# eczema matters

RESEARCH, SUPPORT, AND EDUCATION FOR THOSE AFFECTED BY ECZEMA SUMMER 2018

## IT'S A FAMILY AFFAIR

When one family member has eczema, it affects the whole household. *P.14* 

## **BEYOND THE RASH**

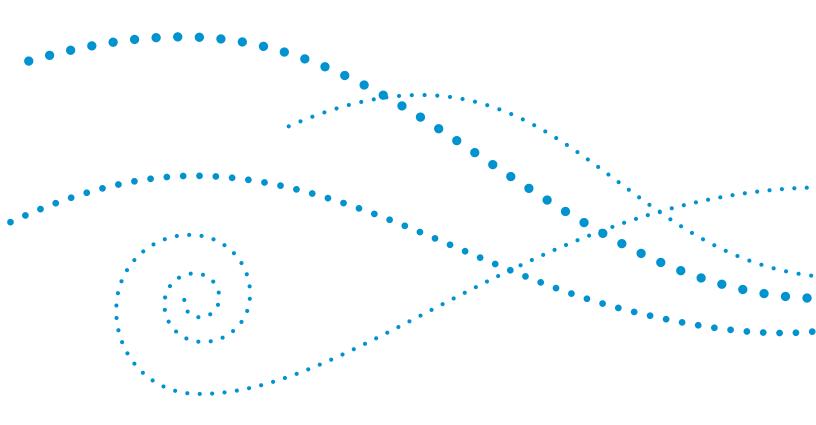
There's more to atopic dermatitis than what meets the eye. *P.9* 

ECZEMA EXPO '18

Eczema Warriors across the country will meet up in June. Join us! *P.32* 



ASSOCIATION



# Pfizer is proud to support National Eczema Association



Working together for a healthier world®

advertisement

## czema **matters**

#### EDITORIAL STAFF

EDITORIAL DIRECTOR Karey Gauthier, MS EDITOR-IN-CHIEF Kathryn Jones **GRAPHIC DESIGNER** Scott Oswalt CONTRIBUTORS Margaret W. Crane and Helen Piña

#### **NEA STAFF**

SENIOR MANAGER, OPERATIONS Christine Anderson MANAGER, COMMUNITY ENGAGEMENT Jessica Bartolini ADMINISTRATIVE ASSISTANT Robin Blaney **PRESIDENT & CEO** Julie Block VP, STRATEGIC PARTNERSHIPS Lisa Butler, MBA DIRECTOR, COMMUNICATIONS Karey Gauthier, MS MANAGER, EVENTS & MARKETING Lauren Hewett VP, OPERATIONS Scott Sanford, MS VP, ADVOCACY & ACCESS Tim Smith, MPP DIRECTOR, RESEARCH Wendy Smith Begolka, MBS DIRECTOR, DEVELOPMENT Fran Quinn van Bergen

#### **NEA BOARD OF DIRECTORS**

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

#### SCIENTIFIC ADVISORY COMMITTEE

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

#### NEA DIRECTOR EMERITUS

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

#### SCIENTIFIC EDITORIAL COMMITTEE

Jeffrey Bienstock, MD, FAAP Tali Czarnowicki, MD Adam Friedman, MD Emma Guttman, MD, PhD Tamar Hajar, MD Jennifer LeBovidge, PhD Peter Lio, MD Amv S. Paller, MD Robert Sidbury, MD, FAAD Eric L. Simpson, MD, MCR Elizabeth (Lisa) Swanson, MD Paul Yamauchi MD PhD

#### SCIENTIFIC ADVISORY COMMITTEE EMERITUS

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

## In This Issue

#### Featured

## 09 Beyond the rash

There's more to atopic dermatitis than dry, itchy skin. An expert explains the art of pinpointing triggers and AD's connection to asthma, hay fever and food allergies.

## $oldsymbol{14}$ All in the family

When one family member has eczema, it affects the whole household.

## 25 Happily ever after

A diverse group of people around the world share their eczema journeys and best relationship advice.

#### Departments

- 02 Letter from Julie: Updates from NEA's President and CEO
- 03 Scratch Pad: Advice from the NEA community
- 04 Community Spotlight: Dove models with eczema
- Discovery Zone: Exploring the latest in eczema research
- 30 Ask A Doctor: Newly diagnosed with AD
- 32 NEA News: What's happening at NEA
- **36** My Journey: Helen Piña on eczema in the workplace



#### **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 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.

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 © 2018 National Eczema Association. All correspondence and requests for copies should be directed to:

National Eczema Association 4460 Redwood Highway, Ste. 16-D San Rafael, CA 94903

Phone: 800.818.7546 or 415.499.3474 Fax: 415.472.53.45 Email: info@nationaleczema.org nationaleczema.org



ow many of you have heard some variation of this from a well-meaning stranger? *Oh, you have eczema? My mother's neighbor's cousin has that. Have you ever tried putting lotion on it?* And you think to yourself, "Gee, if I had a dollar for every time I heard that, I could afford every lotion and potion on the market!"

By definition, eczema is a medical condition in which areas of the skin become dry, itchy, cracked or inflamed. But there is more to eczema than what meets the eye. The word "eczema" is an umbrella term for a group of skin conditions that might have similar symptoms but are vastly different in other ways. To complicate matters further, it's common to have more than one type of eczema in your lifetime. No wonder finding your triggers and the right treatment can feel like a guessing game!

So, for this issue, we're going "Beyond the Rash" to shine a spotlight on the myriad ways eczema impacts our day-to-day lives. Those living with atopic dermatitis have experienced their fair share of comorbid health conditions, including asthma, allergic rhinitis (hay fever) and food allergies. How are these illnesses related, and what's the best way to treat them? We asked the experts to weigh in on page 9.

Doctors emphasize the physical effects of eczema, but what about the emotional toll? On page 36, you'll meet a business professional who's mortified whenever her skin sheds in the conference room at work. On page 14, you'll hear from exhausted parents who feel helpless as their children struggle with unbearable itch, and a young adult who feels guilty for monopolizing her parents' time and attention due to growing up with severe eczema.

If dating isn't stressful enough, eczema can wreak havoc on a person's self-esteem. On page 4, you'll meet two ladies whose problematic skin tormented them as teens but recently landed them in a global ad campaign for Dove. What's the secret to a successful courtship and a blissful love life when you have eczema? We were shocked by the sheer volume of people brave enough to reach out and speak candidly on this topic. What they had to say on page 25 will tug at your heart – in a good way!

