

eczema matters

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

HEY, GOOD LOOKING

Consider these tips before scheduling
your next salon appointment. *P. 4*

.....

'TIS THE SEASON FOR FLARES

Learn how to ring in the holidays without
triggering your eczema or allergies. *P. 9*

.....

THE MAGIC OF EXPO '19

It wasn't just an event — it was an
eczperience for the whole family. *P. 31*



Natralia Happy Little Bodies Eczema Care Regimen for Kids

Born in Australia, and now available worldwide, Natralia grew from a father's desire to help his young son, who faced the day-to-day challenges of eczema.

Understanding the side-effects of long-term hydrocortisone use and knowing that eczema is a chronic condition that often results in extensive rashes, he was uncomfortable having his young son use steroid-based creams on a long-term basis.

He knew there had to be a better option. He worked alongside experienced pharmacists to develop **Natralia Eczema & Psoriasis Cream**, free from petro-chemicals, parabens and hydro-cortisone.



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

That is our promise.

Natralia offers eczema care products for both adults and children and we understand that eczema requires more than just a rash cream; it requires a regimen of care.

Both our adult line of eczema products and our children's line include a:

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



Natralia's **Happy Little Bodies** products contain colloidal oatmeal to help soothe itchy, eczema rashes and restore moisture. The line is pH balanced for children's skin.



The Natralia brand is the result of in-depth, focused product development. Each product that carries the Natralia name has been specifically developed to deliver superior efficacy through an innovative and exhaustive research process. Lacorium Health, the owners of the Natralia brand, are renowned for their innovative approach and global knowledge and have more than 20 years of experience.

natralia
NATURALLY AUSTRALIAN

For more information about Natralia, visit www.natralia.com.

EDITORIAL STAFF

EDITORIAL DIRECTOR Karey Gauthier, MS
EDITOR-IN-CHIEF Kathryn Jones
GRAPHIC DESIGNER Scott Oswalt
COPYEDITOR Heather Pendley
CONTRIBUTORS Margaret Crane, Emily Delzell, Andrea Goetz

NEA STAFF

SENIOR MANAGER, OPERATIONS Christine Anderson
OPERATIONS ASSISTANT Yessica Ayala
MANAGER, GRASSROOTS ADVOCACY Kelly Barta
MANAGER COMMUNITY ENGAGEMENT Jessica Bartolini
PRESIDENT & CEO Julie Block
VP, STRATEGIC PARTNERSHIPS Lisa Butler, MBA
DIRECTOR, COMMUNICATIONS Karey Gauthier, MS
MANAGER, EVENTS & MARKETING Lauren Hewett
DIRECTOR, DEVELOPMENT Rachel Lee Holstein
SENIOR MANAGER, CONTENT Kathryn Jones
VP, OPERATIONS Scott Sanford, MS
DIRECTOR, RESEARCH Wendy Smith Begolka, MBS
WEB DEVELOPER Jose Torres

NEA BOARD OF DIRECTORS

CHAIR Lisa Choy
SECRETARY Christina Crowley
CHIEF FINANCIAL OFFICER Cynthia Kim
 Mike Bristol
 Rachael Bronstein
 John Crossen, PhD
 Elizabeth Hoff
 Nathan Jetter, MD
 Peter Lio, MD
 Sarah O'Donnell
 Dinesh Shenoy
 Susan Tofte, RN, MS, FNP

NEA DIRECTOR EMERITUS

Irene Crosby
 Philip Crosby
 Jon M. Hanifin, MD
 Tom Reese
 Don Young, JD

SCIENTIFIC ADVISORY COMMITTEE EMERITUS

Lisa A. Beck, MD
 Kevin D. Cooper, MD
 Jon M. Hanifin, MD

SCIENTIFIC ADVISORY COMMITTEE

Gil Yosipovitch, MD – CHAIR	Morgan Maier, PA-C
Andrew Alexis, MD, MPH	David Margolis, MD, PhD
Jeffrey Bienstock, MD, FAAP	Amy S. Paller, MD
Stuart A. Cohen, MD, MPH, FAAP	Robert Sidbury, MD, FAAD
Lawrence F. Eichenfield, MD	Elaine Siegfried, MD
David M. Fleischer, MD	Jonathan Silverberg, MD, PhD, MPH
Adam Friedman, MD	Eric L. Simpson, MD, MCR
Emma Guttman, MD, PhD	Jonathan Spergel, MD, PhD
Jennifer LeBovidge, PhD	Paul Yamauchi, MD, PhD
Peter Lio, MD	

In This Issue

Featured

04 Navigating the Salon

Treat yourself to a day of pampering without triggering a rash.

09 Holiday Hazards

'Tis the season for flares. Here's how to prepare for the holidays.

14 Dupixent Two Years Later

Eczema warriors around the world discuss their experiences with the biologic dupilumab.

Departments

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

03 Scratch Pad: Advice from the NEA community

18 Ask the Eczperts: You ask — we find answers

20 Get the Facts: Celery juice

23 PEER: Your #1 source for eczema research

26 Community Spotlight: Ella Gradowski

30 NEA News: Eczema Awareness Month

36 My Journey: Ode to the Itchy

Eczema Matters is published quarterly by the National Eczema Association (NEA). All rights reserved. No part of this publication may be reproduced without permission from NEA. Copyright © 2019 National Eczema Association. All correspondence and requests for copies should be directed to:

National Eczema Association
 505 San Marin Drive, suite B300
 Novato, CA 94945

Phone: 800.818.7546 or 415.499.3474
 Fax: 415.472.5345
 Email: info@nationaleczema.org
nationaleczema.org



International Alliance of
 Dermatology Patient
 Organizations



give.org



OUR MISSION

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

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

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



Hello, and happy ECZEMA AWARENESS MONTH to all! October is the time of year when we invite eczema warriors from all over the world to help us #unhideECZEMA by raising public awareness and changing the social stigma.

Throughout Eczema Awareness Month, we will have various calls-to-action via email and social media encouraging you and your loved ones to share your stories, tune in to our webinar, take an important survey and participate in our annual Itching for a Cure fundraiser to help NEA raise funds for eczema research and a cure. Learn more about our Eczema Awareness Month activities on page 30. Together, we will build a better future for all those impacted by eczema — better understanding, better care and better treatments as we set our sights on a cure.

There were definitely moments at this year's Eczema Expo when I got a little (OK, more than a little!) misty-eyed witnessing the magic that happens when we connect as a community. (See page 31 for a recap.) I can't help but reflect on how far we've come over the past 30 years, from our humble roots in Portland, Oregon, (page 35) to the powerful global network we are today.

Eczema isn't just a skin condition — it's more like a lifestyle because it permeates every aspect of our day-to-day lives. Those living with atopic dermatitis, the most common form of eczema, also have to contend with related conditions such as asthma, hay fever, and allergies, along with the psychosocial impacts. Simple pleasures most people take for granted, like treating yourself to a salon appointment (page 4-7), come with their own unique set of challenges.

The fall and winter holidays are notorious for bringing on seasonal stress. But when you or a loved one has eczema, you're constantly worrying about things like, "Will this pine-scented candle bring on a flare?", "Is that ugly holiday sweater made of wool?", or "Get those nuts out of my fruitcake!" We'll help you handle holiday hazards on page 9.

Thank you for making 2019 such a memorable year — and not just because it's our 30th anniversary! YOU are the real reason to celebrate here at NEA.

Yours,

Julie Block
President & CEO

This issue of Eczema Matters is dedicated to Karey Rose Gauthier, Director, Communications and Marketing, who passed away on June 25, 2019. Karey was an extraordinary visionary who embraced the eczema community with a deep understanding of what it means to share our individual challenges, get empowered and persevere. She was a warm, witty, talented and all-around remarkable human being whose legacy will #kareyon in our hearts forever.

What are your top eczema-friendly salon tips?



"Before they start, I always inform the person who is doing any kind of salon treatment on me that I have a skin condition that is NOT contagious and will not hurt them in any way." ~ maddy_harman

"Whenever I go to a new threading salon and have my eyebrows threaded or other facial hair waxed, the lady working there always notices the hyperpigmentation and flaking skin on my face and asks me why that is."
~ nickyroshiniacting

"Finding an establishment that understands your condition and expresses compassion, care and consideration really helps. Having a positive relationship with a business like that can really work wonders on your stress levels!" ~ castawaycarol

"Literally found out I had a flare at the salon. She lifts my hair to snap the cape, and says, 'Whoa, you have eczema!' Yes, thank you. Maybe say it louder for the people in the back? In her defense it was a beauty school, so she was learning." ~ elisekayyy

"Salons usually have candles lit or air fresheners plugged in which flare my eczema and asthma horribly. I also bring my own shampoo and conditioner if I'm going to a hair salon because I'm allergic to most hair products." ~ littlebitt18

"I don't go! I taught myself how to do at-home pedicures and eyebrow waxings! It saves me from the questions and comments from the beauticians." ~ nikkipoleyy

"I don't go anymore. I decided to do my skin a favor and use as little product as possible and skip exfoliating. I miss the feeling of being pampered at the salon, but I now see that going natural is much better for my skin!" ~ joannedekkerjewelry



"I have a hair colorist that does research to find dyes with no ammonia or paraphenylenediamine, and I use my own shampoo and place a barrier on my ears and around my hairline (try Vaseline 100% Pure Petroleum Jelly). And we allergy test a week before we dye my hair." ~ Andrea R.

"I wash my hair at home and have a dry trim." ~ Elaine T.

"I ask for a hair washer that doesn't wear nail varnish, as this can cause a scalp flare. I explain that sprays can cause problems. If I need hairspray, I cover [my] face, hands and neck with a towel; for nails I take my own cream, and I can't wear nail varnish on fingernails." ~ Joanna P.

"I take my own prescription shampoo. I have had the same hairdresser for years, so she's used to my condition."
~ Beverley S.

"Tell them before they touch you that you need hypoallergenic! I am lucky that one use of something on my scalp is unlikely to cause major issues — it's more repetitive use. The sprays cause the real problem for me, so I don't usually have them style my hair." ~ Mackenzie S.

CONNECT WITH US ONLINE!



@nationaleczema

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



The eczema warrior's guide to irritation-free beauty

Salon visits are meant to leave you feeling confident and relaxed — not embarrassed or covered in an itchy rash. Here's how to get groomed without getting triggered.

By Emily Delzell

When Zainab Danjuma got her first manicure, a gift for her 16th birthday, she worried about what the nail technician might think and say about her hands; her skin showed the marks of the atopic dermatitis she'd had since birth.

