're a parent, you know the struggle is real when it comes to raising a child with eczema from infancy through adolescence. The sleepless nights, the constant worrying, the feelings of helplessness — these are common challenges that all parents face. We asked world-renowned pediatric dermatologists and allergists to offer their best advice on page 9.

If being a teenager (or raising one) isn't challenging enough, having atopic dermatitis can make those awkward teenage years even more vulnerable. That's why NEA is ramping up its efforts to better support teens with eczema. Instead of making assumptions about what teens with eczema want to know, we went straight to the source on page 19. You'll also meet members of our Teen Engagement Program Steering Committee on page 30.

Eczema can feel like the loneliest disease in the world despite the fact that more than 31 million Americans have experienced it at some point in their lives. I like to think of NEA as the glue that helps eczema warriors stick together. And, remember, there is strength in numbers. You'll see what I mean when you join us for Eczema Expo 2019 in Scottsdale, Arizona, from July 18-21. See you there!

PS: Don't forget your swimsuit!

Julie Block President & CEO

#### What are your top eczema-friendly travel tips?



Make sure you have enough meds and that you can take them with you. – eczemasupportuk

On the plane I use wet dressings to keep my skin hydrated. – morgpops

I always ask for non-feather pillows and try to find hotels with no carpet. – micaelavorch

You can ask hotels for dust mite allergy accommodations. Some may be able to help. – itchypineapple

Whatever you do ... DO NOT USE THE HOTEL LOTIONS!!! I learned that the hard way. – chronicallybrie

Creams and medicines are always the top priority; own bedsheets, blankets and pillowcases come next; and super loose and comfortable traveling clothes are a must! – ayeshailyas21

I always bring my own moisturizer, soap, conditioner and washing liquid and softener for clothes. A small pack of moisturizer and thermal water spray are always with me on the plane and on the road. – myfuelforlife

My best advice is to keep smiling and exploring. Good mood means good eczema condition. – maharummani

I use travel containers for my eczema-friendly soaps and creams to pack with my carry-on to keep skin hydrated. I also bring disinfectant wipes to clean the surfaces of the airplane seats since I am more prone to skin infections.

- karen\_tru

Oh man! When I travel with my son it feels like a production. I bring allergy-free food/snacks, and although I hate it, I utilize devices when needed. Sometimes a movie or video game can distract him enough to refocus his fixation on his scratching. – thesaltyfig



The worst part is packing up all the creams, ointments and moisturizers — some of which need to fit in a bag with other 3 oz stuff. – Diane E.

I bring my own towel (so I don't get a flare from the hotel's detergent) and small ice packs to put in the freezer in case I need to numb and cool down a flared patch. – Ashley B.

Bring your own pillow and blanket or just a pillow case and sheets. - Anna B.

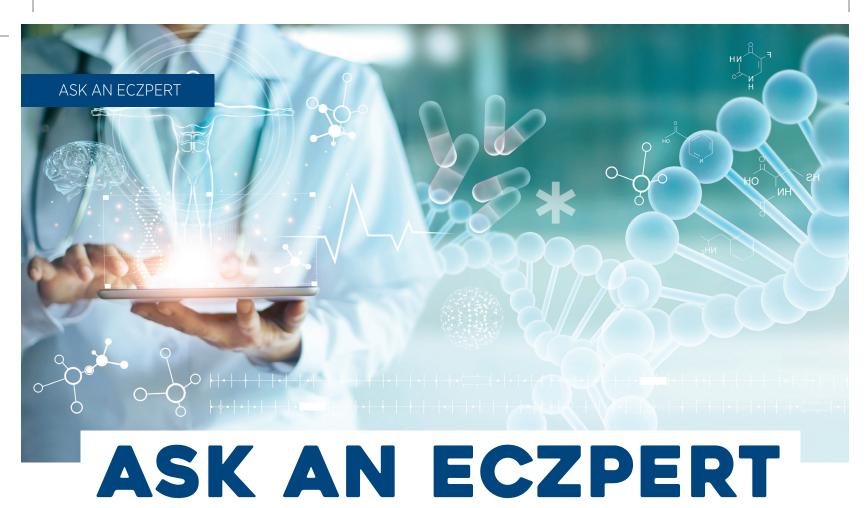
Layers are a must. That way if you start to overheat, you can take off one layer at a time. – Emily B.

I'm allergic to basically everything, so I just don't travel. I can't sleep in a room with carpet and everything else that triggers a flare-up - Scott T.

Bring long sleeve/pant pajamas to sleep in; most hotel sheets are washed in heavy duty or scented detergent. I usually do wet wraps the week before so I can travel with my skin being as moisturized as possible! - Caity H.

Make yourself a "sheet/pillow sleeping bag." Take two twin sheets, sew together at bottom, fully up one side and 3/4 up opposite side. Leave top open! Sew/attach pillow case at top. This way you know your skin is enclosed as much as you can in a material that you are comfortable with, not washed in harsh chemicals, etc. It can be easily rolled/folded up for travel. – Stephen G.





Leading medical experts answer your most pressing questions about eczema.

#### Q: How can I get rid of dry skin for good?

Follow these tips to combat dry skin:

- Cleanse the skin daily in a 5- to 10-minute lukewarm water soak with a gentle liquid cleanser such as Vanicream Free and Clear liquid cleanser. If you have very predictable "eczema seasons" and hate the feeling of liquid cleansers, then in the off season, you can use a liquid body wash such as Dove Baby or CeraVe body wash.
- 2. Pat dry the skin vs. wiping completely dry.
- 3. Within three minutes of getting out of the bath or shower, lock in the moisture your skin absorbed from the bath/shower with your moisturizing cream and/ or medicated treatments.
- 4. Be intentional about moisturizing often and liberally. My patients have had the best success with CeraVe moisturizing cream and Vaseline jelly.
- 5. When needed, follow the instructions for anti-bacterial control, i.e., diluted bleach baths. If your skin barrier is disrupted by overgrowth of skin bacteria, this can disrupt the ability of your skin to heal and increase the risk of developing skin infections.
- 6. Stay hydrated with water throughout the day, and if you live in a dry climate, consider using a cool mist humidifier in your room.
- 7. Lastly, I would be remiss if I did not ask you to follow your health care provider's instructions specifically. Utilize NEA's Eczema Provider Finder to find a clinician specializing in atopic dermatitis with whom you can build a trusting relationship with. EczemaProviderFinder.org

 $Samantha\,B.\,Casselman,\,pediatric\,nurse\,practitioner\,at\,Phoenix\,Children's\,Hospital\,\blacktriangleright$ 



#### Q: Is there any true link between gut health and eczema? Q: Are my seasonal allergies and eczema all connected, and could they be treated

While there are still many unanswered questions here, there is reasonable evidence that suggests gut health and skin health are closely related. Indeed, if you think about it, as you follow your skin to your lips, the same lining just continues on into your gut: it's really all part of the same epithelium.

There are studies that suggest "leaky gut" (increased permeability of the gut) is related to the "leaky skin" (weak skin barrier) of eczema. We wrote an article about it a few years ago that has a lot more information: https://nationaleczema.org/leaky-gut-and-atopic-dermatitis/.

One important thing that I have learned is that to truly be healthy, all the systems have to be working well and working together, much like an orchestra. Many times, when one system starts to falter, others will follow, which is why we think a more holistic approach is always an important consideration.

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

## all connected, and could they be treated with one medicine like Dupixent instead of multiple meds? Dupixent (dupulimab) is currently approved for both

Dupixent (dupulimab) is currently approved for both asthma and atopic dermatitis in patients over 12 years of age. Dupulimab has not been studied for seasonal allergies, however, in theory, it would improve both indicated conditions (asthma and atopic dermatitis) at the same time.

Dupixent, when studied for asthma, led to an increase in lung function and a decrease in severe asthma exacerbations, but it does not treat acute bronchospasm. You will still need your albuterol as needed. It was also used in patients with moderate to severe disease who were on inhaled corticosteroids for their asthma. There is no data if it would improve patients with mild asthma or seasonal allergies.

For the treatment of seasonal allergies, in theory, Dupixent should work as it blocks the interleukin (IL) 4 and IL 13 pathways. But there is no data at the current time to prove it. When treating with dupulimab other potential other biologics, if the diseases use the same pathway (for allergies — Th2 pathway), the medication might work for multiple diseases as the medication is available systemically.

However, it is very important to remember that you cannot stop your asthma medications or other medications. You need to talk to your physician before you can wean off any medications as you might have increase of symptoms or side effects.

Jonathan Spergel, MD, PhD, chief of the allergy section at Children's Hospital of Philadelphia ►





#### **ASK AN ECZPERT**

#### Q: How come there aren't any treatments that specifically target topical steroid withdrawal?

Topical steroid withdrawal (TSW) is a serious condition that appears to be relatively new. We are still learning about why it happens, which patients are most susceptible, and hopefully how best to treat it. Unlike eczema — a disease for which we have descriptions over hundreds and perhaps even thousands of years — cortisone itself was discovered in the 1920s, with little information about it published until almost 1950.

One of the hardest parts is that many people are able to use topical steroids safely. TSW seems relatively rare, though we really don't know how widespread it is, which adds to the problem. Another problem is that we don't have a clear way to diagnose it. Many times, it's hard to know if it is the underlying eczema or TSW, although some recent papers are making headway into better identifying TSW.

Hopefully, as we gain better understanding of this terrible condition, we will identify and develop targeted treatments to give relief. Meanwhile, it is our great hope that better education and careful monitoring will prevent others from developing TSW in the first place. Visit https://practicaldermatology.com/articles/2015-sep/the-challenges-oftopical-steroid-withdrawalogy? to read a paper we wrote about TSW.