So, remember, there are millions of people around the world with eczema who share the same thoughts, feelings and experiences. Together, we can build a network of support that will educate the public, end stigmatization and bring us closer to a cure.

Yours, Julie Block

P.S. Last call: Join NEA at the 2018 Eczema Expo in Chicago, June 21-24. Turn to page 32 for details!

# Itch, also known as pruritus, is the most common symptom of eczema. Do you have any tips or tricks for managing itch?



Cold water or ice packs. – RAW'A H.

White vinegar. – BECKY F.

*I mix tea tree oil with my CeraVe ointment to help calm my itchy skin. – SANDRA C.* 

*I refrigerate apples and eat them when I feel itchy and inflamed. The cold helps the heat, and the apple helps with inflammation and anxiety. – NELA C.* 

I had never known a day without severe itch until I found Dr. Richard Aron on Facebook. Thanks to him, I no longer itch. I can finally take showers without pain. It is all about treating the staph infection. – TRACY M.

Bleach bath. – JACKIE S.

Cold compress, wet wrap and bleach baths are what have been helping my son for 10 years now. – CHERYL W.

Drinking apple cider vinegar or having a bleach bath are my main go-to's. – CASSIE L.

Benadryl, cortisone cream and probiotics. – SUZANNE T.

The eczema creams work very well, but don't over use them because they are very strong. Stay away from harsh soap like Irish Spring and Dial. I use Dove for sensitive skin. – JOVAN L.

Keeping my nails trimmed super short has helped me from waking up with bloody scratches, but sometimes I scratch so hard in my sleep that I end up with bruises. – RACHEL E.

A life-saving trick for me is a seven-minute lukewarm soak in the tub. I fill the water only as high as I need for the areas of my body that are itchiest. After soaking for seven minutes (always use a timer!), I put on a thin layer of Theraplex's barrier balm. – LAUREN M.

Dead Sea salt baths, Westlab brand. – JENNIFER E.

Cold shower. – JASON L.

Eucerin healing ointment mixed with carrot seed oil and lotion. Spread on big patches (I get mine mostly on my hands) cover with gauze, and put on cotton gloves and leave overnight. – MARIA S.

Sit on my hands. Just kidding. Kind of. – ALLY T.



@nationaleczema



inspire.com/groups/national-eczema-association

Responses have been edited for length and clarity. The opinions expressed by NEA contributors are their own and do not necessarily reflect the opinions or positions of the National Eczema Association.

# **READY FOR THEIR CLOSE-UP**

## Dove launches new advertising campaign featuring women with eczema and other skin conditions.

BY MARGARET W. CRANE

bout a year ago, Alexis Smith received a surprising message via email and Twitter. A global skincare brand wanted to interview her by phone after finding her on Instagram (@eczemalove), and she promptly responded to that request.

Next, the brand representative asked Smith to tell her story in a short video, and once again, she followed through. The 21-year-old from Harford County, Maryland, soon learned that she had been selected as one of six women with skin conditions to be featured in Dove's upcoming DermaSeries campaign.

Meanwhile, in Chicago, 23-year-old Mercedes Matz learned that she had been chosen as well. Matz had responded to an ad she spotted on Twitter. A mysterious global beauty brand was looking for women aged 20 to 60 with skin conditions to participate in an advertising campaign. When Matz learned that brand was Dove, she leapt at the chance to shed her insecurity and be seen in an entirely new light.

## **BEAUTY IS FOR EVERYONE**

The beauty industry is changing. After decades of promoting a single standard—one that most of us have a hard time achieving—diversity has become the new industry watchword. It's about celebrating all the ways in which we're gloriously different from each other.

The DermaSeries campaign challenges women to "make peace with dry skin"—not just by using the Dove DermaSeries line of products, but by learning how to "feel comfortable in their own skin," whether they have eczema, psoriasis or any other skin condition.

"For me, the idea is to normalize eczema," Smith said. "I want people to see it so that they don't feel eczema makes us ugly. That's why I started my Instagram in the first place. Instead of just talking about how much it sucks to have eczema, I try to spread a positive message."

And Matz does the same on her Instagram (@keystothecedes). "It's about lifting up unconventional beauty," she said.

"I feel like imperfections are real beauty. Eczema is one of mine, and that's just what makes me unique," Smith explained on the DermaSeries website. ►

## **OUT FROM THE SHADOWS**

Many children and adolescents with eczema constantly deal with put-downs—and even in adulthood, those wounds still sting.

Smith can still recall the cruelty of her peers when she was in her teens. "I remember someone saying to me, 'Hey, Alexis! You've got something on your face!"

She has mild to moderate eczema now, thanks to red light therapy—a treatment that has worked well for Smith.

She had the condition as an infant, but she seemed to grow out of it until it came roaring back when she was 12, just in time for adolescence and the onset of painful self-consciousness. She longed to wear cute, backless tops and dresses, but the eczema on her back made her feel like that wasn't in the cards.

Hundreds of miles away, Matz was on her own eczema journey. She had always done her best to conceal her inflamed skin. But the more she hid, the worse she felt.

"I built a wall to protect myself," Matz said. "That wall has crumbled now. Being seen, first on Instagram and now in the DermaSeries ads, has been incredibly freeing. Instead of explaining eczema to every person who crosses my path, I get to tell my story all at once." ►

0) -

Photo courtesy of Unilever, Dove DermaSeries



Photo courtesy of Unilever, Dove DermaSeries



## **TWO TRANSFORMATIONS**

Social media outlets have played a major role in helping Smith and Matz break through the stigma and their feelings of isolation. Both women said they have received a healthy dose of support from their followers on Instagram.

That sense of community was heightened during their trip to New York City for the Dove photo shoot. For three days, "We all bonded over our skin issues," Smith said. "We went from 'Don't you hate it when you wear black pants and they get all flaky?' to 'How do you adjust to the feeling of being visible after so many years spent in hiding?""

Adjust they did, and quickly! Smith saw herself in a Facebook ad for Dove DermaSeries just the other day. Matz, who was selected for the North American print ad campaign, has already appeared in O Magazine, Essence and CVS store displays.

Matz had a major epiphany during the photoshoot. When she mentioned how self-conscious she felt about the eczema on her hands, the women she met there told her they hadn't even noticed it. "All these years, people hadn't even been paying attention to my eczema," she said on the campaign website. Most of her fears around criticism and rejection, Matz realized, had been in her head.

"Now, I imagine a little girl with eczema seeing my smiling image in a pharmacy display," she said. "I see myself in that little girl, and I imagine that she can see herself in me. It's amazing to be able to be a source of inspiration for another human being."