"When I was younger, my hands were the most affected part of my body, so I felt nervous about the nail tech seeing the backs of my hands as they were scarred, thickened and dark," said the London-based Danjuma, now 30.

Danjuma was lucky. The tech made the shy teenager feel secure and relaxed, and her well-groomed hands gave her self-assurance a lift.

"It was a good experience, and it was a confidence booster," she said. "I've come to terms with my dry skin and scarring now, and my skin is doing a lot better than when I was younger, but it's still molded me to be quite shy about how I look."

Danjuma is working to overcome her lingering insecurity by sharing her eczema-related challenges on her YouTube channel — "being open about something that's usually hidden" — as well as tips for caring for her curly hair, an inheritance from her African heritage.

Not every person with eczema leaves the salon feeling better about their appearance. In a social media discussion, Kelly Goodin wrote about a nail technician who turned down her request for a pedicure for her young daughter because the technician worried the child's eczema was contagious.

"She refused to touch my child, then age 5, [even though] we tried to assure her it was not contagious," Goodin wrote.

JiaDe (Jeff) Yu, MD, a board-certified dermatologist at Massachusetts General Hospital in Boston, said that, unfortunately, patients with visible skin diseases sometimes face stigma like that experienced by Goodin's daughter. ►

Along with the possibility of embarrassment and shame, people with eczema also risk allergic reactions when they enter a product-laden salon atmosphere.

We asked Yu and salon-goers with eczema to share their advice for getting professional grooming services that leave both the mind and the skin calm and clear.

Take a confident approach

Conquer salon-related apprehension by being up-front and forthright about your eczema. If you're scheduling a first-time visit at a salon or with a stylist, mention your skin condition and allergies when you make the appointment, and ask if someone on staff has experience with eczema.

"Always tell your nail tech or hairstylist about your skin," Danjuma advised. "They have seen it all before, but you want to prepare them. Also, try not to be embarrassed by scars or discolored skin. You shouldn't miss out on pampering because of that."

If you do find yourself with someone who's not familiar with eczema, remember that education is the best way to combat stigma and lower your risk for an allergic reaction, Yu said.

"The most important thing to convey to the technician or hairstylist is that the condition is not infectious. This is what most people are worried about," he said. "Once you establish that, it can open up a broader conversation about the condition and how to be careful with your skin."

You can also ask your dermatologist for a letter that details your eczema-related issues and suggests some ways to avoid triggering reactions, something Yu has done for his patients. Another option is to bring a NEA education brochure to the salon to help educate and raise awareness about what eczema is and isn't.

Like any other personal service, having a satisfying salon experience also depends on finding the right fit between the stylist or technician and the client. Goodin, for example, now takes her daughter to a nail salon with owners who have a child with eczema.

"They are so tender and sweet," she wrote. "They always ask to be sure all products are OK for my daughter's skin and try to ensure she has a great visit. My advice is to find someone you can be comfortable with. Don't stick with someone if they don't make you feel welcome."

Pay attention to products

When you have eczema, just walking into a salon, which may have allergy-triggering chemicals wafting through the air, can cause your skin to flare.

The good news is that rising awareness of the potential dangers of chemicals used in salon treatments means many beauty shops are emphasizing less-toxic options and environments that minimize chemical exposure.

Google "non-toxic hair salon" or "organic nail salon" and you'll likely find several businesses in your area that offer hair and nail color and care products without some of the ingredients known to cause allergic reactions or other health problems. Organic salons may be more sensitive to your skin issues, but Yu warned that they can still harbor allergens and other potentially irritating substances.

"There is little correlation between how natural or organic a salon sounds and whether it's likely to cause an individual with atopic dermatitis to flare," he said. "People are just as likely to react to organic preservatives and products, such as essential oils, coconut-derived preservatives and 'natural' fragrances, as they are to synthetic fragrances."

He suggested focusing on the ingredients in products and how you react to them.

"It's important for people with atopic dermatitis or eczema to know that they may react to products the general population doesn't," said Yu. "People can also tolerate one product fine for years and develop new allergic reactions at any point in their life."

"The best thing to do is to be vigilant about the skin and pay attention to flares," he continued. "If the skin flares within three to four days of exposure, there's a good chance you may be allergic to a product used." ►



Zainab Danjuma

ECZPERT TIPS FOR NAVIGATING THE SALON

Hair

WATCH OUT FOR:

Hair color. It's one of the most common salon-related causes of skin irritation and allergic contact dermatitis. "Paraphenylenediamine, or PPD, is one of the top 10 most common allergens used in personal products in the United States. It's in almost all hair dyes, especially various shades of brown and black dye," Yu said. PPD reactions include itching of the scalp, swelling of the eyelids, and rash behind the ears, forehead and the back of the neck.

Allergens. Most shampoos and conditioners include preservatives and fragrances. These tend to cause fewer scalp reactions than hair color because they aren't left on for long periods but can irritate the side of the face, forehead, and back of the neck in a "rinse-off" pattern, said Yu.



Hair sprays. They release allergens into the air. Small particles land on the skin and can trigger irritation or allergic reactions. Eyelids are the most common location for reactions to hairspray because of their thin, ultra-sensitive skin, according to Yu.

TRY:

Asking for PPD-free hair color. "Goldwell Elumen, for example, makes hair dyes that don't contain PPD and are thus tolerated by those with PPD allergy," said Yu, adding that he has no financial or professional relationships with any personal product manufacturer.

Using fragrance-free shampoo and conditioner. If your salon doesn't offer this option, ask if you can bring your own products for the stylist to use. Yu recommends Free & Clear shampoo and conditioner.

Nails

WATCH OUT FOR:

Nail polish. Many polishes contain chemicals, such as toluene sulfonamide and formaldehyde resin that can provoke allergic reactions and rashes.

Gel or shellac nails, dipped nails and acrylic nails. Chemicals in these products are also common causes of irritation or allergic reactions, said Yu.

TRY:

Finding a salon that uses polishes without the most common allergens. Nail polishes labeled 3-, 5-, 7-, 9- and 10-free eliminate that number of potential allergens. Yu recommends choosing a polish marked 5-free or above.

Skipping acrylic, dipped or gel nails.

Waxing

WATCH OUT FOR:

Beeswax and propolis, or "bee glue." This resinous substance is made from tree sap by honey bees. These waxes are the most common sources of allergic reactions to this treatment, though waxing doesn't commonly cause allergic reactions. All types of waxing will temporarily irritate the skin, however, said Yu.

TRY:

Skipping beeswax and propolis waxes or getting a pre-service patch test. *

FOR ADULTS WITH UNCONTROLLED MODERATE-TO-SEVERE **ECZEMA** (ATOPIC DERMATITIS)

HELP HEAL YOUR SKIN FROM WITHIN

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 looks clear.

In Two Clinical Trials with Adults Taking DUPIXENT*

- Nearly half of patients saw **75%** 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.

DUPIXENT 
(dupilumab) Injection
200mg • 300mg

Jennifer W., actual DUPIXENT patient.
Individual results may vary.

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 to come back.
- are scheduled to receive any vaccinations. You should not receive a "live vaccine" if you are treated with DUPIXENT.
- are pregnant or plan to become pregnant. It is not known whether DUPIXENT will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known whether DUPIXENT passes into your breast milk.

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

DUPIXENT can cause serious side effects, including:

- **Allergic reactions (hypersensitivity), including a severe reaction known as anaphylaxis.** Stop using DUPIXENT and tell your healthcare provider or get emergency help right away if you get any of the following symptoms: breathing problems, fever, general ill feeling, swollen lymph nodes, swelling of the face, mouth and tongue, hives, itching, fainting, dizziness, feeling lightheaded (low blood pressure), joint pain, or skin rash.
- **Eye problems.** Tell your healthcare provider if you have any new or worsening eye problems, including eye pain or changes in vision.

The most common side effects 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 copay¹ for DUPIXENT.

¹Limitations apply. Visit DUPIXENT.com for full program terms.

© 2019 Sanofi and Regeneron Pharmaceuticals, Inc.
All Rights Reserved. US-DAD-14758(2)

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.
- 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)

May your Holidays be Merry and Flare-Free

It's not always the hap-hap-happiest season of all when you have eczema and allergies. Our holiday guide offers tips and tricks for spotting and avoiding triggers, lowering stress and finding the perfect gift for that special eczema warrior in your life.

BY EMILY DELZELL

Along with shorter days and cooler temps, autumn heralds the start of the end-of-the-year holiday season. This can mean a flurry of family gatherings, special foods and events, and for people with eczema, an upswing in contact with potential allergy triggers.

Anticipating and planning for the irritants and allergens likely to be lurking amidst the festivities is the best defense against flares, said allergist and immunologist Thimiris V. Palacios-Kibler, DO, who is in private practice at the Asthma and Allergy Clinic in Portsmouth, Virginia.

'Tis the season for triggers

The time of year alone presents a host of possible hazards for people with eczema.

In many parts of the United States, the air is drier now, and low humidity primes the skin for flares. Bundling up for outdoor activity and returning to overheated homes can mean setting off a cycle of sweating, itching, scratching and irritation. Rapid temperature changes also contribute to dry, cracking skin.

And that's not all. Besides sending out asthma-triggering smoke and waves of hot, skin-parching air, that inviting fireplace or cozy wood-burning stove is likely harboring dust. The pile of leaves your child wants to play in is probably full of mold and mildew. And, while a wool sweater may seem like appropriate wear, it can leave you with an itchy rash.

Try these tips to keep skin calm:

- Step up your moisturizing routine and use a thick, oil-based cream or ointment as opposed to a water-based lotion. The more oil a product has, the better it prevents moisture loss. The soak-and-seal method is also a good way to combat dry skin, said Palacios-Kibler.
- Add moisture to the air with a humidifier and keep your distance from direct heat sources and smoke.
- Avoid long, hot showers which strip skin of natural oils. Instead, opt for shorter lukewarm showers and baths. Skip harsh soaps with fragrances and use a gentle cleanser instead.
- Keep wool, which can trigger itching in people with eczema, and synthetic clothes away from direct contact with skin. Palacios-Kibler suggested wearing loose layers you can take off as you heat up. For clothes that come in direct contact with the skin, choose natural fabrics that are less likely to irritate, such as cotton, silk or cashmere.
- Don't put off calling your doctor, she warned. If your skincare routine isn't working, see your dermatologist before your eczema gets out of control. They can prescribe prescription topicals and medications that will help stop the itch and allow skin to heal. ►

Watch out for these Holiday Hazards

Halloween, Thanksgiving, Hanukkah, Christmas, Kwanza and New Year's Eve are sneaking up on us. Be prepared to fight flare-ups.