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

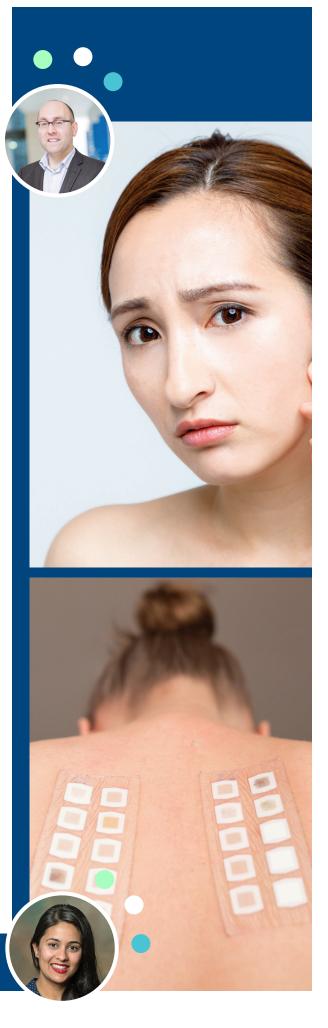
Q: Are people with eczema more likely to have a vaccine reaction due to formaldehyde and aluminum ingredients? Is there a way to test allergies to these ingredients, and would that be a reason to avoid a particular vaccine? Could receiving a vaccine with these irritants cause a person's eczema to get worse?

People with eczema are not more likely to have a vaccine reaction to these ingredients. Aluminum and thimersol are possible contact allergens in vaccines. If you suspect you have a contact allergy to these ingredients, then you should have patch testing done. Contact allergy to these ingredients is not a contraindication to vaccination.

There is no literature indicating eczema could get worse after vaccines. I was able to find a single case report of systemic contact dermatitis after a formaldehyde-containing vaccine indicating how rare this phenomenon is. Kuritzky LA, Pratt M. Systemic Allergic Contact Dermatitis After Formaldehyde-Containing Influenza Vaccination. J Cutan Med Surg. 2015 Sep-Oct;19(5):504-6.

Kanwaljit K. Brar, MD, pediatric allergist and immunologist at National Jewish Health st

Do you have a question for our eczperts? Email it to editor@nationaleczema.org.



## FOR ADULTS WITH UNCONTROLLED MODERATE-TO-SEVERE **ECZEMA** (ATOPIC DERMATITIS) Jennifer W., actual D<mark>UPIXENT patient.</mark> ndividual results m<mark>ay vary.</mark>

## HELP HEAL YOUR SKIN UM WIT

DUPIXENT, the first eczema treatment of its kind, is not a steroid. It is a biologic treatment that helps manage the inflammation deep beneath the surface that causes the flare-ups you see and feel on your skin-and keeps working, even when your skin

#### In Two Clinical Trials with Adults Taking DUPIXENT\*

- Nearly half of patients saw 75<sup>%</sup> skin improvement and some even saw 90% improvement
- · Almost 4 times more patients taking DUPIXENT saw clear or almost clear skin as compared with those not taking DUPIXENT -37% taking DUPIXENT as compared with 10% not taking DUPIXENT
- Patients experienced significant itch reduction, some patients as early as 2 weeks \*16-week trials compared to placebo.



Learn more. Talk to your eczema specialist. Visit DUPIXENT.com, or call 1-844-DUPIXENT (1-844-387-4936).

#### **INDICATION**

DUPIXENT is a prescription medicine used to treat people 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. 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
- 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

The most common side effects include injection site reaction, eye and eyelid inflammation, including redness, swelling and itching, pain in the throat (oropharyngeal pain) 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, or call 1-800-FDA-1088.

Use DUPIXENT exactly as prescribed. DUPIXENT is given as an injection under the skin (subcutaneous injection). 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. In adolescents 12 years of age and older, it is recommended that DUPIXENT be administered by or under supervision of an adult.

Please see accompanying Brief Summary on next page.

SANOFI GENZYME • REGENERON

#### You may be eligible for a \$0 copay<sup>†</sup> for DUPIXENT.

†Limitations apply. Visit DUPIXENT.com for full program terms.

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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.
- with other asthma medicines for the maintenance treatment of moderate-to-severe asthma in people aged 12 years and older whose asthma is not controlled with their current asthma medicines. DUPIXENT helps prevent severe asthma attacks (exacerbations) and can improve your breathing. DUPIXENT may also help reduce the amount of oral corticosteroids you need while preventing severe asthma attacks and improving your breathing.
- DUPIXENT works by blocking two proteins that contribute to a type of inflammation that plays a major role in atopic dermatitis and asthma.
- DUPIXENT is not used to treat sudden breathing problems
- It is not known if DUPIXENT is safe and effective in children with atopic dermatitis under 12 years of age.
- It is not known if DUPIXENT is safe and effective in children with asthma 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 (if you also have atopic dermatitis)
- 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.
- $\bullet$  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 adolescents 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.

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

#### 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. If you have atopic dermatitis, tell your healthcare provider if you have any new or worsening eye problems, including eye pain or changes in vision.
- Inflammation in your blood vessels: Rarely, this can happen in people with asthma who receive DUPIXENT. This may happen in people who also take a steroid medicine by mouth that is being stopped or the dose is being lowered. It is not known whether this is caused by DUPIXENT. Tell your healthcare provider right away if you have: rash, shortness of breath, persistent fever, chest pain, or a feeling of pins and needles or numbness of your arms or legs.

The most common side effects of DUPIXENT include: injection site reactions, pain in the throat (oropharyngeal pain) 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, 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. 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 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

Manufactured by: Regeneron Pharmaceuticals, Inc., Tarrytown, NY 10591 U.S. License # 1760; Marketed by sanofi-aventis U.S. LLC, (Bridgewater, NJ 08807) and Regeneron Pharmaceuticals, Inc. (Tarrytown, NY 10591) DUPIXENT is a registered trademark of Sanofi Biotechnology / ©2019 Regeneron Pharmaceuticals, Inc. / sanofi-aventis U.S. LLC. All rights reserved. Issue Date: March 2019

US-DAD-14946(1)



#### THE STRUGGLE IS REAL

A parent's guide to caring for kids with eczema from infancy through adolescence

Eczema families, pediatric dermatologists and a pediatric allergist share their best advice for raising little ones with atopic dermatitis and allergies and preparing them for adulthood.

BY MARGARET W. CRANE

hristine Pham-Cutaran's infant son, Drew, developed a rash just two weeks after he was born. No biggie, she thought. "We were sure it was baby acne or a reaction to hormones or nursing," she said.

But shortly before his 2-month checkup, Drew rubbed his cheeks raw in his sleep. In the morning, Pham-Cutaran saw blood on his sheets. That's when she realized his rash was much more serious than baby acne, and she was right. At 6 months, baby Drew was diagnosed with atopic dermatitis (AD).

Pham-Cutaran and her husband, Joseph, were up every night, holding their baby's arms down so he wouldn't scratch. Following their pediatrician's advice, they applied an antifungal cream to his oozy, red cheeks, but "his eczema just got worse," she said.

Dr. Robert Sidbury, a pediatric dermatologist at Seattle Children's Hospital, knows the Cutarans' struggle all too well. Based on recent research, he endorses early, consistent moisturizing of the skin of infants born into eczema-prone families. Eczema runs in Joseph Cutaran's family, so his son fits that profile to a T.

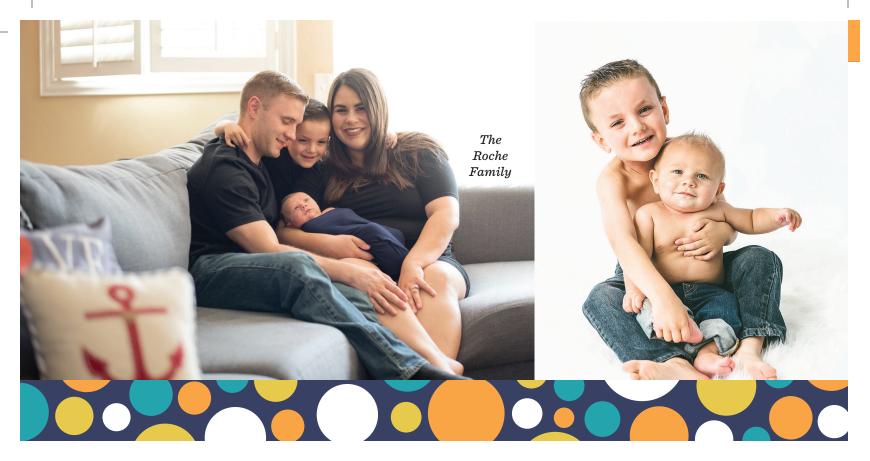
#### An ounce of prevention

Sidbury cited a 2014 study published in the Journal of Clinical Immunology that explored the benefits of moisturizing the skin of high-risk infants as early as two days after birth.

First, author Dr. Eric Simpson, a professor of dermatology at Oregon Health & Science University in Portland, found daily moisturizing with a petroleum- or plant-based emollient reduced AD risk by 50% by the time the babies reached 6 months old.

"That's a significant finding," said Sidbury. "The only caveat is that it's still early in the research process. We're not sure if early moisturizing will prevent AD from developing later on, and we don't know whether it will prevent comorbidities like asthma and allergies."

Still, he said, parents have every reason to embrace this potentially preventive strategy — one that's also comforting for parent and baby alike. ▶



#### Trigger avoidance vs. tolerance

#### Eczema triggers

For now, there is no sure-fire way to prevent eczema and its comorbidities from happening, but managing flares is well within parents' reach, especially if their children have less severe forms of the condition.

Some parents try to keep their kids with eczema away from every known trigger, while others adopt a more "laissez-faire" attitude. Brittney Decker-Roche falls somewhere in the middle.

"Our son, Payton, is allergic to grass, dust mites, cats and dogs," she said, "and he's severely allergic to peanuts and fish. But you can only eliminate so much. It hasn't been easy, but we've learned to pick our battles."

Asked whether parents should aim to eliminate all potential irritants and allergens or help their children learn to tolerate them over time, Dr. Elaine Siegfried, a professor of pediatrics and dermatology at Saint Louis University School of Medicine, seconded Decker-Roche's view, urging parents to choose their battles wisely.

"The biggest eczema triggers are germs, products and changes in ambient humidity," she said. "Germs are everywhere, so there's no point in trying to eliminate them. The same goes for environmental allergens, such as dust and pollen. And if you live in a part of the country that has four seasons, dry air can be challenging during winter."