Since the start of the Dove campaign, Matz has continued to blossom. On a new treatment for the past two years, her eczema has gone from severe to mild, with "just a little hyperpigmentation here and there, but no open cuts or sores—and the medication has cut my pain and itch down to size," she added.

Smith has returned to her job as a receptionist in her father's physical therapy office, and Matz is back to being a freelance hair stylist. But their lives have changed forever. The Dove campaign has only just begun to spread its wings—and so have these two young women, eczema and all. \*

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

## **DUPIXENT** can help heal your skin from within

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

#### SEE AND FEEL THE CHANGE

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

#### In Clinical Trials at Week 16:

INDICATION

- More than 1 in 3 patients saw clear or almost clear skin
- Almost half of patients saw significant skin improvement
- Patients experienced a significant reduction in itch

DUPIXENT is a prescription medicine used to treat adult

patients with moderate-to-severe atopic dermatitis (eczema)

that is not well controlled with prescription therapies used on

the skin (topical), or who cannot use topical therapies. DUPIXENT

can be used with or without topical corticosteroids. It is not

Do not use if you are allergic to dupilumab or to any of the

Before using DUPIXENT, tell your healthcare provider about

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

are breastfeeding or plan to breastfeed. It is not known

whether DUPIXENT will harm your unborn baby.

whether DUPIXENT passes into your breast milk.

Tell your healthcare provider about all the medicines you

take, including prescription and over-the-counter medicines,

vitamins and herbal supplements. If you have asthma and are taking asthma medicines, do not change or stop your asthma

known if DUPIXENT is safe and effective in children.

**IMPORTANT SAFETY INFORMATION** 

all your medical conditions, including if you:

have a parasitic (helminth) infection

ingredients in DUPIXENT.

have eve problems

have asthma

 Most Common Side Effects were injection site reactions, eye and eyelid inflammation, including redness, swelling and itching and cold sores in your mouth or on your lips.

So stay ahead of your eczema symptoms with DUPIXENT.



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

 Allergic reactions. Stop using DUPIXENT and go to the nearest hospital emergency room if you get any of the following symptoms: fever, general ill feeling, swollen lymph nodes, hives, itching, joint pain, or skin rash.

 Eye problems. Tell your healthcare provider if you have any new or worsening eye problems, including eye pain or changes in vision.

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

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

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

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

medicine without talking to your healthcare provider.
SANOFI GENZYME **REGENERON** 

 $\ensuremath{\mathbb{O}}$  2017 Sanofi and Regeneron Pharmaceuticals, Inc. All Rights Reserved. US-DAD-14339

Talk to your doctor and call 1-844-DUPIXENT (1-844-387-4936) or visit DUPIXENT.com for more information.

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

#### What is DUPIXENT?

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

#### Who should not use DUPIXENT?

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

## What should I tell my healthcare provider before using DUPIXENT?

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

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

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

#### How should I use DUPIXENT?

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

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

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

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

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

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

## 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 / ©2017 Regeneron Pharmaceuticals, Inc. / sanofi-aventis U.S. LLC. All rights reserved. Issue Date: April 2017

# BEYOND THE RASH

THERE'S MORE TO ATOPIC DERMATITIS THAN DRY, ITCHY SKIN. AN EXPERT EXPLAINS THE ART OF PINPOINTING TRIGGERS AND AD'S CONNECTION TO ASTHMA, HAY FEVER AND FOOD ALLERGIES.

BY KATHRYN JONES

hen we hear the word *eczema*, visions of red or dark, dry, itchy, inflamed patches of skin come to mind. After all, the eczema rash is a tell-tale sign of the inflammatory skin disease that affects more than 30 million Americans. But there is more to eczema than what meets the eye. Have you ever thought about what goes on beneath the surface of your skin to bring forth this annoying rash?

Why does exposure to certain things like household cleaners, pet dander or cigarette smoke trigger flares in some people with eczema, but not in others? And why is it common for people with atopic dermatitis (AD) to also have asthma, hay fever, food allergies, or a combination of all three? How are they connected?

While scientists don't have all the answers yet, they are making strides in understanding the mechanisms of this disease. This has allowed them to develop advanced treatments like the first biologic for moderate to severe AD, which tackles inflammation at the cellular level.

Ready for some movie trivia? There was a 1966 science fiction film called "Fantastic Voyage," starring Raquel Welch, about a submarine crew who shrunk themselves to microscopic size to venture inside the body of an injured scientist to repair the damage to his brain. (If you haven't seen it, you're missing out!)

Join us as we take our own "fantasic voyage" and go beyond the rash and underneath the surface of the skin to better understand how eczema impacts our day-to-day lives. ►

## **INSIDE THE TRICKY WORLD OF TRIGGERS**

People with eczema tend to have an over-reactive immune system. When triggered by a substance inside or outside the body, the immune system responds by producing inflammation. It is this inflammatory response that causes the itchy, painful, rash-like symptoms common to several types of eczema.

Types of eczema include: contact dermatitis, atopic dermatitis, dyshidrotic eczema, nummular eczema, seborrheic dermatitis and stasis dermatitis. It's common for people to have more than one type of eczema simultaneously throughout their lives, especially those living with AD.

Eczema affects people uniquely. Each type of eczema has different triggers, symptoms and treatments. A substance that triggers eczema in a parent may not do the same to their child. That's why it's important to know what type of eczema you have and what substances triggered the flare-up so you can manage symptoms appropriately.

Keith Heeley, who works at a commercial real estate firm in Los Angeles, developed atopic dermatitis in his mid-20s. "I have really dry skin," he described. "Sometimes I will get weeping on some of the open wounds where water will start pouring out. But by far the most frustrating part is the itch. It's like having a bottomless itch that you can't get to. You want to scratch to the very bottom of your being."

According to Dr. Michael Wein, chief of allergy and immunology at the Florida State University College of Medicine in Tallahassee, there have been a "plethora of potential triggering factors" for eczema documented in scientific literature over the years.

These run the gamut from irritants and allergens you come in contact with through touch or inhalation, to food allergies, microbial colonization leading to skin infections, changes in climate and temperature, and whether the disease runs in the family.

"I used to think our bodies were made with such brilliant resiliency," Heeley said. "When eczema hit, I thought I could cure it with whatever lotion. As I got older, it just kept getting worse and coming back. I didn't understand what it was for the longest time. When I learned that it is a widespread disease, it helped me come out of my sense of denial."