Forewarned is forearmed, goes the old saying. In that spirit, here's a look at some pitfalls you or your child with eczema may run into as you move — and sometimes sprint — through the busy holiday season.

Halloween

Trigger: Costumes, candy and makeup. Candy can cause problems for kids with food allergies. Costumes and cosmetics can also provoke reactions.

What Happens: Many common face paint and cosmetic ingredients, such as methylisothiazolinone, are known skin allergens. There is no federal standard for the label “hypoallergenic,” and these products can't guarantee a pass on rashes. Costumes made from synthetic materials can also raise a rash, as can that nickel-containing princess crown or superhero belt.

Solutions: Skipping makeup is safest; if you use it, do a patch test. Make or shop for natural fabric costumes (try Etsy) or wear a safe fabric between costume and skin. Choose plastic accessories or make your own.

Also consider: Getting a stash of safe candies and swapping them for problem items post trick-or-treat or joining the Teal Pumpkin Project. A teal-painted pumpkin by the door means treats are non-food.



Thanksgiving

Trigger: Travel. More people travel for Thanksgiving than any other holiday, according to AAA.

What Happens: Preparing for long car trips, wrangling luggage and kids at the airport, and simply getting ready to go can leave you stressed out and prone to flares (See “Easing stress.”) Bedding washed in allergen-laden detergent, unfamiliar personal care products, dusty guest bedrooms, and pet dander are also common pitfalls.

Solutions: Moisturize well in the days before you leave. Carefully pack medications, creams, and other care products, and bring your bedding and towels.

Also consider: Staying at a hotel, giving you more control. Some offer allergy-friendly and/or carpet-free rooms. ►



Hanukkah

Trigger: Food allergies.

Most holidays include this hazard, and Hanukkah, with its emphasis on dairy and gluten-containing foods, is no exception.

What Happens: From latkes with sour cream to sufganiyot (deep-fried donuts filled with jelly) to cheese blintzes, traditional Hanukkah dinners are heavy on dishes that can trigger allergic reactions.

Solutions: Hosting dinner yourself is safest. If you're a guest, call your host as soon as you get the invite to explain potential food allergies and cross-contact issues and precautions.

Also consider: Preparing allergy-safe versions of your favorite traditional dishes or creating a new, allergy-friendly food custom. Include an ingredient card to assist guests with food allergies and to raise awareness.

Christmas

Trigger: Christmas décor. Both the tree itself and decorating it can leave you itching.

What Happens: Natural Christmas trees and greenery can cause contact allergies, thanks to an oil (terpene) found in sap, as well as reactions from inhaling mold spores and pollen. Storing artificial trees and ornaments in the attic often leaves them layered in reaction-triggering dust.

Solutions: Hose down real trees and allow to dry fully before setting up. Clean ornaments, dust/vacuum artificial trees, and wear gloves and long sleeves while decorating.

Also consider: Skipping poinsettias if latex allergies are an issue. The plants are related to the rubber tree family and can cause reactions in people with latex allergies.



Kwanzaa

Trigger: Scented candles. Lighting the kinara is a centerpiece of Kwanzaa, and some people use scented versions of the traditional red, green, and black candles.

What Happens: Fragrance and other compounds in candles, air freshener, potpourri and other home fragrance products make allergens airborne and leave susceptible people vulnerable to allergic and asthmatic reactions.

Solutions: Choose unscented candles and ask hosts well before an event to consider removing products that scent the air.

Also consider: Gifting fragrance-free candles — along with a card explaining why they're a good choice.

New Year's

Trigger: Alcohol. Champagne and other alcoholic beverages often take center stage at New Year's celebrations.

What Happens: Preservatives and other ingredients in boozy beverages can cause stuffiness, headache and skin flushing in people with an intolerance. Alcohol may also interact with a component involved in allergic response and worsen reactions in those who aren't alcohol intolerant.

Solutions: Choose non-alcoholic offerings — if you know what's in them. "Mocktails" are becoming more creative as the trend catches on.

Also consider: Bringing your host the components for your favorite allergy-friendly mocktail to offer at their bar. ▶

Surviving Holiday Stress

When the holidays are supposed to be holly jolly, but you're over here trying your best not to fa la la la freak out.

Stress spikes to unhealthy levels for many during the holiday season, according to the American Psychological Association. Whether it's too many family obligations (and sometimes family feuds), late-night trips to the refrigerator, or overspending on gifts, all sorts of things can take a toll on your holiday cheer.

And for people with eczema, it can cause flare-ups, intensify itching and fuel the urge to scratch. Stress — particularly this time of year — isn't always avoidable, so managing it is key to keeping eczema under control and safeguarding your overall health.

To lower your anxiety load, try:

Managing expectations for yourself and for others.

If you expect to produce a dinner where the food and décor are flawless and everyone arrives on time and behaves beautifully, you're going to be disappointed. Be realistic, know that it's not the end of the world (probably not even a big deal) when events stray from the plan, and be compassionate to yourself and to others when the unexpected happens.

Learning to say no. Some of us are hardwired to say yes to requests, and the holidays — a prime time for guilty feelings make it even harder to say no. If your child's wish list is outside your budget, explain and help them prioritize. When you get an invite to a holiday party you'd rather skip, politely decline. The more you practice delivering a courteous, "I can't make it, but thank you for asking," the easier it becomes.

Making time for yourself. Besides providing much-needed time for decompression and relaxation, self-care can help keep eczema in check and stave off viral illnesses to which stress makes you susceptible. Make time for skincare, nutritious meals and enough sleep, and try scheduling a day for a massage, some downtime with a book or movie, or whatever else calms your mind. ►



Spoil your Favorite Spoonie

Whether you're shopping for a parent, partner, child or even yourself, these are the gifts that keep on giving.

Spoonie
/ spoo*nee/
noun

Based on the "spoon theory" by Christine Miserandino, "**spoonie**" is a term commonly used in the chronic illness community to refer to those who have limited amounts — or "spoons" — of energy each day due to their illness.

Presents that help pamper sensitive skin or that can be enjoyed without fear of an allergic flare are thoughtful options for adults and children with eczema. Here are some suggestions:



- "Experience" gifts. Tickets to a special show or concert, gift certificates for spa services or workshops, and passes to a zoo, museum, or game center deliver fun and lasting memories.
- A basket of eczema-friendly products, such as the Honest Company's Soothing Therapy Body Wash and Eczema Balm (these carry the NEA's Seal of Acceptance) and KeaBabies' organic bamboo, dye-free baby washcloth pack.
- Silk pillowcases are a luxurious present that eases friction on skin and hair. Slip's pure silk pillowcases are highly rated.
- An organic cotton or silk scarf or pajamas or "flare ware," like Skinnies line of seamless eczema clothing that helps prevent irritation and regulate body temperature. (Skinnies clothes for children and adults also carry the NEA Seal of Acceptance.)
- Allergy-friendly chocolates. Amanda's Own Confections makes holiday-themed chocolates and other treats, like chocolate chip cookie dough, free of the 14 most common food allergens in an allergy-free facility. The chocolates and the facility where they're produced are kosher and free of gluten, soy, dairy and nuts. *

It begins with a promise to discover medicines that make life better.

Since 1876, we have worked tirelessly to discover medicines that make life better, finding ways to come through no matter the odds. From the development of insulin to the discovery of new treatments for mental illness, we have pioneered breakthroughs against some of the most stubborn and devastating diseases. We bring this same determination to our work today, uniting our expertise with the creativity of research partners across the globe to keep finding ways to make life better.

To find out more about our promise, visit www.lilly.com/promise.

2016 CA Approved for External Use PRINTED IN USA ©2016, Eli Lilly and Company. ALL RIGHTS RESERVED.

Lilly



Hong Hu, Research Advisor,
Lilly Research Laboratories

Has Dupixent delivered on its promise?

The eczema community offers honest feedback

More than two years after the FDA's approval of the first biologic treatment for atopic dermatitis, many patients taking Dupixent report dramatic improvement in their symptoms and quality of life.

BY MARGARET W. CRANE

Carol Greenspun was told she'd probably outgrow her eczema once she reached puberty. That didn't happen.

Then, her doctors predicted she'd find relief during and after pregnancy — another hormonal inflection point — but four pregnancies later, that didn't happen either. More recently, she hoped menopause would shake things up. No such luck.

The 57-year-old from Gaithersburg, Maryland, had resigned herself to a life sentence in the prison of atopic dermatitis (AD), the most severe and difficult-to-treat form of eczema. That is, until August 2018, when she had two back-to-back Dupixent (dupilumab) injections. Within six weeks, Greenspun said her skin dramatically improved.

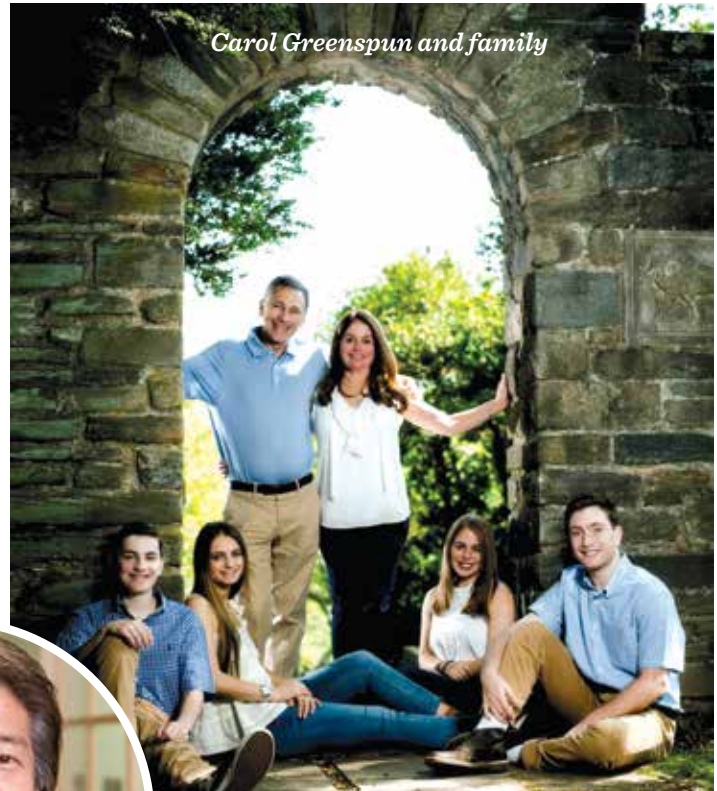
Greenspun is one of many who have reported a favorable response to the drug, which is the first — and, for now, the only — biologic treatment for AD. Instead of damping down the entire immune system, Dupixent specifically interferes with interleukin-4 (IL-4) and interleukin-13 (IL-13) inflammatory responses that play key roles in AD.