It can take time and extra effort — using a humidifier, for instance — to adapt to low humidity, she said.

"Of course, parents should keep their kids away from clearcut triggers," Siegfried said. "If a child has contact dermatitis in reaction to a specific substance, avoiding that substance is paramount. However, we don't want kids to live in a bubble, nor is that a realistic goal."

Siegfried went on to name another under-recognized source of eczema triggers: baby products, which are part of a larger phenomenon that she calls the "cosmeceutical industrial complex."

"With the best of intentions, parents can be misled by a product's advertising claims," she said. Hypoallergenic, gentle, 100% pure — these are meaningless terms, and they conceal more than they reveal."

Her best advice? Read not just the front but the back of every label. Figure out what's really in those products. Avoid complex topicals that contain dozens of ingredients. You might even save a bundle by resisting the temptation to buy into the "cosmeceutical industrial complex."

Parents of children with eczema already have a powerful alternative resource at their fingertips that will help them make smarter, safer choices for their children. NEA's Seal of Acceptance™ product directory allows you to filter your search by product type, age group or brand. You can even plug in an unwanted ingredient to filter out products that contain it. Visit EczemaProducts.org to learn more. ▶

#### **Environmental triggers**

When it comes to allergies and environmental triggers such as trees, grasses, pollen and dust, the avoidance vs. tolerance question gets more complicated, said Dr. Jonathan Spergel, chief of the allergy program at Children's Hospital of Philadelphia.

"In the Northeast, during pollen season, if you go outside, you can't avoid being exposed to it. I advise my young patients to wash it off once they're indoors, take their medication and come in for regular allergy shots," he said.

In other words, Spergel said children should do their best to live with the allergens that surround them rather than try to avoid them altogether. But if a child is allergic to cats and dogs, avoidance is the best strategy, he added.

#### Food allergies

"Food allergies are perhaps the hardest of all to manage, especially given their complex relationship with AD," Spergel explained.

Most foods don't actually trigger AD, he said. Recent studies indicate that it's the other way around: an AD flare can aggravate a child's food allergies.

But in a small percentage of patients, food allergies can trigger an AD flare — especially IgE-mediated allergies, said Spergel.

Associated with an antibody called immunoglobulin E (IgE) that's found in the bloodstream, these can cause a range of allergic symptoms from mild to serious, including anaphylaxis, a dangerous whole-body allergic reaction.

The most common IgE-mediated food allergens include:

- Milk
- Egg
- Soy
- Wheat
- Peanut
- Tree nuts
- Fish
- Shellfish

"Most children
outgrow a milk
allergy," Spergel
said, "but many
kids with eczema
remain allergic to one or
more of the foods on the list.
If your child reacts violently
to peanuts, you have no choice but to eliminate them."

In most cases, though, parents can opt to gradually introduce tiny amounts of wheat, eggs, fish or other problematic foods to their child with particular food sensitivities or allergies. And if the child tolerates the food in question, it's safe to increase it little by little over time, said Spergel.

#### 'This is us!'

A few years ago, when she was nursing Drew, Pham-Cutaran tried to eliminate every food on the problem list.

Committed to breastfeeding, she eliminated "gluten, dairy and a whole slew of other foods from my diet. The only result was that I lost a tremendous amount of weight, while Drew's AD continued to make him look like a burn victim.

"I got a lot of judgmental feedback from people," she continued. "It was 'mom guilt' times 20."

Pham-Cutaran then decided to adopt a more aggressive approach to treating Drew's AD that included bleach baths, topical steroids and oral antibiotics, but nothing worked—at least not for long.

Finally, about a year ago, she stumbled across the Facebook page of Dr. Richard Aron, a pediatric dermatologist based in Cape Town, South Africa, who would change everything.

Pham-Cutaran watched a couple of Facebook videos showing families coping with their children's AD, along with before and after pics following treatment with Aron's unique formula: a personalized topical that he compounds using three ingredients: a corticosteroid, an antibiotic and a moisturizer.

She recognized her own family's story in theirs. "Something clicked when I saw those images. All I could say was, 'This is us!'

"Cape Town is a long way from our home in Fort Worth, Texas," she added, "but Dr. Aron's approach struck us as simple and low-risk. It's all about compounding and tapering how much and how often you apply his formula — the bottom line is that it worked [for us]."

Today, 4-year-old Drew is doing well on the Aron regimen as maintenance therapy. "He's living his best life now," Pham-Cutaran said. "Eczema no longer defines him. And it's so good to see him smile." ▶



### Adherence: The path to healing for children at every age

Whatever the severity of your child's eczema, always start with topicals as they are the cornerstone for treating the disease in infants, school-aged kids and teenagers alike, said Siegfried.

But there's a big problem: non-adherence. "Studies show that 75% of families are afraid of topicals — especially steroids," Sidbury said. "But if they don't use topicals as prescribed, their children probably won't get better.

"If used appropriately, topical steroids can be safe and highly effective for use in children," Sidbury explained. "Parents are right to use caution where prescription medications are concerned. They're understandably alarmed at the prospect of side effects, and they don't want a bell that they can't unring. But even side effects like skin thinning are avoidable and even reversible."

As a general guideline, he said, use a fingertip's worth of steroid cream or ointment per day for a maximum of two weeks per month. Then, ratchet down the dose to twice a week, and take a complete steroid break once your child's skin clears up.



#### En route to adulthood

At some point, usually when they reach their double digits, children start to develop their own ideas and preferences, Siegfried said. They also tend to fall under the sway of peer pressure, and parents can feel sidelined in the process. That's precisely the time to rethink the best ways to care for your child in transition to adulthood.

Parenting styles can range widely, she explained. "There are 'helicopter parents' who try to organize everything in their child's life, and then there are those who turn everything over to their kid, often prematurely. Whatever a parent's philosophy, I encourage them to ask themselves the following question: 'What's the best way to prepare my child for independent living?'"

It's all in the timing, she said. And the best time to start transitioning care is during early adolescence when a child is 12 or 13. To avoid a crisis later on, teach your child to practice regular skincare, read a prescription label and adhere to treatment under the care of a trusted specialist. That way, an older child will be prepared to deal with eczema — and with life — en route to adulthood. ▶



## Caring for the Caregiver

Eczema in children, especially when it's severe, can wreak havoc on the lives of everyone in the family. If you're a parent or caregiver of an infant or child with AD, you already know all the "should-do's" like get plenty of rest, take time for yourself and live your own life to the fullest, right? Easier said than done.

According to Sidbury, studies show that eczema families average a loss of about two hours of sleep per night, and that goes for both parents and children. Good sleep hygiene can help. Here are five sleep hygiene basics from the Centers for Disease Control and Prevention that can help the whole family get their zzzs:

- Aim for the same bedtime every night and get up at the same time every morning, even on weekends.
- Keep everyone's bedroom dark and comfortably cool.
- Turn off all TVs, computers and smart phones. Turn your bedrooms into phone- and screen-free zones from bedtime to rise-and-shine.
- A small snack is fine, but try to avoid eating a large meal before bed. Caffeine and alcohol are no-nos as well.
- Get plenty of exercise during the day and encourage your kids to do the same.

In an effort to help a child get past their itchy skin long enough to fall asleep, some parents turn to antihistamines for help. Sidbury thinks it's reasonable to try them, but he warned against regular use.

Siegfried agreed, saying, "Antihistamines are sold overthe-counter, making them easy to overuse. And overuse can lead to unwanted side effects — especially agitation and even attention deficit/hyperactivity disorder (ADHD)." However, intermittent use is fine, she noted, especially on those nights when nothing else seems to do the trick.

Sidbury also suggested parents form a partnership during their child's eczema flare, each taking a four-hour shift. That's not always an option if you're a single parent, he admitted. Still, "there are different kinds of partnerships, and NEA can become your long-distance partner"—bringing you the information and support you need, even in the middle of the night.

Turn to page 25 for more information on how eczema can impact caregivers' sleep cycles. \*

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## Bon Voyage, Eczema! How to travel without triggering a flare

Whether it's a business trip or a family vacation, adults and children with eczema often struggle with travel-related flares or avoid traveling altogether. Here's how to expand your horizons while keeping allergies in check.

BY EMILY DELZELL

here are few places hotter than Birmingham, Alabama in July, as Bryson Doyle and his family found out when they traveled to the Deep South for a family reunion from their milder home climate in Pontiac, Michigan.

"Bryson's atopic dermatitis can be triggered by almost anything, but heat is a real big trigger," said his mother, Lynell Doyle. "Birmingham is the hottest place I've ever been in my life. Bryson broke into rashes often, and we had to spend a lot of time in air-conditioned areas."

Lynell starts planning weeks in advance for travel with Bryson, 12, his brother Brenden, 9, and their father, Garland. She'd prepped well for the sizzling Alabama climate by bringing a stash of components for ice compresses, chilled towels, as well as Bryson's moisturizers, medications and EpiPens. When they travel, the largest bags the Doyles bring are the ones packed with these necessities, plus food and beverages they know won't result in an allergic reaction.

Although the Birmingham heat — along with its bugs — presented more of a challenge than Lynell anticipated, the Doyles adapted and enjoyed reconnecting with extended family. "There was a picnic, and we were able to attend — we just didn't stay as long as everybody else," she said.

Bryson made the evening fireworks show too. His parents wrapped him in a light blanket to keeps bugs off (like many people with atopic dermatitis, Bryson's skin can't tolerate insect repellent).

The Doyle family's proactive, flexible approach is the way to go when it comes to travel, said Jennifer Moyer Darr, a licensed clinical social worker in the division of pediatric behavioral health at National Jewish Health in Denver.

"Eczema and atopic dermatitis don't have to prevent adventure," she said. "You may have to go about it a little differently than your neighbors, but you can still go, and you can still enjoy it."

#### **Challenges and Solutions**

The best defense against eczema flares when traveling is anticipating them and having the right tools at the ready to combat them, said Karol Timmons, a pediatric nurse practitioner and clinical coordinator in the division of allergy and immunology at Boston Children's Hospital.

Here are some smart solutions to common travel challenges:

**Challenge: Travel stress** — Travel stresses everyone out, and for people with eczema, pre-trip jitters can trigger a flare.