### THE TRICK TO IDENTIFYING TRIGGERS

Patch testing is a tool many doctors use to diagnose potential eczema triggers. In this test, allergists like Wein apply adhesive strips or "patches" to an eczemafree area of the back. The patches contain substances that are believed to cause irritation in people with eczema.

After 48 hours, the doctor removes the patches and inspects the skin for reactions. After two more days, the doctor looks at the patch sites for signs of inflammation. If there is inflammation, the allergy to a particular substance is confirmed.

"Most scientific evidence regarding trigger factors in AD relates to dietary exclusions or house dust mite avoidance strategies," Wein said. "There is little consistency across studies in the type of diet evaluated, and indications for special diets were not always made clear. It is also unclear what role factors such as stress, humidity or extremes of temperature have in causing flares—just that these factors should be avoided where possible." ►

created by kjpargeter Freepik.com Heeley knows firsthand the frustration that comes when elimination diets fail to identify triggers. He wonders if the stress of trying to identify triggers might contribute to his flare-ups.

"Maybe I need to tone down my stress level and think more calmly about tackling the problem," he admitted. "I just knew that it had something to do with food and my digestive tract. I thought I tried all of the elimination diets, but I couldn't find anything that correlated.

"Then a couple nights ago, I ate some honey-roasted peanuts. I've never had an allergy to peanuts, but boom! It just kicked in," he lamented. "It's so hard to isolate what's causing it. You have to take it one day at a time with this disease."

Don't rely solely on medical providers to identify triggers. Empower yourself to do a little investigating of your own. NEA recommends keeping a trigger tracker notebook with a detailed log that addresses the following questions:

- What time of year is it?
- What was the weather like?
- What time of day or night did the flare occur?
- Where was I, and what was I doing at the time?
- Where on my body did the eczema appear?
- How was I feeling when I developed the flare?
- What type of allergens or substances did I come into contact with?
- What did I eat and drink that day?

## WATCH OUT FOR THESE COMMON ECZEMA TRIGGERS!

• **Dry skin** can easily become brittle, scaly, rough and tight.

• **Chemical irritants** are everyday products or substances (hand and dish soap, laundry detergent, shampoo, bubble bath and body wash, or surface cleaners and disinfectants) that can cause your skin to hurt or itch.

• Stress can causé a person's atopic dermatitis to flare or worsen.

• **Hot/cold temps** and sweating can lead to itchy skin, or "prickly heat" symptoms can develop during the cold winter months.

• **Infection** from bacteria and viruses that live in your environment (like staph, herpes or certain types of fungi) can lead to a flare.

• Allergens wreak havoc on our lives and come from everyday materials in the environment like seasonal pollen, dust mites, pet dander and mold.

• **Hormones:** Flares may happen, especially in women, when certain hormones in the body increase or decrease.

### WHEN YOU FEEL ALLERGIC TO EVERYTHING

Eczema and allergies go together like bread and butter or Batman and Robin. It's rare to find one without the other. In fact, the word *atopic* in atopic dermatitis translates to allergy. AD can bring on a host of other allergic conditions: asthma, hay fever and food allergies. If you already have one of these conditions, chances are high that you'll develop one or more of the others.

Almost half of people living with AD develop the tell-tale signs of allergic asthma: coughing, wheezing, shortness of breath and a feeling of tightness in the chest. About 75 percent experience symptoms of allergic rhinitis (hay fever): itchy, watery eyes, nose and throat; stuffy, runny nose; ear pressure and fatigue. Up to one-third have some sort of food allergy—most commonly, peanuts, eggs, milk or soy.

"Most patients are already familiar with allergen immunotherapy, also known as allergy shots, which can decrease symptoms for many people with allergic rhinitis, allergic asthma, conjunctivitis or stinging insect allergy," Wein said. "Allergy shots work like a vaccine. The body responds to injected amounts of a particular allergen, given in gradually increasing doses, by developing immunity or tolerance to the allergen." Allergy shots are not used to treat food allergies, Wein specified. "Patients should base a decision regarding allergy shots on how much time each year is spent suffering with allergy, how well medications and environmental controls are helping, and whether the medications are too costly or causing side effects," he said.

"Many patients with allergies can find wonderful relief with over-the-counter (OTC) treatment options," Wein added. "If they cannot avoid the allergen, the FDA has approved several previously 'prescription only' medications for OTC use, including Flonase, Rhinocort, Claritin and Zyrtec."

"I've been thankful that I haven't suffered from asthma," Heeley said. "I do get a lot of sinus pressure and head congestion when I'm around certain pollens. It would affect my ability to think. One day, I took an antihistamine. It took all the pressure out of my head and made me feel alert, like I could actually function. I never realized I'd been walking around with sinus pressure for years."►



EO PHARMA® IS PROUD O SUPPORT THE NATIONAL ECZEMA ASSOCIATION



# we help people achieve healthy skin



LEO, LEO Pharma and the LEO Lion Design are registered trademarks of LEO Pharma A/S. Copyright 2018 LEO Pharma Inc. MAT-15724.2018



### SHOW THOSE ALLERGENS WHO'S BOSS

"Typically, the only way to lessen an allergic reaction is through desensitization, a process in which you gradually introduce small amounts of the allergen into your body," Wein said. "That is how allergists can stop you from being allergic to pollen, mold, dust, cats or even venom."

You could also take on allergies the old-fashioned way: by cleaning thoroughly and often to reduce the levels of pollen, mold, dust and pet dander lurking in the nooks and crannies of your home. Just be sure to wear gloves while cleaning to protect your skin from irritating chemicals and detergents, and a mask to avoid breathing them in.

Most allergists recommend purchasing a HEPA filter, but it won't protect you from all airborne allergens, Wein warned. "Dust mite allergen, which is carried on larger particles that fall rapidly to the ground after a disturbance is much less responsive to a HEPA filter," he said.

Wein also recommends investing in allergy pillow and mattress covers that act as a barrier against pet allergens. "Animal dander can stay airborne for hours," he said. "Levels in homes without animals are generally much lower but can still be detected. Interestingly, sometimes the pet fur can collect pollen or dust mite allergens and act as a vector for another allergen, but my experience is that this is much less common."

Always be on the lookout for mold, which are tiny fungi, and the spores float through the air. "If you are allergic to mold, your immune system is overly-sensitive to specific mold spores and treats them as an allergen. Mold thrives in humid and damp environments. This is a real problem in Florida where I practice," Wein said.