The drug performed well in clinical trials, but the eczema community has been waiting to see whether it would do so in the real world.

In the two years since its approval by the U.S. Food and Drug Administration in March 2017, opinions have been overwhelmingly favorable. However, some patients have reported side effects or have not benefitted as much as they had hoped.

Paul Yamauchi, MD, PhD, a dermatologist in private practice in Santa Monica, California, estimates that between two-thirds and three-fourths of his patients with AD have done well on the drug.

"Dupixent doesn't totally clear the risk of future eczema outbreaks, but it succeeds in managing symptoms," he said. "Most of my patients experience less itching, a reduction in the rash, better sleep and a better quality of life overall."



Carol Greenspun and family



Paul Yamauchi, MD, PhD

But Dupixent isn't a cure, and it's not perfect. Like virtually all pharmaceuticals, its benefits come with side effects. Injection site reactions are among the most common, followed by cold sores on the lips or in the mouth, and eye problems such as conjunctivitis (pink eye) and inflammation of the eye or eyelid.

Greenspun developed conjunctivitis and a corneal ulcer about eight months after her first dose and a corneal ulcer in the other eye six weeks after that. Determined to stay on her self-proclaimed "miracle treatment," she vowed to stop rubbing her eyes and use the eye drops her ophthalmologist prescribed.

"I use the drops at night and throughout the day," she said. "As long as I keep my eyes moisturized, my doctors say I'm good to go. Dupixent is the closest thing I have to a 'cure,' and I'm hanging onto it tightly!" ►



When the eczema patient is also a doctor

Vivian Shi, MD, a dermatologist on the faculty of the University of Arizona Health Sciences in Tucson, brings a unique perspective to her medical practice, teaching and research: she's an AD patient herself.

Shi spent her childhood in China, and her family emigrated to the United States when she was in her early teens. Her AD only added to her feelings of vulnerability as an immigrant.



But as she matured, Shi made it her mission to become a physician and work on finding improved treatments for the condition that had haunted her for most of her life. Today, her greatest wish is to help her patients "not be defined by their AD," she said.

Eye problems are concerning, Shi admitted, but her approach is to refer patients on Dupixent to an ophthalmologist the minute eye symptoms show up. And even if a patient has unwelcome side effects, "They'll usually say, 'Please don't take me off it!' So far, I haven't had to," Shi said.

Asked whether Shi is taking Dupixent herself, the answer was no. "Moving to Arizona has made my AD better," she explained. "I also recognize my triggers. As I often tell my patients, knowledge is power."

Dupixent is still a work in progress

As time passes, researchers are learning more about Dupixent's effectiveness as well as its limitations.

Some patients turn out to be partial responders to the drug, meaning it improves their condition but not as much as expected after 16 weeks of treatment. Another small group — called "non-durable responders" — do well on Dupixent at first, but the drug's benefits gradually wear off.

In a study co-authored by Shi and published in the American Journal of Clinical Dermatology in March 2019, researchers recommend therapeutic strategies for treating both partial and non-durable responders that don't require them to stop taking Dupixent.

They urge doctors to boost these patients' use of topical therapy, increase their Dupixent dose or frequency of use, and add phototherapy sessions along with an immunosuppressant into the treatment mix.

As for patients who don't respond at all to Dupixent, "They've received the wrong diagnosis," Shi speculated, and their doctors need to go back to the drawing board. ►

Controlling side effects and staying on course

"I've been on Dupixent for two-and-a-half years, and it's the most effective treatment I've ever had," said Jeffrey Lin, a 35-year-old from Los Angeles whose AD is so severe that he didn't qualify for inclusion in clinical trials.

Lin was born with every conceivable sensitivity. "I have severe asthma and allergies to everything on the planet," he said. "At a certain point, I couldn't even touch water. And as for my skin, I looked like a burn victim. It was as if my whole body was leaking fluids. Every pore was like an open wound."

Lin said Dupixent has improved his AD and asthma significantly. "I still have allergies," he admitted, "but Dupixent reduced two out of my three major health problems, which is amazing."

Lin's life has been improving day by day and month by month. But he confessed to a feeling of disorientation after struggling with AD for so many years.

"I grew up thinking that suffering was normal," he said. "It's actually a bit disorienting to feel better. It's kind of like a phantom limb feeling. What should I do with my hand if I'm not using it to scratch?"

Like Greenspun, Lin has had eye problems that come and go. Steroid eye drops have helped, but his dermatologist found an additional way to deal with the side effect.

By extending the period between his injections from six to eight weeks, he reduced Lin's dose by one-third. So far, that strategy has worked well for Lin, keeping his AD symptoms along with his eye issues under control.

Insight from a Dupixent ‘partial responder’

Rasmus Mikkil Soendergaard, a 34-year-old who lives in Copenhagen, Denmark, is a partial responder to Dupixent. He has been on the medication for about 14 months. Despite its failure to clear all aspects of his AD, he said has no intention of getting off it.

Soendergaard struggles with several conditions that may or may not be related to his AD. For one, he has ankylosing spondylitis, a type of spinal arthritis that can worsen over time. He also has what he describes as unusual, small wounds that resemble ulcers and seem to develop underneath his skin and then erupt on the surface.

So far, his doctors haven’t been able to agree on the source of these ulcer-like symptoms, Soendergaard said. “I have skin, joint, allergic and connective tissue symptoms, and it’s possible that some of these aren’t directly related to AD.

“Dupixent may not be my be-all and end-all treatment, but because of it, my AD no longer affects my professional or personal life,” he added. “The treatment has cleared my skin from the neck down, and I have no asthma issues now.”

Soendergaard uses a tacrolimus cream to manage the eczema patches on his face. For now, he describes himself as a successful partial responder who’s waiting for something even better to come along.

Shi and her fellow researchers are certain that it will.

The study’s authors encourage patients, caregivers and doctors to remain optimistic given the number of new targeted treatments in the pharmaceutical pipeline. In the conclusion of their article, they expressed their own optimism, envisioning a “renaissance era of AD treatment, with unprecedented breakthroughs on the horizon.”

Researchers also have alluded that people living with AD can look forward to treatments administered in pill form, treatments with longer-term disease and quality-of-life efficacy, and treatments with easier-to-manage side effects.

As for patients like Greenspun, Lin and Soendergaard who have struggled with symptoms for longer than they can remember, Dupixent is nothing short of a “miracle” treatment.

“No more skin flakes on my desk and keyboard at work. No more depression. No more anxiety about being touched or touching others,” Greenspun said. ►



Rasmus Mikkil Soendergaard

Researchers investigate Dupixent side effects

In addition to conjunctivitis, a widely reported side effect of the atopic dermatitis biologic Dupixent (dupilumab), researchers report that eosinophilia and facial eczema could also be side effects.

Injection site reactions are among the most common side effects of the biologic Dupixent (dupilumab), followed by eye problems such as conjunctivitis (pink eye) and inflammation of the eye or eyelid, and cold sores on the lips or in the mouth.

According to a JAMA Dermatology study that published online May 1, 2019, Dupixent may cause a newly observed side effect in a subset of patients. Out of the 73 patients analyzed who were taking Dupixent, nearly one-fourth (23%) developed new regional dermatosis appearing mostly on the face.

The study’s co-authors suspect these new symptoms may have something to do with allergic contact dermatitis, although this may not explain all cases. The researchers indicate larger studies involving skin biopsies and patch testing are needed to better define the subset of patients to which this pertains.

A French study published online in the Journal of the American Academy of Dermatology on Feb. 27, 2019, found that Dupixent may increase the risk for eosinophilia — a higher-than-normal number of a type of disease-fighting white blood cells. This potential side effect has been previously reported in clinical trials; this study investigated it in a real-world setting.

About 57% of the 241 patients had elevated eosinophils within six months of their follow-up exam compared with 33.7% at the start of the study. The researchers indicated that further investigations are needed to determine if there is a clinical impact related to these findings.





Eczema warriors around the country sum up their Dupixent experiences

“The results have been nothing short of a miracle for me — not just for my skin but for every facet of my life. Being on this medication has allowed the real Ashley to emerge.” – *Ashley Blua, Hermosa Beach, California*

“Dupixent cleared up my pain and other AD symptoms almost instantly. I had the starter dose administered before going to bed, and I woke up six hours later to find that I was pain-free with my stubborn AD skin patches gone.” – *Morgan Brunson, Tinton Falls, New Jersey*

“My eyes are a little itchy and gunky, but I would choose that side effect in a heartbeat rather than go back to the way things were before starting the treatment. All I can say is, I don’t know if I would be here today without Dupixent. It saved my life.” – *Emily Coffman-Peerson, Richmond, Virginia*

“Within two to three months of my first dose of Dupixent, I felt myself becoming the old Lisa-Marie — feeling social and allowing myself to find romance again after feeling like no man would ever put his hands on my skin.” – *Lisa-Marie Freire, New York, New York*

“Is my skin better since starting on Dupixent? Yes. Is it hit-or-miss? Yes. Do I feel like poo for several days, but my skin still looks okay? Yes. Have I figured out a pattern? No. I never know how I will feel from one day to another.” – *Melissa Hornick, Conway, Arkansas*

“I am eternally grateful to the team of scientists and doctors who made Dupixent possible. Eczema warriors are finally being heard, and our cries for help are being answered.” – *Dara Korn, Los Gatos, California*

“Now that I’m taking Dupixent, I’m living again. I’m smiling a true smile again. I’m free. I feel like a badass when I give myself that shot!” – *Raissa Schurawel, Costa Mesa, California*

“It was like something out of a dermatology fairy tale. I cried hopeful tears as I gave myself my first Dupixent injection. Within a week, my constant itch was nearly gone. By my six-month checkup, only about 10% of my skin showed signs of the disease. For the first time in years, I was wearing short-sleeved shirts and taking long, luxurious showers.” – *Jacqueline Snyder, Minneapolis, Minnesota **



Ask the Ecz-perts

Leading medical experts answer your most pressing questions about eczema.

Q: Can probiotics, prebiotics, or vitamins have any effect on the development or management of eczema?

I'd say that the jury is still out, unfortunately. There is some pretty convincing evidence that taking probiotics during pregnancy and then administering probiotics to the infant (especially *Lactobacillus rhamnosus* GG) has a modest effect on prevention and/or delaying the development of atopic dermatitis in some [pediatric] patients.