**Solutions:** Step up your skincare regimen a few days before you leave, whether that means two baths a day to maximize moisturization or extra vigilance in applying topical steroids to hot spots, said Darr.

"If you're teetering on the edge of a flare, the odds are good that travel will knock you over. With extra care, you might still experience issues, but they'll be less likely to ruin your trip," she said.

**Challenge: Changing climates** — Like Bryson Doyle, many people with eczema flare when they travel into a different environment, said Timmons.

**Solutions:** "Understand what kind of climate triggers skin irritation for you and think about what you'll be doing so you can bring everything you might need," Timmons said. She advises packing about twice as much medication and moisturizer as you think you'll need.

Challenge: Flying — Recirculated air and close quarters mean you're easily exposed to other travelers' illnesses. And, if you check a bag, it may not arrive at your destination when you do. ▶

**Solutions:** Wipe down your seat, arm rests and other surfaces with antibacterial wipes. Pack a carry-on with a two-day supply of medications, moisturizers, inhalers and EpiPens. Keep medications in their original containers and bring a letter from your physician if you want to pre-board (a good idea to get time to settle in and relax) or need to carry on liquid medications that exceed the normal limits (3.4 ounces).

**Challenge: Contact allergies** — You can encounter everything from dusty rugs and pet dander in a friend's home to feather pillows and reaction-causing cleaning products in hotels to dust mites almost anywhere.

**Solutions:** Lynell Doyle travels with Bryson's own pillow and sheets. If you're allergic to dust mites, Timmons suggests taking along a fitted dust mite bedsheets and pillow cover. "Some hotels offer feather-free rooms in which you're less likely to be exposed," she said.

Call hotels in advance and request accommodations that will lower your risk of a flare. "Ask them to use unscented cleaning products or to let you clean the room with your own products, for example," Timmons said.

"Look for hotels with bathtubs for soaking in moisture and rentals with hardwood floors. If you're staying with a friend or relative, discuss your needs well before you go to give your hosts time to prepare."

Use a grocery delivery service like Instacart to supply bleach for baths or the cleaning and laundry products you use at home.

**Challenge: Food allergies** — It's easy to end up hungry with few safe food options when you're stuck in an airport terminal or driving the last stretch of a long road trip.

**Solutions:** Include a stash of your go-to snacks in your carryon or easily accessible bag. Call restaurants in advance and ask if they can accommodate your or your child's food restrictions.

**Challenge: International travel** — When you're traveling in the United States, you can usually find your brand of moisturizer or laundry detergent. Overseas, all bets are off. It may also be hard to tell if menu items contain ingredients you or your child is allergic to.

**Solutions:** Ship needed products to your destination a couple weeks before leaving. Visit FARE (Food Allergy Research & Education) at foodallergy.org, where you can print out a "chef card" that lists in one of 11 languages the

foods you need to avoid.

Challenge: A bad flare.

**Solutions:** If you think a bad flare is likely, ask your healthcare provider to write a prescription so you'll be able to get the medication you need quickly. "Also keep in your back pocket all the eczema tools you've learned about," said Timmons. "For example, you may not have needed to do wet wraps in years, but when you're on vacation and have a bad flare, it might save



Photos courtesy of Bry Penney

## Tips from a world-traveling eczema warrior

Camille Knowles, 27, identifies as a digital nomad. The blogger, founder and author of "The Beauty of Eczema," who has had severe eczema since she was six, is based in the U.K., but works on the go as she travels the world.

"I was always afraid to travel growing up, afraid of not having the right creams or a doctor to turn to during a flare-up," she said. "That is why I truly embrace traveling now. I am on a mission to show eczema warriors that they can travel and live their dream life."

#### Her top tips:

- Be prepared and stay calm.
- Sleep whenever and wherever you can. A good eye mask works wonders.
- Pack a lot of healthy snacks and hydrate often.
- Move motion creates positive emotion. Yoga and walking are great on-the-go activities.
- Be positive. Traveling is nourishing for your soul. Read affirmations or try journaling to enhance the experience. \*



#### A Passion for Science and a Commitment to Dermatology

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#### **GET THE FACTS: ACUPUNCTURE**

WHAT IS ACUPUNCTURE, AND CAN IT REALLY HELP SYMPTOMS OF ECZEMA?

IF YOU'RE NEEDLING US FOR AN ANSWER, THEN WE'LL GET RIGHT TO THE POINT.

BY KATHRYN JONES

f a certified acupuncturist were to strategically insert tiny, hair-thin needles into the skin, would it help symptoms of eczema? Just like many of the other topics in our "Get the Facts" series, the answer to that question is a resounding ... maybe?

Acupuncture is a technique in which practitioners stimulate specific points on the body called "acupoints" by inserting thin needles through the skin. It's used as an alternative or complementary treatment for many ailments, including chronic pain, nausea, anxiety and depression.

Acupuncture is a key component of traditional Chinese medicine (TCM), which is considered a pseudoscience among Western medicine practitioners. This means the theories and practices of TCM are not based on medical knowledge and therefore cannot be scientifically proven.

TCM defines acupuncture as a technique for balancing the flow of energy or life force — known as chi or qi (chee) — believed to flow through pathways in the body. By inserting needles into specific points along these pathways, acupuncture practitioners believe that the energy flow will rebalance.

Western practitioners offer a more practical outlook, speculating that the acupoints cover target zones in the body that, when pricked by a needle, will stimulate nerves, muscles and connective tissue. When this stimulation occurs, the body's natural painkillers are released.

#### IS THERE EVIDENCE THAT ACUPUNCTURE WORKS FOR ECZEMA?

There have been extensive studies conducted on acupuncture, especially for back and neck pain, osteoarthritis and migraines. According to the National Center for Complementary and Integrative Health, research suggests that acupuncture can help manage certain pain conditions.

Only recently have there been studies conducted specifically on acupuncture and atopic dermatitis (AD). According to the results of a randomized, 30-person study published in the December 2018 issue of Complementary Therapies in Medicine, acupuncture was found to improve symptoms of mild to moderate AD, particularly in controlling pruritus (itch).

Results of a similar study published in the July 2018 issue of the International Journal of Allergy Medications saw a reduction in itch, lesion size and recurrence in the acupuncture group compared to the control group. The study's authors went on to say that acupuncture was valuable in the treatment of AD "by virtue of the fact that it can reduce a patient's level of stress."

#### ARE THERE ANY RISKS WITH ACUPUNCTURE?

The risks of acupuncture are low as long as you have a competent, certified acupuncture practitioner using sterile needles.

Common side effects include soreness and minor bleeding or bruising where the needles were inserted. Single-use, disposable needles are now the practice standard, so the risk of infection is minimal.

Not everyone is a good candidate for acupuncture. You may be at risk of complications if:

- You have a bleeding disorder. Your chances of bleeding or bruising from the needles increase if you have a bleeding disorder or if you're taking blood thinners.
- You have a pacemaker. Acupuncture that involves applying mild electrical pulses to the needles can interfere with a pacemaker's operation.
- You are pregnant. Some types of acupuncture are thought

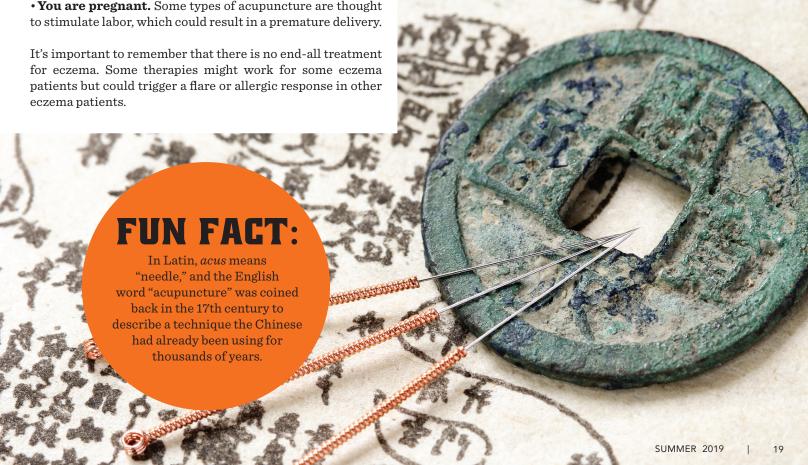
Tell your doctor if you're considering acupuncture. They may offer their opinion on the effectiveness or safety of this treatment based on your unique health profile. Some doctors might even refer you to a trusted acupuncturist.

When you do find a practitioner, check their credentials. Most states require non-physician acupuncturists to pass an exam conducted by the National Certification Commission for Acupuncture and Oriental Medicine.

Before the session, ask the acupuncturist what's involved in the treatment and how much it will cost. Some insurance providers cover acupuncture in their health care plans. Also ask the acupuncturist whether they've practiced acupuncture on eczema patients before. Let them know whether you are experiencing a flare. They may not feel comfortable puncturing areas of the skin directly affected by eczema rash.

Curiously, acupuncture doesn't work on everyone regardless of the ailment it's supposed to treat. There are some people who experience noticeable changes in their bodies during or after an acupuncture session. Others have said they felt no difference at all.

Will acupuncture work for you? Maybe. Is it worth a try? That's for you and your doctor to decide. \*





BY BROOKE BILYJ

eing a teen is tough enough, as you learn to juggle more challenging classes, more time-consuming extracurricular activities and more complicated social interactions. Atopic dermatitis (AD), the most common form of eczema, can magnify that stress — turning everyday tasks into major obstacles.

"As a teen with eczema, I wanted to disappear when I was struggling with a flare," said Kristin Boelter, a 24-year-old from Chicago who has dealt with eczema her entire life. "When you're irritated, it's exhausting to take on normal daily activities."

Eczema impacts every aspect of a teen's life from what you wear, to where you go, to how you feel. Your parents probably helped manage your AD for you when you were a child, but now that you're getting older and gaining more independence, your skin becomes your responsibility.

Learning to take control of your eczema is an important part of transitioning from adolescence to adulthood, and there's a lot to learn from others who have survived those awkward teenage years.