There are hundreds of types of molds, but the most common allergy-causing molds are Alternaria, Aspergillus, Cladosporium and Penicillium, he said. "In exceptional cases in which asthma is unusually severe, such as Alternaria species-induced asthma in the Midwest, it might be advisable to chat with your

MY HEART WANTS TO SEE A BREAKTHROUGH SO KIDS WON'T HAVE TO GROW UP WITH ECZEMA." - KEITH HEELEY

doctor. Also, buy a hygrometer!" Wein advised. That's an instrument used for measuring water vapor in the air.

And if you happen to spot a cockroach, get rid of it immediately. Exposure to cockroaches is another important asthma trigger, particularly for children with asthma living in inner cities, Wein said, citing a study that tested for cockroaches in the homes of children with asthma in New Orleans.

"The strategic placement of insecticidal bait—which is inexpensive, has low toxicity, and is widely available resulted in sustained cockroach elimination over 12 months and was associated with improved asthma outcomes," he said.

Heeley put it best when he called eczema a "stubborn" disease. "It doesn't know gender, age, lifestyle, race—it affects all kinds of people and doesn't discriminate" he said. "Millions of people are touched by eczema. It's had a huge impact on society as a whole, and it took me far too long to get my mind around the fact that this is a clinical diagnosis and a life-changing disease.

"We're blessed to have organizations like NEA doing so much to help our community and doctors who really want to get to the root of this thing," Heeley continued. "Hopefully in the future, people won't have to go through what we've gone through. My heart wants to see a breakthrough so kids won't have to grow up with eczema." \*

# All in the Family

When one family member has eczema, it affects the whole household.

By Margaret W. Crane

n her way home from her job at Walmart in Fort Walton Beach, Florida, Stephanie Powell picks up treats for all three of her children. She does this to signal that she loves all of them equally, even though it may not always appear that way.

Her middle child, Isabelle, has severe eczema, requiring Powell to spend much more time with the 9-year-old than with Gabrielle, Isabelle's hearing-impaired older sister. As for the littlest Powell, 18-month-old Christopher Jr. (C.J. for short), his mother can often be found holding him with one arm while using the other to help Isabelle with her complicated after-bath skincare ritual.

"Gabrielle is so endearing with her sister," Powell said, "but she does feel left out. Having one child with eczema means that I can't always be there the way I want to be for my other kids. If Isabelle's skin breaks open, that determines how I'll be spending my time on any given day."

Diagonally across the country in Spokane, Washington, Heather Sullivan's daughter, Hazel, also shows great tenderness toward her younger brother, Sawyer, whose eczema is at the extreme end of the severe range. Sawyer has lived in near-constant torment since infancy, his mother said. A baby who failed to thrive, he ingested nothing but liquids until age 3.

Sullivan tried everything—even cyclosporine, considered controversial and sometimes dangerous when used to treat children. "I knew it was risky. He was only 15 months old. I guess I felt we had nothing to lose," she said. "Between his round-the-clock symptoms, lack of sleep and life-threatening allergies, Sawyer's quality of life was so poor that the risk seemed worth taking."

Because of his mother's desperate decision, Sawyer got a twoyear break from eczema, giving him a chance to start learning a few coping skills, such as "how not to scream, scratch violently and react to every stimulus," Sullivan said. Eventually, she took her son to a new hospital, where he was weaned off cyclosporine. But then his eczema returned with a vengeance. To make matters worse, 12-year-old Hazel has eczema too—the moderate type.

"Sawyer's health has always taken precedence," Sullivan admits. "Hazel is mostly on her own when it comes to taking care of her skin. Obviously, this isn't an ideal parenting dynamic."

## Getting past the guilt

Jennifer LeBovidge, a psychologist at Boston Children's Hospital and a member of the Harvard Medical School faculty, believes that parents like Powell and Sullivan are way too hard on themselves.

For parents of children with eczema, feeling guilty is the air they breathe, LeBovidge said. And there's no shortage of reasons for these feelings, which are often unjustified. "Focusing on the child with eczema and spending less time with the other children is a big one," she noted.

To put things into perspective, parents should remember that they're only human, LeBovidge explained. "No individual human being can be in two or three places at once or deal with everyone's needs on demand, 24/7," she said.

There's also the ever-popular, "I must be doing something wrong," LeBovidge continued. "One parent recently told me he had used topical steroid cream on his child's inflamed skin, but that the disease 'came back.' He was convinced that its return was his fault," she recalled.

"Eczema is a chronic condition, so it can have a mind of its own. By 'chronic,' we mean that it's lifelong and that it comes in cycles. You can do everything in your power to help your child avoid triggers, and you can try all kinds of treatments, but eczema eventually flares no matter what you do. Its reappearance doesn't mean you did anything wrong or failed to do something right." ►

## The Powell Family



## **The Sullivan Family**

## Balancing responsibilities

Parents can also feel divided between their responsibilities at work and at home, LeBovidge added. That's true for all parents. But multiply that feeling by a factor of a hundred, and you begin to sense the magnitude of the inner conflict eczema parents experience when work and family duties rip them in two.

Desirré Buck, a married mother from York, Pennsylvania, went back to work as a retirement planner soon after the birth of her first child, Sophia, who developed eczema shortly in infancy—but she lasted all of six months on the job.

"I wanted to be a supermom and do it all," she confessed, "but my daughter's skin issues consumed me at work. I was constantly thinking about what I was going to do to make it better. My heart and my brain were in two different places, with finance, investment and numbers on one side and Sophia's inflamed skin on the other."

Buck was able to make the decision to stay at home with her children. That has worked out well for the whole family. Now, she can devote herself to tending to her children's needs during the day.

But then, there's night, with its own line-up of challenges and frustrations.

## The impact of lost sleep

"Sophia, our toddler, digs into her skin in her sleep, making herself bleed and causing her itchy patches to open," said Buck. "She screams and kicks at night due to aggravation from a lack of sleep. My husband and I are often up dealing with our toddler while trying not to wake Dominic, our infant. The stress on our family can feel unendurable."

The Bucks are far from alone, said LeBovidge: "Hands down, the disruption of sleep is the No. 1 issue affecting eczema families. More than 60 percent of parents report between one and two hours of lost sleep per night. And these numbers are a lot higher for parents of children with severe eczema."