However, there are other studies that show no such effect, so we're left wondering, "Is it finding the right group, the right probiotic, the right dose, the right frequency?" There are so many questions, and this is a very difficult thing to study in general since you really have to "wait and see" who develops atopic dermatitis (AD) over several years.

The story for vitamin D is similar. Some studies really do show an effect in helping existing disease, and there are several studies that suggest AD is correlated with lower vitamin D levels, and that this relationship actually follows disease severity as well.

That being said, because the cost is low, the risks are low, and the potential for benefit is high, I do routinely recommend both vitamin D and probiotic supplementation for my patients. I do this with hopes that, until we can better identify who is mostly likely to benefit, some may benefit while the others will have minimal risk by trying these supplements.

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



Q: Organic powdered turmeric (not extract) is an essential part of my atopic dermatitis treatment plan. When I stop taking it, my AD returns, and sometimes I get hives. But this form of turmeric gives me cramping and diarrhea (which stops when I stop the turmeric powder). Is there an equally effective/safe form of turmeric that is less likely to cause this problem?

Turmeric is a powerful natural product that has been used for its anti-inflammatory properties for quite some time. While there are a number of ways to take it, I find that making a "turmeric milk" (sometimes called "golden milk") is the most effective and least troublesome to the gut.

My recipe is:

- 1/2 cup unsweetened non-dairy milk (such as hemp milk)
- 1 teaspoon organic powdered turmeric
- 1/2 teaspoon ginger (ground spice or grated fresh ginger root) [This may help against the upset stomach as well.]
- 1/2 teaspoon ground cinnamon
- Dash of ground black pepper (helps your body to absorb the beneficial curcumins in turmeric)
- 1 teaspoon honey or maple syrup, optional

Instructions:

Combine the ingredients in a saucepan. Bring to a boil and then lower the heat to simmer. Cook for about 10 minutes or until the turmeric milk is a uniform color. Strain the milk into a mug. Enjoy immediately or keep the golden milk in the refrigerator for up to three days. ►

Q: Is there anything I can do to get rid of dark spots caused by eczema?

The dark spots left behind on skin after eczema clears is a feature of eczema that primarily affects patients of color. It's an additional challenge on top of the itching, scaling and redness. Once the eczema clears, there is a tendency for increased pigment to be left behind. That's because, in darker skin, the pigment-forming cells (called melanocytes) are sensitive to inflammation and a variety of other inflammatory factors that can turn on increased pigment production.

Once the eczema clears, it leaves behind a persistent dark spot that can last for several weeks or months. When it comes to managing those dark spots, I like to start with prevention. The cause of dark spots is the eczema itself. The better we can control the eczema, meaning if we take a broad and aggressive approach to all the factors that contribute to eczema, we can reduce the severity and duration of the dark spots. So that's step one.

But even with the best efforts, one still frequently gets persistent dark spots after the eczema resolves. In scenarios when eczema has completely cleared but has left a patch of hyperpigmentation, we can employ various strategies to reduce it, including prescription skin lightening creams that might contain hydroquinone- or non-hydroquinone-based therapies that reduce pigment.

We could very cautiously and carefully use procedures in the office such as superficial chemical peels containing salicylic acid or glycolic acid as long as the skin is completely intact, not inflamed and not involved with eczema. I would be applying that strategy in addition to topical skin-lightening products.

Finally, we can also use some lasers to get at deeper pigment that is deposited in the skin as a result of eczema. But, again, I hold off any of those cosmetic procedures and skin-lightening treatments until the eczema has resolved in that particular area. Controlling the underlying cause of the pigment, in this case, eczema, or atopic dermatitis, is the first step and the most important key.

*Andrew Alexis, MD, MPH, chair of the department of dermatology at Mount Sinai St. Luke's and Mount Sinai West, and professor of dermatology at the Icahn School of Medicine at Mount Sinai. **



Do you have a question for our eczperpts? Email them to editor@nationaleczema.org.



GET THE FACTS: CELERY JUICE

WILL DRINKING 16 OUNCES OF STRAIGHT CELERY JUICE ON AN EMPTY STOMACH EVERY MORNING HELP CLEAR YOUR ECZEMA OR PREVENT FLARE-UPS FROM HAPPENING?

BY KATHRYN JONES

Drinking 16 ounces of straight celery juice on an empty stomach every morning has become one of the hottest holistic health trends of 2019.

Developed by Anthony William, the self-described “Medical Medium,” the celery juice diet is based on the notion that drinking the fibrous green vegetable in liquid form can improve almost every function of the body. It’s been purported to help with a number of skin conditions, including acne, psoriasis and eczema.

William is not a medical doctor nor a healthcare professional, but what he lacks in medical education or training, he makes up for in faith. He believes he was born with the innate ability to converse with a paranormal entity he calls the “Spirit” who gives him medical advice, which he then bestows onto others.

He says his psychic gift of being able to “read” people’s health problems and tell them how to recover from them started at the age of 4, when the Spirit helped William diagnose his symptom-free grandmother with lung cancer. Medical tests later confirmed his premonition was true.

William also says the Spirit told him about the power of celery juice as a “miracle tonic” for good health. Since then, he has made millions of dollars on a handful of bestselling books and has traveled the world spreading the gospel of celery juice.

His website is plastered with testimonials from celebrities ranging from Gwyneth Paltrow to Robert De Niro who claim that celery juice has worked wonders for their health. And let’s be honest, whenever a celebrity we admire endorses a product or therapy that’s all-natural, affordable and accessible, our collective ears are going to perk up.

William also alleges to be an “invaluable resource” to doctors who need help solving their most difficult cases — similar to how mediums use their psychic powers to help detectives solve cold cases.

However, more often than not, doctors have been quick to cast doubt on William’s credibility due to the lack of research supporting his claim that celery juice does all the things he says it does. ►

THE JUICY DETAILS OF WILLIAM'S CELERY THEORY

William believes the real cause of eczema stems from the liver. He says that there is a group of highly inflammatory toxins called dermatoxins that are released from the liver and only come out through the skin, which causes the skin to break and bleed as it tries to eliminate these toxins.

“Dermatoxins are created by a pathogen that has made its home in the liver,” reads William’s website. “The pathogen consumes and eliminates copper, and this is what creates the dermatoin that leads to eczema and psoriasis. The copper the pathogen feeds on in the liver is very old copper from generations ago, specifically from the pesticide DDT from 1874 onwards. Previous to 1874, eczema and psoriasis was practically unknown.”

Dermatologists and medical research scientists who have devoted entire careers to studying the origins and mechanisms of inflammatory skin diseases would argue that this is simply not true. For starters, a fundamental contributor to the development of skin disease is conspicuously missing from William’s theory: genetics.

Research shows that some people with eczema have a mutation of the gene responsible for creating filaggrin, a protein that helps our bodies maintain a healthy, protective skin barrier. Without enough filaggrin to build a strong skin barrier, moisture can

escape and cause the skin to break and bleed, which then allows bacteria, viruses and other substances to enter.


Then, there’s the fact that psoriasis and eczema have been plaguing civilizations for hundreds of thousands of years, with evidence of dermatological conditions appearing on the remains of Egyptian mummies. In fact, the Greek philosopher and “Father of Medicine” Hippocrates (460-377 B.C.) was among the first to prescribe tar-based topicals to help relieve itch.

As a side note, Hippocrates did prescribe celery to treat nervous disorders. Historians claim that Hippocrates thought celery had the potential to calm patients or help them fall asleep — most likely due to the fact that celery is loaded with soothing magnesium.

Keep in mind that nobody is debating the health benefits of celery. It’s packed with beneficial nutrients like calcium, potassium, protein, beta carotene and vitamins A, B6, C and K.

Research from the University of Chicago has found that celery contains a chemical called phthalide that may help lower cholesterol and inflammation.

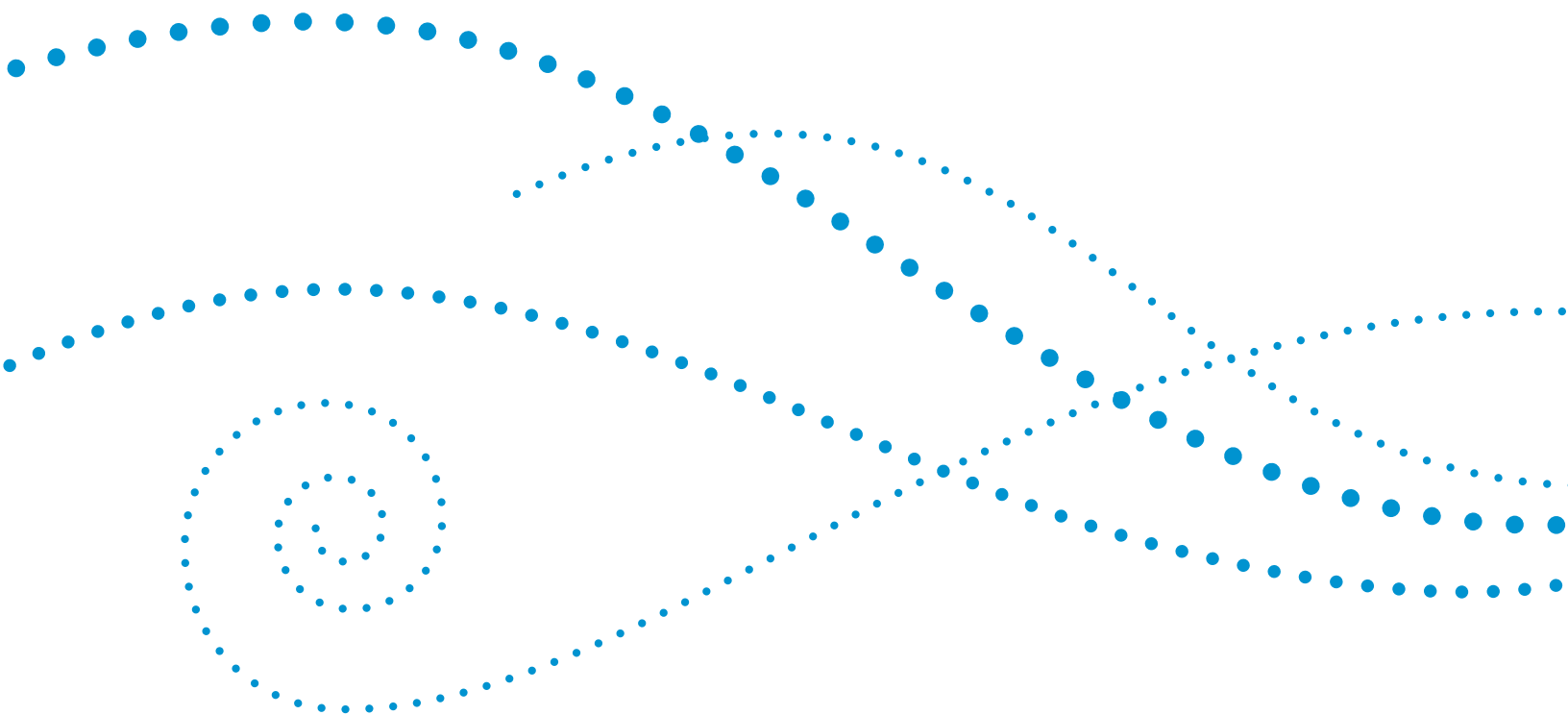
Is celery good for us? Absolutely! Will drinking 16 ounces of celery juice on an empty stomach make your eczema go away or prevent flare-ups from happening? Probably not. *



Skin-science, re-examined

Our mission is to bring biotech ingenuity to medical dermatology by delivering important new treatments to the millions of people living with chronic skin conditions.