#### **WEIGHING EVERYDAY DECISIONS**

Often diagnosed during early childhood, AD is an inflammatory skin condition that typically manifests in dry, itchy, inflamed patches of skin along with related health conditions such as asthma and allergies. The pain of severe flare-ups can seriously derail a teen's daily schedule.

"Flare-ups and even regular itches make simply existing more stressful than it ought to be," said Tyler Berryman, a 25-year-old from Michigan who has had eczema his whole life. "Everyone learns to 'grin and bear it,' but you have to do it while dealing with the very real discomfort of a flare-up that you cannot immediately heal."

To make matters worse, even simple everyday objects and activities can trigger eczema and the allergies that accompany it — making the average teenage lifestyle feel like an obstacle course.

"Teens with eczema find themselves facing daily questions that most wouldn't think twice about," Boelter said. "Should"

I wear this outfit, or will it make me uncomfortable? Can I wear makeup today or will it cause a flare? Will I be able to get through sports practice? Is it noticeable that I can't stop itching?"

AD can sometimes be "the uncomfortable answer to many questions" when teens get invited to events or activities that might trigger a reaction, said Stephanie Knox, whose 16-year-old daughter Paige was diagnosed with eczema as a baby.

When friends ask Paige if she can go to the beach, help with a carwash fundraiser, go horseback riding or just spend the night, she has to consider how her eczema might react.

"Most kids can just jump in the shower and head out to a social event, but she has to have excuses ready," Knox said. "Eczema is always at the front of her mind and impacts every decision."

For example, sweat is a common eczema trigger that can make teens with eczema think twice about sports, especially when scratchy uniforms are involved.

"Maybe you don't want to join the football team because the pads are sweaty and they'll stick and rub," said Berryman, who played soccer, tee-ball and other youth sports as a young child but gave them up because the sweat irritated his skin.

"Having to avoid triggering activities creates extra pressures for teens with eczema. You steer yourself away from things without really being aware of it."

But don't let eczema stop you from doing things you enjoy, he added. Berryman took up swimming for a couple of years in high school. As long as he applied plenty of moisturizer, the chlorine in the pool actually calmed his skin. He also participated in marching band, even though the woolen uniform irritated his skin.

Boelter, meanwhile, pursued cheerleading. Since her squad stretched in the grass before practice, she brought towels to sit on so the grass wouldn't make her itchy. She couldn't wear makeup like the other cheerleaders because it would cause her to flare. But it didn't stop her from making the varsity cheer team her freshman year.

#### **BEARING THE STRESS OF ECZEMA**

After puberty, Berryman's eczema moved from his arms and legs to his face and torso, making the visible impact of his condition harder to hide from his peers.

"The social consequences of eczema are often the hardest part of teen life. There were times when you'd want to go talk to that cute girl you like, and she gives you a funny look because half your face is red," said Berryman, who studied optical engineering at the University of Rochester in New York and now works in Silicon Valley.

"It just compounds the already natural self-consciousness that any kid in high school has, and it adds extra social pressure to scenarios that are already tough enough."

These embarrassing experiences add stress during a traditionally stressful age, which can exacerbate eczema even more. Tyler urged teens with eczema to prioritize their care and comfort first, "and worry about social concerns second."

"If someone gives you a funny look, that's not your problem," he said. "It may certainly feel like your problem, especially when you're self-conscious. But at some point, you just have to roll with it and keep going on with your day."

As a child, Boelter used to isolate herself and avoid social activities during flares. As she grew up, she discovered healthier ways to handle the stress of eczema. The first and best defense, she advised, is "to get as much sleep as possible, as it's your body's natural healing state."

But that's easier said than done, especially when the itch keeps you awake at night. Finding other ways to relax is critical to breaking the cycle between stress and eczema.

"When I'm stressed or having trouble taking my mind off the itch, I'll pray, use a meditation app or read. All of these things help me relax," Boelter said. "Find something you love that is eczema-friendly and spoil yourself with it. I like to watch a movie with my favorite snack and an ice-pack." ▶



Several studies suggest connections between severe eczema and mental health issues like anxiety and depression. Research indicates that teens with eczema are more likely to have suicidal thoughts or attempt suicide. To manage these emotions, find someone to share your feelings with, whether it's a parent, a friend, a counselor or NEA.

"It's hard to talk about mental health, but it's so important to reach out and talk your struggles through with someone you trust," Boelter said. "As a teen, you're constantly worrying about what others think when it's much more important to focus on yourself."

#### MANAGING YOUR TREATMENT ROUTINE

Every morning, Berryman abides by a simple but critical skincare routine to keep his eczema in check — starting with a shower, followed immediately by topical corticosteroid on problem areas, then a layer of moisturizer all over.

He repeats this process as needed after workouts or before going out. He also gives himself a weekly biologic injection. He said the sooner teens can develop a routine that works for them, the better off they'll be.

"Teens need to learntime budgeting to plan skincare into their schedules. It's a prerequisite to getting ready to go out, so it should be treated as a necessity, not a chore," Berryman said. "Although this mental transition is difficult for teens, it's key in easing the transition of responsibility away from your parents."

Of course, teens tend to rebel against anything their parents tell them to do regularly, even if it's just a reminder to apply more lotion or stop scratching.

"As a teenager, you bristle at that because you're like, 'No, it's my skin, it's my problem. I don't have to listen to you,' even though what they're saying is the right thing to do," said Berryman, who finally came to grips with his skincare regimen after meeting adults through NEA who had their routines down and their eczema under control.

"The longer you put off shouldering the responsibility, the worse your problems are going to be," he said. "There's no reason why you should avoid things that you have to do to make yourself feel better."

A big part of taking responsibility for your own eczema care is paying attention to your skin and what triggers your flares. "My best advice to teens is to keep track of your most common

triggers," said Berryman, who also has multiple food allergies in addition to AD and asthma. "Knowledge is power, and for the eczema patient, it's also safety. It's extremely important to know how a serious reaction begins to manifest so you can avoid the worst of it."

For Berryman, this means asking about ingredients when he eats at restaurants and keeping EpiPens on-hand just in case. Boelter keeps a journal to track what she eats at the recommendation of her dietician. She also adds notes about environmental factors that might cause a flare, like visiting a friend's house where she's around dogs.

"Don't deny your symptoms," she said. "I was denying my triggers because I didn't want them to be true. But journaling about things that I thought might irritate my eczema really helped me monitor my environment and reduce my chances of triggering a flare. I have never felt more in control of my skin than I do now."

#### TAKING THE FIRST STEP

The teenage years can be tricky. Learning to manage a chronic condition like eczema makes growing up seem even more daunting. But Knox suggests looking at it this way: Eczema gives you the strength to endure challenges that other teens will never understand.

"Your battle with eczema [can] empower you to overcome obstacles and be a successful adult," Knox said. "Your journey can be unpredictable, but no matter how it flows, your ability to care for yourself will empower you."

Boelter said AD has forced her to grow up faster—
developing her character and giving her a greater
Stephanie and Paige
sense of empathy toward others. Her advice to
teens with eczema is to focus on the positives.

"Don't get discouraged. It's easy to get upset and wallow in it for a while, and that's OK, but don't get stuck there," she said. "You can only start with small steps, so break it down into manageable tasks that allow you to feel like you're in control. Every little adjustment works together to help you feel more comfortable in your skin."

As you make the transition to taking control of your own eczema care, Berryman said to remember you're never alone. Don't be afraid to ask for help when you need it.

"Teens need to know that the transition, while daunting, is far from impossible, and leaning on others does not make you weak," he said. "Just take one day at a time, keep going, and you'll get through it."▶

## QUESTION: HOW CAN PARENTS HELP TEENS WITH ECZEMA TRANSITION INTO ADULTHOOD?

Here is a teen's perspective from Tyler Berryman, 25, who was diagnosed with eczema at a young age:

"Getting teens to accept themselves is tough, even without eczema. This is where parents come in. Providing an environment at home where the teen can feel safe and confident is invaluable. Emphasize that having eczema doesn't make the teen a burden.

"I think the biggest challenges for parents are getting your teen to take responsibility for their own skincare and getting them to love and accept themselves — eczema and all. Gradually, give them more responsibility with their skincare.

"This shift will not be easy, and teens often learn by shooting themselves in the foot first, which can tempt parents to hold onto control longer than they should. No teen wants to have their parents breathing down

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their neck, especially with something as emotionally sensitive as their skin."

Here is a parent's perspective from Stephanie Knox, mother of a 16-yearold daughter with eczema:

"If I could talk to a younger parent, I would say to train your children by example while they are young. Make their skincare a priority. Stop the world to grease them up, while at the same time taking an attitude that it's no big deal, it's just our routine.

"Make it a routine, like brushing your teeth or eating. It's a lifestyle they will learn to live. Then, when it's their time (and let them decide when), they can take over their skincare with you close by for support. The way you did it at home will stick with them, especially if it worked. Your role through the years is to train, then support, then encourage." \*





## peer into the future

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

BY KATHRYN JONES

#### Two new biologics show promising results in phase IIb clinical trials

ver since the U.S. Food and Drug Administration (FDA) approved Dupixent (dupilumab), other biologics have been making their way through clinical trials.

Biologics are injectable drugs that use an antibody to treat a disease at the immune system level. And the more scientists understand how the different levels of the immune system can be targeted for therapy, the better their chances of developing safe and effective treatments.

The human body uses certain types of signaling molecules called interleukins, or ILs, which help our immune system fight off harmful viruses and bacteria. But for people with AD, their immune system tends to overreact and trigger certain ILs to produce inflammation.

Biologics block ILs from binding to their cell receptors, which keeps the immune system from overreacting — thereby lowering inflammation and decreasing symptoms of AD. Dupilumab, made by Regeneron Pharmaceuticals and Sanofi Genzyme, was the first, and for the time being, remains the only FDA-approved biologic for AD. It targets the IL 4 and IL 13 receptors.

Several more biologics have been making their way through the development pipeline, including Galderma's nemolizumab and Dermira's lebrikizumab. Both treatments recently completed their phase IIb clinical trials.