Siblings are affected too, she added, especially if children share a room. And obviously, the child with eczema suffers hugely from the effects of poor sleep. For eczema families, then, sleep disruption is a whole family affair. ►



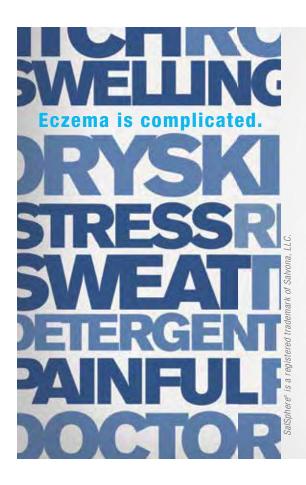
## The Buck Family

## A parent's job description

It took a while for Buck to grasp that she couldn't control her daughter's sleep—or her eczema. She used to run herself ragged trying to create a trigger-free environment for Sophia. But gradually, she and her husband Bill started reading other parents' stories and broadening their awareness of the condition itself.

"Bill actually had severe eczema when he was a child, and he still has a mild case of it," she added. "He remembers all too well what it was like. I've learned a lot from him, and I'm more patient with our daughter as a result. When she scratches herself, when she acts out, when she can't sleep, I remind myself that she can't help it.

"Now that we understand so much more about eczema—the way it has a life of its own—we no longer believe that it's totally up to us to make it go away," said Buck. "That has been a huge relief for both of us." ►



## We make it simpler.



MG217 is specially formulated with a unique, nourishing SalSphere® Skin Repair Complex that helps restore—and improve—your skin's natural moisture, giving lasting relief from eczema symptoms and leaving you with healthier, smoother skin. And because it's National Eczema Association accepted and uses doctor-recommended ingredients, choosing the right cream to treat your eczema is really quite simple.



Full-line of eczema treatment creams for body, face and babies.

MG217.COM/NEA

Albertsons CVS pharmacy CVS pharmacy devertisement

LeBovidge said there's plenty that parents can do to feel more more comfortable and in control, while helping their child with eczema gain a greater sense of control as well. Above all, the psychologist warned against getting into 'don't scratch' mode: "We all know that scratching makes eczema worse, but battles over scratching increase stress for everyone, plus they're counterproductive, only fueling the itch-scratch cycle.

"Instead, parents can develop a toolkit for dealing with severe itch," she added, including moisturizer, a cool compress, a bath ritual, a change of scenery and creative ways to keep the child's hands busy.

"A parent's job is not to stop all scratching," LeBovidge advised. "Mainly, parents need to remember that they're part of their child's treatment team. I remind them to make sure to tell their provider if something isn't working or if they can't afford a product or medication.

"For most families, the burden of eczema tends to get lighter over time," she continued. "Skincare becomes less intensive. Gradually, kids take on a bigger role in their own care, and parents can begin to let go. While remaining available for support and monitoring, parents can start turning over day-today skincare to their older child with eczema, even if that care is less than perfect at first."

## Growing up with atopic dermatitis

Ashley Lora, now 26, has had atopic dermatitis (AD) since she was only 2 months old—and she remembers all too well what life was like as the youngest of three children, the only girl and the only one with eczema.

From the Dominican Republic, Lora's parents raised their children in Fair Lawn, New Jersey, intent on pursuing the American dream. But their daughter's eczema upended their best laid plans.

"Because of my eczema and my asthma, we couldn't have a dog in the house," she said. We couldn't have carpeting. I used to sleep with my parents so they could stop me from scratching myself. I missed a lot of school, and I was in the ER a lot. My parents had to put their own lives on hold to give me a normal childhood. When I think about what they went through, my level of gratitude is huge."

By her early 20s, Lora had become dependent on topical steroids. She finally stopped taking them, but she soon went into serious withdrawal and ended up bedridden for two years.

Then, in 2015, she entered the clinical trial—and about 90 percent of her skin has since cleared.

## The Lora Family



"For the first time in my life, I understand what freedom feels like," said Lora. "I'm interested in and astounded by everything, like sitting in the sun, doing water activities and just being spontaneous and adventurous!"

Today, Lora is a business coach living in Los Angeles who helps people come up with professional goals and strategies for realizing them. She said her own goal is to become a public speaker for the eczema community.

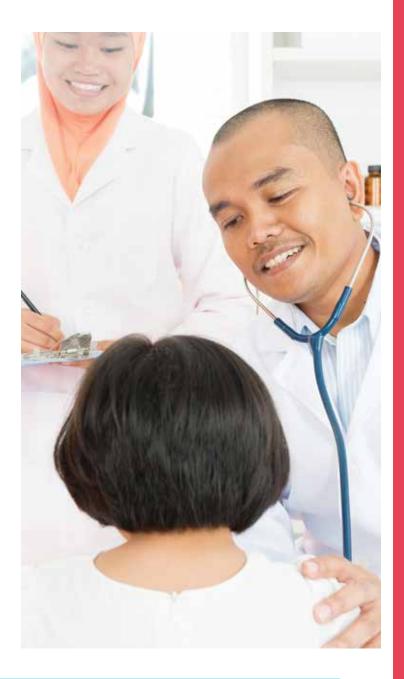
"I never thought I could heal from eczema—but I did, at least for now," Lora said. "For the first time, I can imagine having my own children. I realize they might inherit eczema from me. That could happen. But that doesn't seem quite as terrible as it once did. Now, I see that healing really is possible."

## Extended family

In addition to a great health care team, a solid support system is key to successful parenting, LeBovidge said. That support can come in the form of an extended family, friends, community resources or, optimally, all of the above.

"Think of NEA as part of your extended family," she tells her patients. "Take advantage of their website and use their new provider directory to find a specialist. And take advantage of the greatest benefit of all: When you join the NEA family, you'll never need to feel alone again."\*





## MEET OTHER FAMILIES IN THE ECZEMA COMMUNITY. CONNECT WITH US ONLINE!



#### EczemaWise.org

Don't forget to join us at the 2018 Eczema Expo, a gathering of patients, families and providers, coming up in Chicago from June 21-24.

## **Care for all families**

#### At a hospital-based dermatology clinic, lower-income families strive to overcome obstacles to care

At Seattle Children's Hospital, physician assistant Morgan Meier takes care of patients and families representing every nation, race, age and ethnic group. Many are on Medicare or Medicaid. Serving four states—Idaho, Montana, Alaska and Washington—the dermatology clinic at Seattle Children's is one of the only places where lowerincome families can receive treatment for their child with eczema from a specialist like Meier.

As if eczema weren't enough of a hardship, Meier's patients face a formidable array of barriers to care. "They're short on time, money and gas," she said. "It's hard for them to get to us. If a mother doesn't drive or have a decent car, she has to bring her child to us by bus, adding hours of travel time to her already over packed day. We're expanding our clinic locations to make transportation less of an issue."