**Pfizer is proud to
support
National Eczema
Association**



Working together for a healthier world®

peer INTO THE FUTURE

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

BY MARGARET W. CRANE

One primary bacterial culprit disrupts the skin microbiome and drives AD, researchers say

Approximately 1,000 species of bacteria live on the surface of the skin, but available data suggests one plays an outsized role in atopic dermatitis (AD): *Staphylococcus aureus* (staph).

A Polish research team recently published a review article in the February 2019 issue of *Advances in Dermatology and Allergology* that evaluated the findings of a large number of studies on the complex relationship between staph and AD.

When cultured during an eczema flare, staph overgrowth is seen in the inflamed skin of 90% of eczema patients. What has been unclear is whether the bacterium actually causes an AD flare or simply takes advantage of the favorable environment — the dry, cracked skin that is the hallmark of eczema — to set up shop and cause trouble.

The researchers lean toward the former view based on evidence gathered during their review of the literature.

First, staph tends to crowd out the friendly bacterial species, called commensals, that provide the balance and diversity necessary to a healthy microbiome. The researchers see staph as a likely suspect in causing the unstable skin microbiome that is characteristic of AD.

Second, staph creates all kinds of problematic byproducts that interfere with the immune system's ability to mount a normal response — another hallmark of AD.

Among these by-products is biofilm, a slimy matrix in which bacteria can hide, thrive and evade attack by immune cells that would normally be able to clear the infection. The chronic skin damage seen in AD offers a perfect setting for biofilm formation, the researchers said.

Staph also secretes enzymes that help allergens penetrate the skin and superantigens that provoke an unusually large inflammatory response.

Despite the potential for staph to exert these negative effects, the co-authors warned against antibiotics as a routine treatment for AD, primarily because of concerns around antibiotic resistance, but also because of the chronic nature of AD. Keeping an AD patient on antibiotics over long periods of time is inappropriate and ultimately harmful, they wrote.

With the shortage of effective antimicrobial treatments and the rise of resistant strains of staph — among other virulent species — the search is on for alternatives to antibiotics. Enter endolysin technology.

While antibiotics work by interfering with essential bacterial structures and processes or thwarting their ability to reproduce, the endolysin approach relies on viruses to do the job.

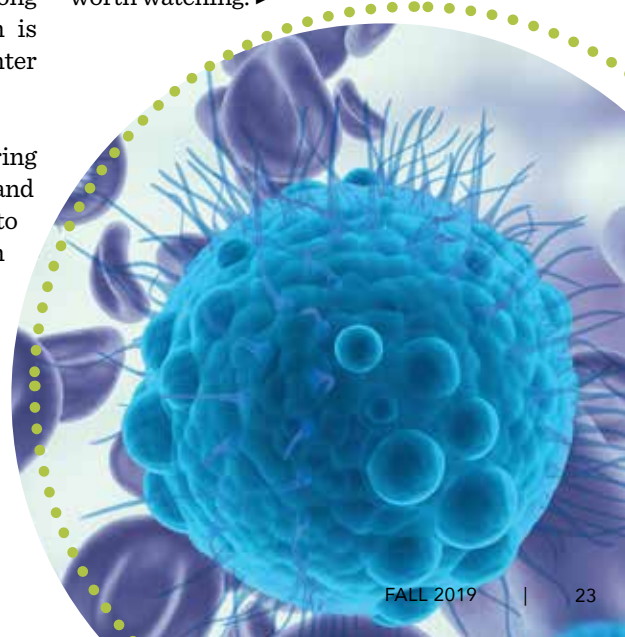
Endolysins are enzymes produced by viruses, called bacteriophages, that infect bacteria. These viruses latch on to the bacterium's cell wall and inject their DNA inside it. That's how the viruses reproduce. To help

new bacteriophages emerge, the endolytic enzyme breaks the bacterial cell wall open and kills the bacterium in the process.

A Dutch company (Microeos) has been investing in this new technology, recently launching its over-the-counter topical eczema product, Gladskin. The product's key ingredient is Staphsekt, the company's version of an endolytic enzyme, which specifically targets staph. Gladskin also aims to restore the balance of the skin microbiome and ease the symptoms of eczema across the spectrum of disease severity.

Because of its unique mechanism of action, bacterial resistance should not be a problem, the manufacturer said, and researchers in the fields of immunology and microbiology agree with that claim.

Time will tell if the new technology takes hold and ultimately replaces traditional antibiotics. For now, it's a trend that's worth watching. ►





Nasal and skin microbiomes are linked to AD severity in children

A study conducted in the Netherlands found a strong association between the severity of pediatric AD and the composition of bacteria found in both the nasal passages and on the skin.

The researchers found that eczema lesions were positive for *Staphylococcus aureus* in 50% of the children enrolled in the study. However, although staph was the most populous bacterial species, other species, such as *Moraxella catarrhalis* in the nose, were also implicated as drivers of disease severity in children.

While the skin microbiome has been the target of eczema research for some time, the nasal microbiome is a newer research focus – one that merits greater attention, especially regarding the role nasal bacteria may play in exacerbating AD in children.

Additionally, identifying the bacterial inhabitants of the nose may help pediatric specialists identify patients at greatest risk for severe AD and treat them proactively.

Although the skin and nose harbor distinct microbial communities, the two microbiomes appear to be related. The precise character of that relationship is a matter for future studies, the researchers concluded. Their findings appeared in the February 2019, issue of the British Journal of Dermatology.

Researchers discover a relationship between scratching, food allergy

Scratching isn't only bad for eczema skin; it also appears to trigger a cascade of immune responses deep inside the digestive tract, according to a study in mice conducted by researchers at Boston Children's Hospital. That cascade ultimately activates immune cells, called mast cells, in the small intestine that are involved in food allergies.

Juan-Manuel Leyva-Castillo, who has investigated on NEA-funded research projects in the past, and his colleagues co-authored the study, which appeared in the May 2019 issue of the peer-reviewed journal Immunity.

The communication pathway between the skin and the gastrointestinal tract may be complex, but it could hold the key to the relationship between AD and food allergies.

The simple act of scratching appears to stimulate the production of a protein called IL-33, which then enters the bloodstream, finds its way to the gut, and joins forces with other proteins that, working together, drive the expansion of intestinal mast cells.

As these mast cells proliferated, the researchers found the intestinal lining became more porous, allowing allergens easier passage into surrounding tissues, where they primed the gut for allergic reactions to food.

The investigators conceded that further research is needed to see whether their findings in mice turn out to be relevant in humans. In the meantime, they suggest that doctors work with their patients with AD to limit the itch-scratch cycle — a strategy that could ease the severity of food allergies in those who are susceptible to them. ►

Atopic dermatitis plus food allergy is a unique subtype of eczema

Researchers at National Jewish Health in Denver examined the skin of children who have AD combined with food allergies and found characteristics that are unique to the dual condition compared to AD alone.

The research team, headed by Donald Y.M. Leung, MD, collected skin samples from 62 children from 4 to 17 years of age and divided them into three groups: those with both AD and food allergy, AD alone or neither condition.

They applied small, clear strips of tape to both inflamed and normal-looking skin — a minimally invasive technique — and proceeded to measure the proteins, fats and microbial populations found in samples from each of the three patient groups.

The skin from children with both AD and food allergy had different genetic, molecular and structural characteristics from the skin of children with AD alone as well as the group with neither condition.

The skin from the first group showed lower levels of filaggrin, a protein that helps seal the skin and lock in moisture. The amount of water loss through the skin barrier was also greater in these children's skin than in the skin samples collected from the other two groups.

Skin from the children with both AD and food allergies also showed higher concentrations of staph than the skin from children in the other two groups.

The findings were published in the February 2019 issue of Science Translational Medicine.

What was surprising, said Leung in a report issued by the National Institute of Allergy and Infectious Diseases (NIAID), was that his team identified the unique profile of the AD-food allergy combination via samples taken from clear skin, not from the eczema-inflamed skin samples.

Of the total number of people with AD, one-third have food allergies. As food allergies usually show up after the onset of eczema symptoms in children with AD, the new information uncovered by Leung and his colleagues could help fine-tune the treatment of the dual condition and even prevent the development of food allergy by treating the child's AD early and aggressively. *

abbvie

Addressing the toughest dermatology challenges takes all of us.

That's why we collaborate each day with physicians, academics, clinical experts, peers, and others. Together, we can truly make a difference for patients.

As a global biopharmaceutical company, we use our expertise, knowledge, resources, and passion to impact millions around the world.

At AbbVie, our solutions start with science but end with a new way forward. For all of us.

AbbVie focuses on many therapeutic areas, including our commitment to lead the way in dermatology.

abbvie.com



People. Passion.
Possibilities.®

GO, ELLA, GO!

With her eczema under control, 9-year-old Ella Gradowski is off to the races in her NEA-themed Mini-Wedge racecar.

BY SARAH HARRIS

If you go to the Arthur Raceway near Essexville, Michigan, on a Friday or Saturday night, you'll likely spot fourth-grader Ella Gradowski zooming around the track in her Mini-Wedge racecar. Ella's a regular, and the speed and thrill keep her coming back.

"It's just fun," the bubbly 9-year-old explained. "I like how you can go really fast, but sometimes you have to go slow. And I just like how some people like to go so fast, and I'm like 'Don't pass me! Don't pass me!'"