Results for nemolizumab's phase IIb trial were presented at the Annual Meeting of the American Association of Dermatology, which took place March 2019 in Washington, D.C. Nemolizumab is an antibody that blocks the IL 31 receptor.

The results of the trial were positive — with participants on the 30 mg dose of nemolizumab achieving a 68.8% skin improvement from baseline Eczema Area and Severity Index (EASI) at week 24, compared to those on placebo achieving a 52.1% improvement in EASI.

This phase IIb study had adults whose eczema was uncontrolled by topical corticosteroids (TCS) and topical calcineurin inhibitors randomized into the placebo group, the 10 milligram (mg) dose group, the 30 mg dose group or the 90 mg dose group.

To qualify for the study, participants had to have an EASI of 12 or greater and a body surface area (BSA) involvement

of at least 10%. Participants had a run-in period of four weeks with midpotency TCS used for stabilization.

The safety profile for nemolizumab was positive — with patients from all dose groups having either a similar or lower rate of

adverse events. The most common adverse events were nasopharyngitis (found in 26.6% of nemolizumab

participants vs. 21.4% in the placebo group), exacerbation of AD (24.9 % in the nemolizumab groups vs. 32.1 % in the placebo group), and non-herpes skin infection (13% in the nemolizumab groups vs. 12.5% in the placebo group). Meanwhile, Dermira announced positive results from its phase IIb dose-ranging study of lebrikizumab, a biologic that targets IL 13, in adults with moderate to severe AD. All three doses of lebrikizumab demonstrated greater improvements in the EASI score compared to the placebo.

The improvement in EASI score was 62.3% for patients receiving 125 mg every four weeks, 69.2% for patients receiving 250 mg every four weeks, and 72.1% for patients receiving 250 mg every two weeks compared to 41.1% for the placebo group.

The most common adverse events reported across all three lebrikizumab dosing groups were upper respiratory tract infection (7.5% vs. 5.8% for the placebo), nasopharyngitis (6.6% vs. 3.8% for placebo), headache (3.1% vs. 5.8% for placebo), injection site pain (3.1% vs. 1.9% for placebo), conjunctivitis (2.6% compared to no reports for the placebo), and herpes infections (2.2% compared to no reports for the placebo).

Overall, adverse events observed in both biologics were mild to moderate in severity and seldom led to treatment discontinuation. To research more eczema treatments in the development pipeline, visithttps://nationaleczema.org/research/eczema-treatment-research/. \*



#### Sleep disturbances, exhaustion common among mothers of children with AD

or parents of newborn and young children, sleep disturbances are a given. But a new study funded by the National Eczema Association has revealed that mothers of children with moderate to severe AD are more likely to experience sleep loss and daytime fatigue than mothers of children without the disease.

In the ongoing Avon Longitudinal Study of Parents and Children, all pregnant women residing in Avon, U.K., with an expected delivery date between April 1, 1991, and December 31, 1992, were recruited.

The objective was to compare sleep disturbances over time between mothers of children with and without AD and to determine whether these disturbances are associated with the child's disease severity and the child's own sleep disturbances.

Participants were followed for a median of 11 years, with 30% of children meeting the definition of having AD at some point between 2 and 11 years of age, and 21.8% to 38.5% were reported to have moderate to severe disease.

A secondary analysis of this cohort took place from September 2017 to September 2018. Mother-child duos were followed up with a time-varying measure of child AD activity and severity and self-reported maternal sleep measures repeated at multiple time points when the child was between 6 months and 11 years.

The results of the study were published in the March 2019 issue of JAMA Dermatology. Researchers found that mothers of children with AD reported trouble falling asleep, insufficient sleep and daytime exhaustion. These effects rose with increasing disease severity and were not entirely explained by the child's nighttime awakenings.

"This study gives me pause to reconsider my approach to parents of children with moderate and severe AD," said Dr. Sarah Chamlin, professor of pediatrics and dermatology at Northwestern University Feinberg School of Medicine and pediatric dermatologist at the Ann and Robert H. Lurie Children's Hospital in Chicago.

"A sleep-deprived and exhausted caregiver may be less able to adhere to time-consuming skincare and to cope with her child's behavioral needs. When a child's AD is not improving despite a prescribed routine that should 'work,' further inquiry into the caregiver's emotional well-being should be considered."

The study's authors suggested that medical professionals caring for children with atopic dermatitis should screen for maternal sleep disturbances and caregiver fatigue.

"A simple question can be asked about how the caregiver herself is coping and sleeping," Chamlin suggested. "Psychosocial support through a patient advocacy group such as the National Eczema Association or the caregiver's provider can be offered and would very likely be appreciated." \*

#### Swiss scientists identify link between skin fungi imbalance and AD

kin, the human body's largest organ, operates much like an ecosystem or a community of living and non-living organisms that interact as a system. Long ago, scientists discovered that our skin is colonized by a diverse milieu of microorganisms, most of which are harmless or even beneficial to our health.

Immunologists at the University of Zurich in Switzerland have shown that our immune system is responsible for maintaining the balance on our skin. But when they researched how the immune system responds to a particular strain of fungus on the skin, they made an unusual discovery.

The Swiss scientists theorized that the same immune cells that protect us against the normally harmless Malassezia fungus might also play a fundamental role in triggering atopic dermatitis.

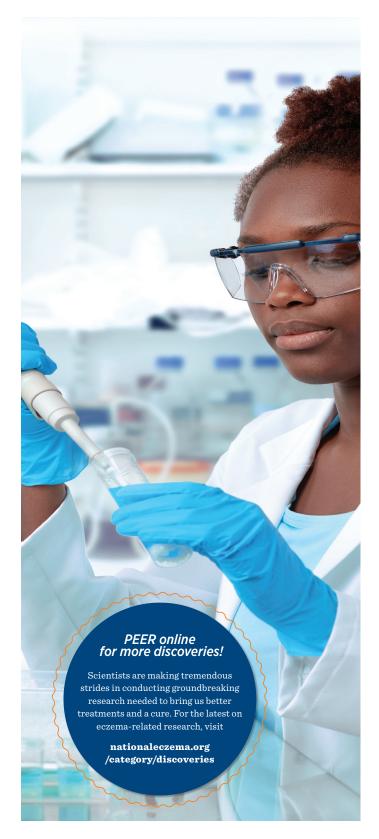
They conducted a study that found that interleukin 17 (IL 17) production by certain immune cells, which normally provide protection against uncontrolled fungal growth on the skin, also contribute to an overreactive immune response and the development of AD symptoms.

The researchers were able to demonstrate in mice as well as in humans that Malassezia fungi stimulate the immune system to produce IL 17. When that happens, the Malassezia fungus becomes an allergen on the skin, so to speak, and triggers an overreaction of the immune system with the same inflammatory characteristics of AD.

"If this cytokine isn't released or if the immune cells that produce IL 17 are missing, there is nothing to stop the fungus from growing and infesting the skin," said Salomé LeibundGut-Landmann, professor of immunology at the University of Zurich.

"The findings of our study suggest that therapeutic antibodies that neutralize the effect of IL 17 could be an effective treatment for atopic dermatitis. These antibodies already exist and are being used to treat psoriasis with great success," said LeibundGut-Landmann.

Like atopic dermatitis, psoriasis is a chronic inflammatory skin condition caused by an overactive immune system. Within the past five years, the FDA has approved biologics for adults with moderate to severe psoriasis that target IL 17, including Saliq (brodalumab), Taltz (ixekizumab), and Cosentyx (secukinumab) — the latter of which is now in phase II clinical trials for adults with AD. \*





When it comes to ecz-ercising with eczema, don't sweat the small stuff. These tips will help you get your fitness game on without triggering a flare.

BY KATHRYN JONES

f you think fitness isn't your forte, you might want to give it another chance.

There are many reasons why exercise helps eczema. It keeps the heart, muscles and bones strong and healthy. It boosts energy levels and the immune system. It improves brain health and memory. It lowers stress, depression and anxiety. It helps you lose weight and get a better night's sleep.

The downside of exercising with eczema is the fact that sweat can trigger flare-ups in some people. The body sweats in order to regulate body temperature. When we get hot and sweaty, the moisture evaporates, cooling us down. As the sweat evaporates, the skin dries out and is left with a salty residue that can irritate eczema skin and bring on the itch.

The good news is that there are steps you can take before, during and after your workout to reduce your chances of flaring. And even if you do have an eczema flare, there are low-impact exercises that will still give you the same fitness benefits without breaking a sweat. ▶

#### FIND AN ECZEMA-FRIENDLY WORKOUT SPACE

Choosing the right fitness club is important when you have eczema. Find a gym that is well ventilated. Look for one that has shower facilities and plenty of fresh, clean towels. Just remember to bring your own personal care products that work best for your sensitive skin, and don't skimp on the lotion.

Keep in mind that exercising in the comfort and privacy of your own home has its perks. You can crank up the air-conditioning or surround yourself with fans and blast your favorite workout music. You can also take a shower immediately afterward to rinse off the sweat. Just make sure the water is cold or lukewarm, as hot water tends to dry out the skin.

If you like to exercise outside, do so in the early morning or evening hours when the sun's rays are less intense. The peak sun intensity hours — when UV light is the strongest and the temperatures are at their hottest — are between 10 a.m. and  $4~\rm p.m.$ 

Even if you avoid peak hours and stay in the shade, you should always wear sunblock. Bring extra bottles of water, not only to keep rehydrating but to also rinse off the sweat. Just as you would after a bath or shower, gently pat the skin dry with a clean towel.

#### SPANDEX AND ECZEMA DON'T GET ALONG

As tempting as it may be to bust out the spandex bodysuit and wool leg warmers, this isn't the 1980s, and you aren't Jane Fonda. Spandex and wool are materials that tend to irritate sensitive skin and exacerbate eczema.

There are new, man-made fabrics on the market designed to wick moisture away from the skin. But these synthetic fabrics can also irritate your skin. Stick with light, breathable fabrics, such as cotton instead. Keep in mind that tight, form-fitting workout clothes will trap in sweat. Your skin will thank you for wearing looser, more comfortable clothing.