Then, there's the language barrier. Meier sees large numbers of families who have limited knowledge of English. The hospital provides interpreters for all who need them—but there's always a risk that critical information will get lost in translation, she said. Medical language also can add a layer of confusion for parents as they struggle to understand their child's needs and follow their doctor's treatment recommendations.

Culture comes into the picture as well, she said: "Here's just one example: Devout Muslim families pray six times a day, and they're required to wash their hands before they pray. That's a lot of irritation for little hands with eczema.

"At the hospital, we do our best to be sensitive to cultural and religious traditions while helping families learn to deal with their child's eczema gently and effectively," she said, stressing the importance of consistent skincare.

"Low income can be the toughest hurdle of all," Meier added. "Many of our parents can ill afford to take time off work, and they're also under constant pressure to pay for gas, copays, specialty soaps, creams and medications" necessities that can seem like luxuries when you barely have enough money to put food on the table."

But despite these many obstacles, many families receive the care they need at Seattle Children's, thanks to dedicated professionals like Meier and her team. "Eczema becomes more manageable over time. When a baby under our care starts to thrive, the sense of relief is palpable. Each step is a small win, and in time, these can add up to become a major victory."

# **DISCOVERY ZONE**

The latest news, research and discoveries about eczema

BY KATHRYN JONES

#### First food allergy treatment seeks FDA approval

here could be relief in sight for people struggling with food allergies, a common comorbidity—or related health condition of eczema. Phase 3 trial results for AR101, an oral immunotherapy medication focused on peanut allergies, have met all the end points required by the U.S. Food and Drug Administration (FDA) for approval, according to Aimmune Therapeutics, which developed the treatment.

AR101 contains a tiny dose of peanut powder—held in a capsule, then opened and sprinkled onto food that trial participants consumed on a daily basis. The amount of protein powder in each capsule gradually increased until it reached a maintenance dose amount of 300 mg, which is approximately one peanut.

During the trial, patients worked up to 300 mg of peanut powder for about six months, and then stayed on that dose for another six months. Out of the 496 patients treated in the study, 372 were in

the active treatment group, while the remaining 124 received a placebo.

At the end of the year-long study, about two-thirds of participants with peanut allergies were able to eat 600 mg—roughly two peanuts—which was considerably more than the placebo group, the company reported, adding "an impressive number were able to tolerate even more at one sitting."

"For the first time in the history of food allergy, a large-scale, late-stage clinical trial has shown that oral immunotherapy, done with our investigational medicine, AR101, significantly increased the amount of peanut protein that a patient could consume with no more than mild symptoms," CEO Stephen Dilly said in a statement.

Aimmune Therapeutics plans to file for FDA approval at the end of this year, and if approved, could begin rolling out the treatment as early as mid-2019. \*



Two new pills show promise for treating atopic dermatitis

he American Academy of Dermatology (AAD) Annual Meeting is a yearly convergence of brilliant minds in dermatological research from around the world. The event, which took place in February 2018 in San Diego, California, included presentations on two new oral treatment options for atopic dermatitis (AD).

Dr. Emma Guttman-Yassky presented on phase 2 clinical trial results for upadacitinib, a Janus kinase (JAK) 1-selective inhibitor, for adult patients with moderate to severe AD not adequately controlled by topical treatments or for whom topical treatments were not medically advisable.

According to the study, the once-daily oral medication made by AbbVie significantly improved symptoms of AD, including a reduction of itch at week one and improvement in the extent and severity of skin lesions at week two.

In January 2018, the FDA granted breakthrough therapy designation (BTD) for upadacitinib in adult patients with moderate to severe AD who are candidates for systemic therapy. The purpose of BTD is to expedite the development and review of medicines that demonstrate substantial improvement over existing therapies based on clinical evidence.

Dr. Jonathan I. Silverberg presented on study results for Lilly's baricitinib, a once-daily oral JAK 1 and JAK 2 inhibitor for moderate to severe AD. For 16 weeks, 49 participants received a once-daily placebo, 49 participants received 2 mg of baricitinib, and 38 participants received 4 mg of baricitinib while on topical corticosteroids.

Researchers used three scoring systems: Scoring Atopic Dermatitis (SCORAD) for itch and sleep, Dermatology Quality of Life (DLQI) and Patient-Oriented Eczema Measure (POEM).

By week one, participants who received either 2 mg or 4 mg of baricitinib experienced statistically significant improvements in mean POEM scores and SCORAD-Pruritus scores compared with those who received the placebo. However, improvements in mean POEM scores by week 16 were significant only for those who received 4 mg dose of baricitinib in conjunction with topical steroids.

While 4 mg of baricitinib showed early efficacy on POEM scores, patients with more severe disease at baseline who received 2 mg of baricitinib showed significant improvements at weeks one and four. By week four, those who received baricitinib experienced significant improvements in SCORAD-Sleep and DLQI compared to patients who received the placebo.

In addition, 45 percent of patients who received 2 mg of baricitinib and 37.5 percent of patients who received 4 mg baricitinib reported clear or almost clear skin or mild eczema by week 16 compared to the placebo group. \*

#### Dupixent faces competition in biologic treatments for AD

upilumab (Dupixent), the first FDA-approved biologic for adults with moderate to severe atopic dermatitis, is quickly gaining traction among patients and their providers as a viable treatment for AD. And according to clinical trial results presented at the February 2018 AAD Meeting, it won't be much longer until more biologics for eczema make their way to pharmacy shelves.

The human body contains a certain type of protein called

an interleukin (IL) that helps the immune system fight off harmful bacteria and viruses. But people with AD have over-reactive immune systems that trigger certain ILs to produce inflammation, which results in itchy, inflamed skin and other symptoms common with eczema.

Biologics block ILs from binding to their cell receptors, which stops the immune system from overreacting, thereby reducing inflammation. Dupilumab, for instance, blocks IL-4 and IL-13. Now there are two new IL antibody medications making their way through the early phases of clinical trials, according to researchers who presented at the AAD meeting.

Germany's MorphoSys AG and Belgium's Galapagos NV, which teamed up to develop

an IL-17C antibody called MOR106 for treating AD, announced positive results from their phase 1 clinical trial, noting that phase 2 would be initiated sometime in the first half of 2018.

Roughly five out of six (or 83 percent) of patients that received the highest dose of MOR106 saw at least 50 percent improvement at week four per the atopic dermatitis area and severity index (EASI) scale. Pooled data across all dose cohorts showed 72 percent improvement of AD symptoms by week 12. Although MOR106 is an investigational drug, and therefore its safety and efficacy have yet to be officially established, no serious adverse effects have been reported by researchers thus far.