It's also hard to miss Ella's car. It's electric green and black and emblazoned with the National Eczema Association's logo: a series of bright-white lowercase 'e's bubbling across its sides. That 'e' is for eczema, of course — but Ella and her mom, Lizz Gradowski, like to think of it as 'e' for Ella too.

Lifelong eczema won't slow this racer down

Ella's eczema started early in life. She was just two weeks old when she woke up from a nap, her face red and blazing. Lizz panicked.

"I called my mom because I didn't know what to do," Lizz recounted. "We took her in to the doctor, and he said that she'd grow out of it. Instead, it's gotten worse and worse and worse."

Desperate to find a solution, Lizz took Ella to specialists at the

Henry Ford Health System and the University of Michigan. They tried many different treatments, but nothing worked.

Racecar driving has been a source of comfort for Ella, although it's not without its triggers.

Racers have to wear a heavy nylon fire suit and gloves, a helmet and a neck brace. It can get hot and itchy, but Ella makes a point to wear comfortable, loose clothes underneath and to unzip her fire suit between races.

Sometimes, she rubs her itchy spots up against the metal frame of her racecar to scratch. But mostly, Ella said, "If I get itchy when racing, I keep going."

Ella's determination is impressive, however, navigating elementary school with eczema isn't easy. Kids can be curious or mean, she said, and either way, it stings.

"People ask me why I'm red, or if we have to hold hands or if we have to touch each other, they'll ask me why I'm so dry," Ella said. "One time or two times, somebody bullied me about my lips because they were all chapped."

"Her classmates get used to it and they understand," Ella's mom Lizz added, "but it gets harder when she gets outside regular class. Kids aren't nice. She's learning to cope with it as she's getting older, but the main thing we have to tell the kids is that they can't catch it." ►



The event that changed everything for Ella

Last year was particularly challenging. Frequent bad infections, including MRSA (Methicillin-resistant *Staphylococcus aureus*), kept Ella out of school.

"I was sitting in the hospital with her on her eighth birthday on the last day of school," Lizz recalled, "my phone rang, and it was the truancy officer."

Lizz explained that Ella was in the hospital and that they were working on getting her eczema under control. But it was heart-wrenching, Lizz said, because she didn't want Ella to miss her birthday and end-of-the-year festivities.

A couple of weeks later, Ella and Lizz attended their first Eczema Expo. It was a game-changer. Ella made new friends with similar life experiences, and Lizz and Ella met Dr. Peter Lio, assistant professor of clinical dermatology and pediatrics dermatology at Northwestern University Feinberg School of Medicine.

They were impressed by Lio's expertise, and they liked how nice he was. Ella became Lio's patient. Every few months, Ella and Lizz make the five-hour drive to Lio's office. Together, they've tweaked Ella's routine and started her on cyclosporine.

Ella now has a 504 plan, a provision that allows children with disabilities to receive necessary accommodations so they can succeed in school. This allows her to miss class when necessary, to stay cool by keeping a fan near her desk, and to access her moisturizers and medications during the school day.

"For us, it changed everything," Lizz said. "There's so much we're able to do now. We're able to feel better." ►

Speeding down the path to recovery

This year, Ella wasn't in the hospital on her birthday, and she got to participate in the field day on the last day of school.

She still has eczema and she still itches, but it's more manageable. When it came time to decorate her new racecar, Ella knew exactly what she wanted to pay tribute to: the organization that helped her find Dr. Lio and get her eczema under control.

"If people have eczema and they don't know about Dr. Lio, I just wanted them to know about [NEA] so they don't have to go everywhere and they could just go to Dr. Lio," Ella explained.

Fittingly, the logo of Dr. Lio's practice — Chicago Integrative Eczema Center — is on Ella's car too.

Ella and Lizz went back to Eczema Expo again this year thanks to a lot of community support. Their friends and family saved aluminum cans and collected bottle deposits, and Ella's grandfather, an avid motorcyclist, sold T-shirts to his motorcycle community to help fundraise for their plane tickets.

Giving kids with eczema the support they need takes a village. Between her family, her school, her doctors and her racing community, Ella has a fantastic support system. And this little champ isn't letting eczema hold her back. She's too busy revving up and hurtling ahead. ✨



LEO Pharma is proud to support the National Eczema Association



Dermatology beyond the skin

The LEO Pharma logo is a registered trademark of LEO Pharma A/S. © 2019 LEO Pharma Inc. All Rights Reserved. April 2019. MAT-24114

natralia[™]
NATURALLY AUSTRALIAN

**happy
little
bodies**[™]



NATRALIA Happy Little Bodies OFFERS A REGIMEN OF EFFECTIVE ECZEMA CARE FOR KIDS

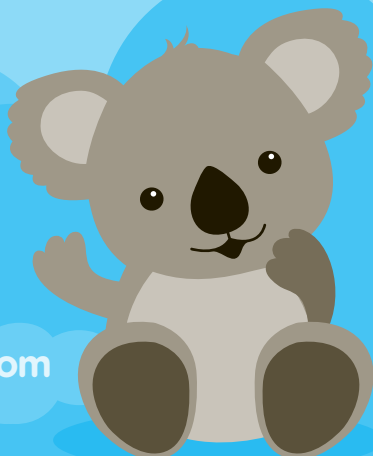
Eczema Relief Cream - with 5% colloidal oatmeal for soothing itchy flare-ups. Hydro-cortisone free.

Body Wash & Shampoo - a soap-free alternative to harsh shampoos & soaps, to help prevent moisture loss while bathing.

Eczema Moisturizing Lotion - for daily use after bathing to restore moisture. Clinically proven* to lock in moisture for 24 hours.

Gentle

Ph Balanced
for children's
sensitive skin.



www.natralia.com



advertisement

*Data on file

WHAT'S HAPPENING AT THE NATIONAL ECZEMA ASSOCIATION

BY KATHRYN JONES

Get ready to unhide the real eczema

October is Eczema Awareness Month (EAM), and once again, we're calling on eczema warriors worldwide to come out of the shadows to #unhideECZEMA.

There are still too many misconceptions floating around about this disease. We think it's time to "be real" with the rest of society about what it's like to have eczema. Each week, we'll explore the realities of eczema with the common goals of raising awareness and changing the social stigma of this common-yet-isolating disease. Are you in? Then, get ready to put that hashtag key to good use because we are about to drop some truth bombs!

Here's a glimpse of what's to come in the weeks ahead:

- Week 1 (Oct. 1–6) #TheRealTruthofEczema
- Week 2 (Oct. 7–13) #TheRealCostofEczema
- Week 3 (Oct. 14–20) #TheRealHeroesofEczema
- Week 4 (Oct. 21–27) #TheRealFeelsofEczema
- Week 5 (Oct. 28–31) #TheRealLifeofEczema

Itching to get involved during EAM2019? We feel you! Here are five options to start with.

1. Share your journey on social media with photos, videos and words. Use the hashtags #eczemamonth #EAM2019 #unhideECZEMA #therealeczema on Facebook, Instagram and Twitter. Always be sure to tag @nationaleczema.
2. Register for the Oct. 16 "The Cure" webinar with eczema expert Peter Lio, MD.
3. Keep your eyes peeled for our Eczema Awareness Month survey.
4. Start or support an Itching for a Cure fundraising campaign.
5. Make a donation at nationaleczema.org/donate.

For more information on ways to get involved during EAM2019, visit nationaleczema.org/eczema-awareness-month/. *

DID YOU KNOW?

The very first Eczema Awareness Month kicked off in October, 2004.

Over the past 15 years, EAM has evolved from a modest grassroots campaign into a rallying cry for the entire eczema community.

In September 2017, NEA launched its advocacy program, Raise Your Voice! We asked members of our community to request their representatives sponsor a resolution declaring October as Eczema Awareness Month. Thanks to their commitment, resolutions have successfully been passed in Louisiana, Georgia, Illinois, Tennessee, Oklahoma, Pennsylvania and Michigan.

To learn more about advocating on behalf of the eczema community or declaring October EAM in your state, visit nationaleczema.org/get-involved/advocacy.





photos by
Tori Soper



The magic of Eczema Expo '19

Remember when we said Eczema Expo '18 was the best expo ever? Somehow, we managed to top ourselves again and couldn't have done it without you! For those who couldn't make it this year, here's what you missed.

What do you get when you bring adults and children with eczema, their loved ones, world-renowned eczema researchers and medical providers, and the companies that make eczema treatments and products all under one roof? MAGIC.

National Eczema Association hosted its annual Eczema Expo in Scottsdale, Arizona, from July 18 through July 21, 2019. As one attendee put it, this was no ordinary expo — it was more like an *eczperience* that resulted in dozens of new friendships and a renewed sense of hope.

Expo has evolved over the years to feel more like a wellness retreat than the traditional patient conference. The event took

place at the Hyatt Regency Scottsdale Resort & Spa at Gainey Ranch, a four-star hotel and 27-acre destination resort adorned with flowering cacti, exotic palm trees and dazzling views of the McDowell Mountains.

NEA wanted to alleviate the usual stress that eczema families face whenever they travel. This meant ensuring the hotel rooms were free of potential allergens. It meant washing the towels and linens with detergents safe for sensitive skin. It meant wet wraps and bleach kits were a part of room service. And, of course, there had to be delicious, allergy-friendly snacks and food options on the menu.

NEA believes that all eczema warriors should feel pampered, especially when attending Expo. That's why we collaborated with contact dermatitis specialist Dr. Jeff Yu and Spa Avania to create a custom spa menu with flare-friendly treatments at a discounted rate. ►

Equal parts informative and invigorating

Of course, Eczema Expo '19 still had the educational seminars hosted by world-renowned research and medical professionals to walk us through the latest eczema science and therapies. It still had the informative breakout sessions covering topics from skincare to sleep deprivation. It still had the compassionate support groups for patients and their loved ones. But those were only a portion of the Expo *eczperience*.

There were also early-morning yoga, meditation and aquatic fitness classes; mid-day acupuncture sessions, moisturization stations and an eczema-friendly product sample buffet; and night-time pool parties, which included a “dive-in movie” where warriors could float on rafts and watch “Harry Potter and the Philosopher’s Stone.”

The resort’s 10 massive swimming pools, 20 fountains, 45 waterfalls, sandy beach area and three-story, high-speed waterslide served as an aquatic playground for kids of all ages and was the perfect oasis for eczema families seeking to escape the hot desert sun.