It's common for people with eczema to feel self-conscious. We wear long-sleeved shirts and pants to cover up as much skin as possible. But this will only make your skin warmer when you work out, causing you to sweat more.

Try to remember that most people go to the gym to improve their health — not judge other people's appearances. Don't be afraid to put on shorts and a T-shirt, good-looking! ►

#### WHAT TO PACK IN YOUR GYN BAG

As we all know, living with eczema means you have to plan things in advance. Before you head out to the local fitness club with duffel bag in tow, don't forget these essential items:

- Water bottle People with eczema have to drink extra water to stay hydrated inside and out. Don't be afraid to fill up that bottle at the drinking fountain multiple times.
- Asthma inhaler, EpiPen, medications and a list of your emergency contacts.
- Clean towel and washcloth from home –
   Fitness club towels are usually washed with harsh detergents.
- Disinfectant wipes to wipe down equipment before use – Why take your chances on the gym's sanitary wipes or spray when you can bring some you know won't aggravate your skin?
- Travel-sized bottles of your favorite eczema-friendly shampoo, condition, soap, moisturizer, deodorant, flip-flops or shower shoes if you plan to shower there.
- Extra change of underwear, socks and clothes Even if you don't shower at the gym, you'll want to get out of those sweaty gym clothes pronto to avoid triggering a flare.
- Plastic grocery bag for wet towels and sweaty clothes.
- Headphones, music to motivate you to move, and an extra battery charger for your phone.

#### IS YOUR ECZEMA FLARING? DON'T SWEAT IT

Sometimes, eczema flares are inevitable, but it doesn't necessarily mean you have to stop exercising. Simply dial back the intensity of the workout until your skin calms down.

If you find your usual go-to exercises aggravate your eczema, think outside the gym. For instance, if you tend to hit the treadmill hard, go for a brisk walk around the neighborhood instead. If you enjoy using a stair-climber at the gym, walk up a set of stairs at home or work at a slower, more leisurely pace.

Strength training with weights will build strong muscles and raise your heart rate. Plus, it has built-in breaks that force you to stop and rest between sets, allowing your body to cool down and your heart rate to return to normal.

If you need to take cardio off the table for the time being, there are low-impact workouts you can do in the interim that won't make you sweat excessively or feel overheated. Tai chi, Pilates and yoga are often just as effective at improving mobility, muscle strength and reducing stress.

If you're experiencing a particularly bad flare and don't feel well enough to work out, don't push it. Always listen to your body when it's telling you to rest. And always consult with your medical provider if you have concerns or questions about exercising. \*



#### TO REMEMBER WHEN YOU ECZ-ERCISE WITH ECZEMA

- 1) Wear loose, cotton clothing.
- 2) Take regular rest breaks.
- 3) Blot sweat away with a clean towel.
- 4) Drink water and bring extra to rinse off sweat.
- 5) Go for low-impact workouts during an eczema flare.

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Members of the NEA's new Teen Engagement Program Steering Committee share their stories to help other teens with eczema overcome challenges in life.

BY BROOKE BILYJ

ore than 31 million Americans have some form of eczema, including nearly 10 million adolescents under age 18 with atopic dermatitis (AD). But teens dealing with skin conditions during the most vulnerable years of their lives often feel like they're facing it all alone.

"I've never known anybody with eczema besides myself," said Silvia Miyares, a 23-year-old public relations publicist from Chicago who's had eczema since she was born. "Having something that you've never seen on anybody else is really hard, so it was difficult growing up. I felt very isolated."

Isolation is a common struggle for teens with eczema, even though millions of people have traversed that tricky stage of life before. To help teens with eczema better understand and manage their condition, the National Eczema Association is ramping up its efforts to serve and support eczema warriors of all ages.

"NEA has always wanted to engage our teen population and address the needs that are unique to them," said Jessica Bartolini, manager of community engagement.

"We want to make sure that we're providing the support, resources and education they need. We could have made assumptions about what that included, but we wanted the teens to tell us what they really want and need to manage their eczema."

Last August, NEA put out a call-to-action for teens and young adults interested in joining its Teen Engagement Program Steering Committee to help guide and influence a Teen Engagement Program. The response was overwhelming as teens (and former teens) jumped at the opportunity to share their eczema journeys.

"The statistics show that there's millions of people with eczema, but most kids my age that live with severe eczema feel like there's no one around that they can talk to," said Harry Do, a 23-year-old from Gainesville, Georgia, who was diagnosed with eczema shortly after birth.

"I decided to get involved with the Teen Engagement Steering Committee because I wish I had someone there for me who knew what it was like living with eczema when I was still in school."

The steering committee has a total of 16 members ranging in age from 12 to 23, all living with eczema. Here's a sneak peek inside some of the committee members' stories and how they're shaping NEA's new Teen Engagement Program. ▶

#### Finding common ground

When Ryland Mortlock was growing up and went to the pool with his family, parents worried that the rashes on his skin were caused by a contagious disease that their kids might catch.

"It's surprising because it's such a common condition. But most people don't have experience with moderate-to-severe eczema," said Mortlock, a 21-year-old who grew up moving around the country as part of a military family.

Mortlock was about nine years old when he and his mom attended an Eczema Expo where they met other eczema families with similar experiences. As he grew up, he continued reading NEA's newsletters and magazines. When he saw the CTA for Teen Steering Committee volunteers, he responded right away.

"When my eczema started [flaring up] in college, I was looking for a way to get involved again, and the Teen Engagement Program looked like the perfect opportunity," said Mortlock, a recent graduate from the University of Southern California with a degree in biochemical engineering.

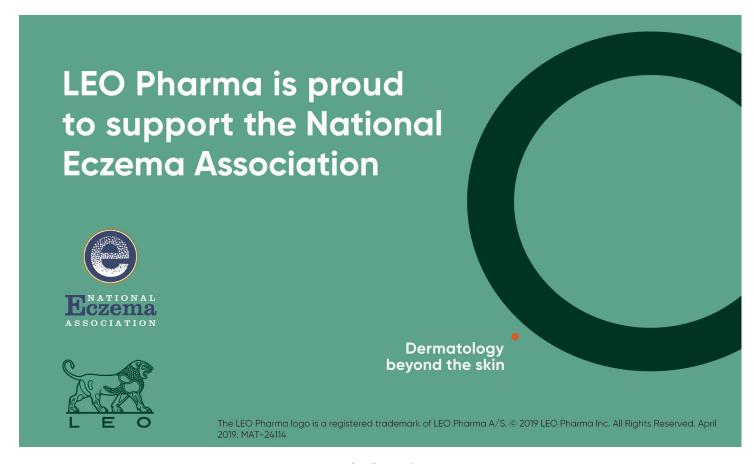
"On one hand, I wanted to meet people with a similar experience and learn from them. And on the other hand, I want to share my

own experience. Having gone through the transition to college and [learning to] manage eczema on my own, I hope I can be a mentor to help guide [other teens] as they face that transition."

More than a dozen teens and young adults like Miyares, Do and Mortlock formed the initial Teen Steering Committee. Using the GroupMe messaging app to communicate remotely, the group convened three times in late 2018 to discuss various aspects of life with eczema.

"NEA sent out questions and polls like, 'What are some of the triggers of your eczema?' or 'What are you doing to manage right now?' and it's been really cool to hear other people's stories," Mortlock said. "Just knowing there's this diverse group of people from all over the country going through a similar experience helps put it in perspective."

The group chatted about everyday issues like how to play sports when sweat can trigger flares, and how to manage treatment routines and the side effects that can accompany medications. "I could relate to a lot of the issues other patients were going through," says Jaeyon Yeo, who will turn 18 and graduate from high school this year. >



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"A lot of girls, especially, go through a period of being self-conscious about eczema because our society idealizes a specific type of body image. I was able to connect with other girls in the group who were also struggling with that, so it felt like I wasn't the only one going through it."

For many of the committee members, this forum was the first platform they've ever had to openly communicate these struggles with full transparency. Through their online interactions, they shared advice and encouragement — even "celebrating each other's milestones and achievements in school," Do said — to help boost each other through the daily struggles of living with eczema.

"Being around other people who understand eczema is very validating because most people don't understand it," Mortlock said. "When you're starting from the same page, you can start having productive conversations about treatment and support, and you can learn from other people's experiences."

#### Developing dedicated resources

Based on the Teen Steering Committee's input, NEA developed a set of personas to capture the typical experiences of teens with eczema.

"The personas serve as guideposts as we start to think about what resources, support and education NEA wants to provide for this demographic," said Bartolini. "As we move forward with tangible programs for teens, we'll be tapping the steering committee for their thoughts and ideas. We want this to be a program built for teens by teens, so we'll continue to lean on them for their expertise."

The first step will be to update NEA's website with dedicated content and resources designed specifically for teens and young adults, addressing topics like dealing with eczema at school, being in relationships, and transitioning into college.

"We want to have teens contributing more by posting blogs or writing for the magazine," Bartolini said. "We want to activate teens to feel empowered to share their stories and come into their own as eczema warriors."

In other words, NEA wants to give teenagers a voice and a platform for sharing their eczema experience with other teens who feel alone.

"What I've gotten out of [the Teen Steering Committee] is that I finally found a group of people who understand me, and it has sparked my interest to be a voice for those who are embarrassed to talk about it," Miyares said.

"It's pushed me to be more knowledgeable about my disease, and stronger and more confident. For teens living with eczema, even if they were just like me and didn't know anybody else with this problem, I want to contribute more visibility so they know they can get help."

Several committee members plan to meet in person for the first time at Eczema Expo 2019. This summer's event will offer more breakout sessions and other resources dedicated to teens with eczema, "based on what we've learned about them through this Steering Committee," Bartolini said.

Eventually, NEA plans to develop some type of teen support network where teens can share encouragement and advice like the Steering Committee has done—letting kids know they have somewhere to go "so they don't feel as alone in this disease as they often do," Yeo said.