But what made it extra special to Expo attendees was the fact that this was a no-judgement zone where people with eczema could feel safe wearing their swimsuits and showing off their beautiful skin without feeling embarrassed or self-conscious.

One of the highlights of the event was the #unhideECZEMA panel and body positivity beach party where eczema warriors had the chance to step up to the microphone, share what it meant for them to #unhideECZEMA and explain how it changed their lives.

Another highlight was the Ecz-travaganza which gave warriors a chance to dress up, grab a cocktail, line up for the build-your-own taco buffet, get their photos taken with silly props at the photo booth and boogie down with NEA staff and members of the Board of Directors.

But, wait! Where were the kids, you ask? ►





“You wouldn’t understand — it’s a camp thing”

- When you grow up attending Expo Camp and can’t wait to return as a counselor ...
- When you used to be embarrassed to wear shorts in public until you saw the other kids at Expo Camp wearing shorts and realized, “Who cares what people think?” ...
- When your squad creates a secret handshake and cheer that only Expo Campers know about ...
- When you were too shy to attend school dances until Expo Camp made you feel brave enough to bust out your best moves on the Ecz-travaganza dancefloor ...
- When your mom asks why you want to wear your eczema swag to school, and all you can say is, “You wouldn’t understand — it’s a camp thing” ...

... that’s when you know Expo Camp is the place to be for kids and teens with eczema.

And for the first time this year, NEA welcomed its mini warriors (ages 0-4) to Expo Camp, who were in the caring and capable hands of Corporate Kids Events while their parents and older siblings attended seminars, workshops and breakout sessions.

Many of the breakout sessions catered specifically to teens, including vision boarding, makeup and skincare tutorials, “how to teen with eczema,” and the highly-anticipated #awkward session where warriors were encouraged to ask medical experts the questions that they would ordinarily be too shy or embarrassed to ask.

There was even an “eczema sucks” session that gave junior and senior warriors the chance to lament to Eczema Expo ’19 Medical Director Peter Lio, MD, about the realities of eczema and how it affects them physically, mentally, emotionally and socially.

After all, eczema isn’t the easiest disease to live with. In a perfect world, we’d all be able to wave a magic wand over our skin to get rid of this painful, itchy rash for good. National Eczema Association will continue to be a mecca of resources and support for eczema warriors until the day a cure is found.

One of the ways we support the eczema community is by investing in research that will lead to better treatments, better care and a better quality of life for eczema warriors of all ages. But we can’t do it without your support. Visit <https://nationaleczema.org/donate/> to donate today. From all of us at NEA, thanks for making Eczema Expo ’19 such a magical eczperience!



MARK YOUR CALENDARS FOR ECZEMA EXPO '20!

Next year, we’re bringing the magic of expo to the home of the Magic Kingdom. Eczema Expo ’20 will take place June 25-28, 2020, in sunny Orlando, Florida!

Do you wish you could attend Expo but can’t afford to go? NEA wants to help make your wishes come true.

We offer two ways to help defray the costs associated with attending Eczema Expo. This year, we gave away nearly \$60,000 in scholarships for individuals and families to attend Eczema Expo ’19 through the Carolyn and Tom Reese Expo Scholarship fund. Another option is setting up a peer-to-peer fundraising campaign.

To learn more about the scholarship fund or how to set up a fundraising campaign, visit <https://nationaleczema.org/eczema-expo/get-help-paying>.



NEA's founders fondly reminisce about the past 30 years

Among the many unforgettable moments at Expo '19 was when dermatologist Jon M. Hanifin, MD; nurse practitioner Susan Tofte, RN, MS, FNP; and lifelong eczema warrior Irene Crosby took the stage on Saturday, July 20, 2019, for the Founders' Fireside Chat in celebration of the NEA's 30-year anniversary.

Hanifin, Tofte and Crosby founded the National Eczema Association for Science and Education in December, 1988. Hanifin, an Oregon Health and Sciences University (OHSU) professor of dermatology and world-renowned expert on skin diseases, was serving on the Board of Directors of the nearby National Psoriasis Foundation at the time when his secretary, Crosby — a passionate activist, advocate and volunteer in her community — suggested that people with eczema should have an organization providing the same level of support.

Tofte, a nurse who had worked closely with Hanifin treating eczema patients, agreed. "We wanted to bring patients and health care professionals together on the same page, with the vision to make this organization a patient advocacy group. There was only a small group of us at the time, but we were determined to give this community a voice," she said.

The three founders put their heads together and started having meetings in the library of OHSU in Portland, Oregon, where they worked. Endless hours went into strategizing, fundraising, making phone calls, stuffing envelopes and doing everything they could to get their small grassroots foundation up and running.

"Keep in mind that this was before the internet was around, so we depended on what the doctors and nurses told us," Crosby noted. "In order for medical professionals to better understand this disease, they had to know what it was like from the patient's perspective. We [patients] wanted to speak for ourselves. We needed an opportunity to be heard. As it turns out, we can get people to listen to us, but it takes funding, research and patient involvement."

NEA eventually relocated its headquarters to Marin County, California, where it remains a small but mighty organization determined to make a difference in the lives of people with eczema. Even when funding waxed and waned through the years, nothing stood in the way of its commitment to educating patients on proper skincare techniques, establishing support groups around the country and investing in research for a cure.

"I'm proud of the way NEA is forming an ever-increasing emphasis on research. That's so important, and it's the reason I'm still doing this," Hanifin said. "I've been ready to retire several times, but new and exciting things keep happening in the field, and I can't escape! But in all seriousness, we all need to chip in and put in what we can afford every year to help NEA because research is expensive but fundamental."

Support NEA in its research endeavors by making a donation at nationaleczema.org/donate.

In Memoriam

It is with profound sadness that we share with you, our NEA community, the passing of our TEAM NEA staff member, Karey Rose Gauthier, on June 25, 2019.

Karey joined NEA in October 2016 to work on our social media programming. Quickly, her remarkable talents, intellect, curiosity, can-do attitude and commitment to our community were shining bright. She was promoted to director of communications and marketing, and took the lead on an array of initiatives that truly sparkled.

Karey embraced the NEA community with a deep understanding of what it means to share our individual challenges, get empowered and persevere. She was an absolutely extraordinary, inspirational human being who gave her heart and soul to NEA. She will always be in our hearts and is missed beyond measure. #Kareyon *



A Passion for Science and a Commitment to Dermatology

Dermavant Sciences, a subsidiary of Roivant Sciences, is a clinical-stage biopharmaceutical company dedicated to developing and commercializing innovative therapeutics in medical dermatology. Dermavant leverages the Roivant platform to develop therapies that have the potential to address high unmet medical needs while driving greater efficiency in research and clinical development. The company's robust medical dermatology pipeline includes both late-stage and early-development product candidates that target specific unmet needs in two of the largest growing immuno-dermatology markets, psoriasis and atopic dermatitis, as well as other large markets, including vitiligo, primary focal hyperhidrosis, and acne. Dermavant is developing its lead product candidate, tapinarof (DMVT-505), as a differentiated therapeutic aryl hydrocarbon receptor modulating agent (TAMA) topical cream for the treatment of plaque psoriasis and atopic dermatitis, which affect approximately 7.5 million and 28 million people in the United States, respectively. For more information, please visit www.dermavant.com.



Dermavant is proud to support the **National Eczema Association**

© 2019 Dermavant Sciences, Inc.



advertisement

Ode to the Itchy

A POEM BY ANDREA GOETZ

And as you sit there, thinking back on your itchy life
I salute you.

You — the red, the overheated, the flaky, the splotchy, the
peeling, the rashy, the inflamed, the irritated, the angry, the
bleeding, the bruised, the raked over.
The so-dry-that-you-could-never-live-in-Arizona-because-
you-are-sure-you-would-disintegrate.

You've had quite a life. And while your itching never stopped
you from doing things, it sure didn't help either.

All you ever wanted was to have skin just like everyone else's.

You are the most creative dresser.
The '80s were great because you could wear the collar up on
every shirt in your closet and feel trendy, and it totally hid that
big red-hot spot on your neck.

You gave up short sleeves, short hair, long nails, long showers,
and ever wearing red or pink, or anything with red polka dots,
because who wants to color coordinate with their skin?
Lace collars are torment.
Wool is hell.
Synthetics should be outlawed and dryer sheets banned.
And thank goodness no one uses starch anymore, because that
stuff was awful.

When you first heard the term, "doesn't feel comfortable in
her own skin" you thought,
You. Have. No. Idea.

You have tried everything —
Vitamin E, Vitamin D, bee pollen, ointments, steroids,
anti-depressants, anti-anxieties, anti-inflammatories,
hydrocortisone, saran wrap, immuno-suppressants, patch
testing, going nut-free, gluten-free, sugar-free, flour-free,
fragrance-free, tar soap, bleach baths, saltwater, steroids
(again), non-steroidals, acupuncture, Chinese herbs,
acupressure, homeopathy, grapeseed oil, coconut oil, oatmeal,
antihistamines, and every single lotion known to mankind.

And each time it didn't work, your heart broke a little more.
All you ever wanted was to have skin just like everyone else's.

The smiling through the itchiness.
The reassuring others that you're fine — it's not contagious,
and yes, you've tried calendula.
The turning down the invitation to the pool party.
The never-wearing-black because it shows the flakes.
The smiling at the manicurist as she tells you how dry your
hands are, and "Have you tried lotion?"
And ...

The knowing ache as the new dermatologist says he's going
to be the one to fix this for you. And you want to believe him.
Because you believe in hope and because you want to escape the
prison that is your skin, and because you promised yourself that
it would never win ... so you agree to the next big discovery.

And each time it didn't work, your heart broke a little more.

All you ever wanted was to have skin just like everyone else's.

This one is different, they said. Really, it's a game changer.
An injectable. It's brand new, just on the market, and
remarkable results.
It was made for people just like you.

You are so brave.
Trusting another doctor one more time who believes she can
make it better.
You've already survived the worst.
You have felt monstrously ugly, unworthy, frustrated, and
angry (oh, the anger).
You have nothing to lose.

Do I have the courage to have hope one more time?
Will it make the purple splotchy thing on my face go away?
(Why is it always on the face?)

All you ever wanted was to have skin just like everyone else's.

But I am here to tell you that you are beautiful.
And I love the skin you're in.

*Andrea Goetz is a lifelong eczema warrior who lives
in Guilford, Connecticut, with her husband and two
children. **

October is Eczema Awareness Month



join us and

#UnhideEczema

**Tell your story, share your flare, join our virtual walk Itching for a cure,
raise your voice as an advocate, make a donation and learn more at
EczemaMonth.org**