"That feeling of being alone in this disease makes you feel very self-conscious, but when you're in a community of people who experience the same issues and support you, it helps you feel more confident with the skin condition you're born with," Yeo said. "I just want to tell [other teens] that they're not alone. There are so many other teenagers out there struggling with this, and if you want to reach out, you can." >

## WHAT'S THE BEST ADVICE YOU HAVE FOR TEENS LIVING WITH ECZEMA?



#### Ryland Mortlock, 21, Los Angeles, California:

"Lean on others for support and try to stay positive through it all."



#### Harry Do, 23, Gainesville, Georgia:

"On the toughest days of your life when you want to give up, just having 1% of trust and belief in yourself will get you through more than you can ever imagine. The battles you face now while living with eczema can only make you stronger."



#### Silvia Miyares, 23, Chicago, Illinois:

"Don't let eczema define you, don't let it get you down, and don't let it stop you from doing what you want to do or being who you're meant to be. It's part of you, and it makes you a stronger, more compassionate person."



#### Jaeyon Yeo, 17, Rochester, New York:

"Have confidence in it. Through eczema, you can grow more as a person and learn to reach out to other people through the disease. If you're confident with yourself, you'll be able to live your life in a happier, more positive way. Be happy that you're able to experience this because you can learn so much from it." \*

## WHAT'S HAPPENING AT THE NATIONAL ECZEMA ASSOCIATION

BY KATHRYN JONES

#### Are you eczema-ready for school?

e're getting closer to that time of year when superstores start stocking their shelves with school supplies for restless, young students (and their relieved parents), while teachers make their own preparations to head back to the classroom.

Preparing for the school year can be challenging for eczema families. An ordinary day at school is filled with possible triggers that can aggravate eczema symptoms — from carpets, to outdoor activities, to standard soaps — making everyday activities like recess or arts and crafts more difficult.

School stress is another less visible but still important classroom trigger. Both the symptoms and treatment of eczema can be stressful for children, as can the social and emotional consequences of the condition. At an age when their classmates are learning social skills, children with eczema can be singled out and even bullied because of their disease. It's important that parents and teachers are aware of

the emotional impact these symptoms can have on a child's self-esteem.

That's why NEA created the Eczema: Tools for School education guides to help parents and teachers create a positive school experience for children with eczema. These handy information booklets offer resources and advice to foster a positive experience for children with eczema.

The guides include strategies for raising disease awareness in class, recommendations for building an eczema school care kit, and a list of books and movies aimed at raising self-esteem, promoting positive thinking and encouraging understanding of people who are different. An educator guide offers a useful work page for teachers and parents to develop an action plan to support the student with eczema at school.

Visit https://nationaleczema.org/school/ to download your copy of Eczema: Tools for School. ►











#### NEA advocates step it up in the Peach State

n Feb. 20, grassroots advocates Kristen Featsent, her children Chase and McKaylie, Rochelle Richter, and NEA's Step Therapy Committee Chair Kelly Barta, met with Georgia State Senators Michael Rhett and Timothy Barr concerning HB 63, Georgia's step therapy bill.

Step therapy, which is sometimes called "fail first," happens when insurers require patients to take and fail on one or more medications before approving the medication originally prescribed by the patient's doctor.

While step therapy can be appropriate in some cases, some believe that insurers use step therapy as a cost control mechanism to steer patients toward drugs that are less expensive than the ones prescribed by their doctors.

In a recent poll of NEA's community members, 29% of respondents reported that at some point in their lives they were required by an insurer to step through a drug before the insurer would approve the drug prescribed by their doctor.

When faced with a step therapy requirement, 86% of respondents reported giving into the insurer's requirement, paying out of pocket for the prescribed drug, or giving up on getting the prescribed medication altogether.

NEA coordinated its advocacy day with its coalition partner Rx in Reach. Advocates attended a three-hour training before meeting with their elected representatives. As it turns out, state legislators heard their voices loud and clear.

On April 25, HB 63, Georgia's step therapy bill, was signed into law by Gov. Brian Kemp after unanimous passage in both houses of the Georgia State legislature. This marks the passage of the third step therapy bill for which NEA campaigned this year, following Ohio in January and Virginia in March.

Based on census estimates of the insured populations in these states and published estimates of the overall prevalence of eczema, we estimate that the bills passed in Ohio, Virginia and Georgia will improve the access of 2.5 million eczema patients to their prescribed medications. \*



## 24 hours of eczema

British recording artist, actress and wellness coach Nataylia Roni walks us through a day in her life as a person with eczema.

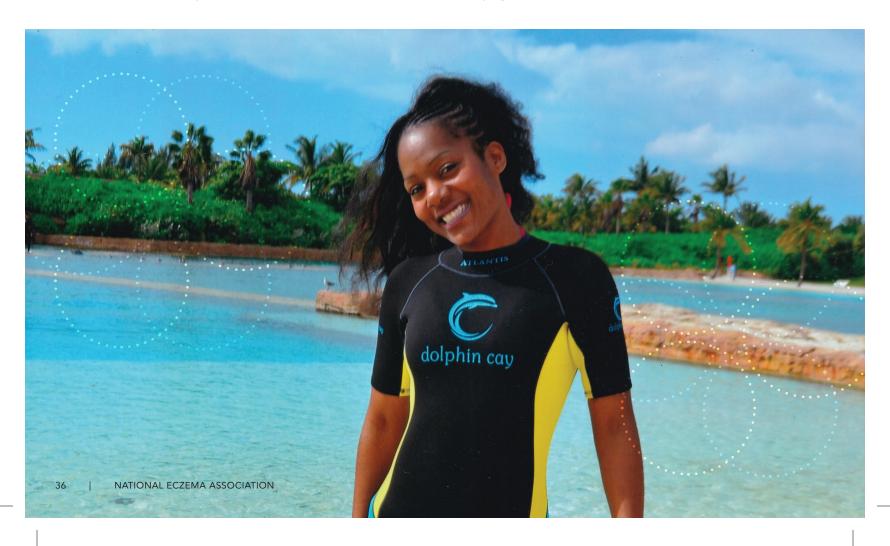
BY NATAYLIA RONI

About 60% of children will have eczema in their lifetime, and for some, this continues into adulthood. It is estimated that 31 million Americans have eczema, so you can only imagine the true statistics worldwide.

When I was a child, I remember the itching would sometimes lead to bleeding. I'm thankful that the skin on the joints of my arms and legs are no longer covered in eczema like they were when I was young. However, I still have to deal with eczema as an adult — on my right hand to be exact.

Whenever my skin is clear, it's like a breath of fresh air. But if I have a flare-up of eczema due to stress, environment, products or food, it will appear on my fingers. It always takes longer to clear than it did to arrive.

Life with eczema isn't easy. Even when my skin is clear, I am still careful of the products I use internally and externally. Here's what I do in 24 hours to help defeat this annoying situation. ▶



**6** a.m. ~ After [a moment of gratitude], I start the day with a tall glass of water. I head to the bathroom to begin my skincare routine. One of my favorite products that I use to keep my eczema at bay is African Black Soap. Once I am all pampered, I am ready to go.

**7 a.m.** ~ Sometimes I make one of my concoctions from herbs and veggies, or I make a raw juice. My favorite is a raw green juice with lots of ginger. Today, I'm switching things up by having peppermint tea. Now, onto my To Do list because there is always something to do.

**8 a.m.** ~ I'm working on some projects on my computer and checking emails. I notice that I have a self-tape to film, and before I even read the script, I start texting and emailing around to see who is available to help with filming.

9 a.m. ~ I'm getting hungry. I do enjoy avocados with my homemade sauce for breakfast, or I will sometimes go for a larger meal of plantains fried with natural oils and salad. When I eat this way, I sometimes feel tempted to eat slices of bread. But I must resist! I've had to cut out wheat. Now I am a glutenfree vegan. There are days when I use the toaster like it's going out of fashion. Most times, it's wheat-free bread, but sometimes it's regular toast. If I receive my irritating reward for eating the toast, then I increase my juice intake.

11 a.m. ~ It's time to get ready for my TV commercial casting. I will read the script upon arrival, so there is little time to prepare. I have to travel two hours to attend this casting. Actually, I just remembered I have two TV castings to prepare for, plus a theatre audition. I take a deep breath knowing that stress triggers my eczema, and then I get busy. Later on, I'll listen to my favorite podcast, which includes meditations, affirmations and recipes for lovely vegan food to eat. It calms me down and keeps me focused.

**1 p.m.** ~ I drink miso soup for lunch, then go to the bathroom to wash my hands. Whoops! I used the wrong hand wash by mistake. Knowing that the ingredients could irritate my skin, I quickly use loads of water and hand wipes. I moisturize my hands with natural products containing essential oils. Sometimes I mix the ingredients together myself, other times, I buy them at stores.

**3:30 p.m.** ~ I collect my little family from school sometimes. Oh, how wonderful it is to be an aunt! I brought them treats to eat like biscuits and fruit. I feel proud of myself that I didn't feel tempted to join in and eat those sugary snacks. Instead, I nibble on seeds.

**5 p.m.** ~ By now, I am walking past shops that sell the kind of food that if I eat, well, I know it would take me two steps back. I resist the temptation with a joyful smile and choose a healthy dinner instead.

**7 p.m.** ~ Off to the gym I go to teach a fitness class. I've found that working out helps my eczema stay away. I enjoy this workout session knowing that I am helping others achieve their health goals.

8 p.m. ~ For me, the best eczema treatment is the sauna and steam. A few of my nutritionists have told me it would help, and it has. I stop in and visit for a short while.

**10 p.m.** ~ I'm at a corporate event for one of my live concerts. I sing a few solos with a live band. The audience was great. I even snuck in a few of my original songs. Here, I might drink soup and eat salad. OK, well, sometimes I eat a few chips. Who doesn't like chips!?

12 a.m. ~ I just finished a lovely salt bath soak. It's time to moisturize using pure natural remedies. I then journal my To Do list for tomorrow. No. 1 on the list is to share my seven-day juice plan online. I was going to meditate, but I'm too tired. Instead I put my hands together and zzzzzzzzzzz. \*



Nataylia Roni is a certified well-being and fitness coach based in the U.K. with a podcast available to download via @ pamperingworld. She's also a professional actress and composer with original music available for download on Amazon via @ iamnataylia. For more information, visit www.nataylia.com.



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