Meanwhile, an IL-33 antibody called ANB020 performed "reasonably well" in a small, proof-of-concept phase 2a clinical study and will proceed along in the developmental pathway, researchers reported at the AAD meeting.

> All 12 patients who received one intravenous infusion of ANB020 achieved at least 50 percent reduction in symptoms per the EASI scale by day 29. Most of the improvement occurred in the first two weeks, was largely sustained for two months, then gradually began to fade, according to Dr. Graham professor Ogg, of dermatology at Oxford University.

> > This IL antibody already passed its phase 1 trials, which included both a fixed and ascending dose study of 10 mg to 750 mg. Ogg said ANB020 has a long half-life of 16 days after IV infusion, inhibits IL-33 for up to 85 days and has no apparent dose-limiting toxicities.

AD, in 17 percent of participants, and mild headache in 25 percent. And there was one serious adverse event, a case of major depression that occurred on day 140, according to Ogg. He added that 200 to 300 adults with moderate to severe AD will be recruited for a phase 2b, placebo-controlled, randomized trial.

Interestingly, AnaptysBio, the maker of ANB020, said the treatment is also being investigated in a double-blind, placebo-controlled study of 20 adults with severe peanut allergy, as well as a phase 2a trial of 24 adults with severe eosinophilic asthma. \*

#### Derms itching for other docs to stop prescribing antihistamines

study published in the February 2018 issue of *Journal* of American Academy of Dermatology revealed that even though the AAD does not recommend the general use of antihistamines for treating itch associated with atopic dermatitis, a wide range of medical providers prescribe the treatment to patients with AD anyway.

The reason? Antihistamines are commonly used to treat comorbidities or related health conditions of AD, such as allergic rhinitis (hay fever), asthma and dermatitis outbreaks related to food allergies. Although the AAD has presented evidence that antihistamines don't necessarily relieve itch, sedative antihistamines are often prescribed by dermatologists and pediatricians to help adult and child patients who struggle with sleep due to nighttime itch.

Researchers pulled data from the National Ambulatory Medical Care Survey (NAMCS) to evaluate the use of sedative and non-sedative antihistamines for managing symptoms of AD between 2003 and 2012.

Apart from pediatricians, all other physician specialties prescribed more antihistamines for AD than dermatologists.

Dermatologists and pediatricians primarily prescribe sedative antihistamines for AD to help with nighttime itching, while other physician specialties, including family/ general practitioners and internal medicine physicians, prescribe non-sedative antihistamines.

Dr. Gil Yosipovitch, professor in the Department of Dermatology & Cutaneous Surgery at the Miller School of Medicine in Miami and chair of NEA's Scientific Advisory Committee, expressed the need for dermatologists to play a larger role in educating primary care providers and other physician specialties to change how they look at treating patients with itch.

"Evidence suggests that the use of non-sedating antihistamines is of little value based on our current understanding of the key drivers of itch in AD," Yosipovitch said. "Already [AAD] treatment guidelines are reducing the use of antihistamines for this indication, and new targeted treatments for itch in AD are emerging. I expect that future analysis of the NAMCS database will demonstrate continuing reduction in the use of antihistamines for the treatment of AD itch." \*

## THERE'S MORE TO DISCOVER ONLINE!

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

> nationaleczema.org/ categorydiscoveries

## Trust Natralia to nourish your skin naturally

Born in Australia, and now available worldwide, Natralia grew from a father's desire to help his young son, who faced the day-today 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 steroidbased creams on a long term basis.

He knew there had to be a better option and so he worked alongside experienced pharmacists to develop **Natralia Eczema & Psoriasis Cream**, a product 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 homeopathic, natural herbs and essential oils, the adult product features licorice root, known for its effective anti itch properties and the children's flare cream contains colloidal oatmeal, known for its ability to gently soothe itchy skin.

natralia

Eczema &

Psoriasis

Cream

natralia

Moisturizing

Lotion

natralia

Eczema &

**Psoriasis** 

Cream

- A soap and sulfate free **body wash and shampoo** with coconut and glycerne that helps prevent moisture loss while bathing.
- A **daily moisturizer**, containing colloidal oatmeal that is clinically proven to restore moisture and hydrate the skin for up to 24 hours.

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

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

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



advertisement



## with eczema,

A diverse group of people with eczema from around the world share their stories and best relationship advice.

BY MARGARET W. CRANE

Steve Gawron

ow am I ever going to talk to a girl, much less hold her hand? Am I ever going to go on a date? And even if I do, will she even want to touch someone like me? Will she feel ashamed to introduce me to her parents?

These are some of the questions that used to race through Steve Gawron's mind as a teenager suffering from a combination of peer pressure, eczema and raging hormones. That was more than 30 years ago, and today, he's happily married to his high school sweetheart, Christine.

But Gawron's adolescent anxiety and self-consciousness won't come as any surprise to the millions of people whose eczema has frustrated their dreams of a fulfilling romantic relationship.

There are few studies on the challenges of love and sex for people with atopic dermatitis (AD) and other moderate to severe skin conditions, and the few that have been published draw on data collected from patient surveys, yielding few surprises.

> A recent French study, for example, found that more than 80 percent of patients with AD said their condition had an impact on their sexual behavior. The French researchers concluded that doctors should do more to support and educate their patients concerning matters of the heart.

• To shed light on this deeply personal topic, the National Eczema Association recruited a group of volunteers from all over the world to share their stories, insights and advice with the larger eczema community.

Each one stressed the need to commit to a nurturing, deeply meaningful relationship with the No. 1 person in your life: yourself. ►

SUMMER 2018 | 25

## Building confidence with eczema

At 25, India Henriquez runs her own housekeeping business in Brooklyn, New York, and she has been in a stable relationship with her boyfriend for the past four years. She also has AD.

"When we met, my AD wasn't that bad," she said. "But then it came back with a vengeance. I had to explain to him that it comes and goes, and that there are times when I don't feel well. He has never freaked out about it-not once."

Henriquez has always been able to let her natural confidence shine through, even back in college when she faced social exclusion and outright rejection. She recalled a time during her freshman year when she needed to work on "the dreaded group project." Noting her inflamed skin, her project partner said, "I'm not really comfortable working with you."

That hurt, she admitted, but it was also a turning point. "Something in me got stronger," Henriquez said. "Since then, I've developed a tough skin. It hasn't always been easy, but I never let myself get to the point of feeling defeated by the negativity or ignorance of other people."

Nodding her head in agreement on the other side of the globe is Chawa Munthali-Mphande, the marketing manager for an Internet provider in Malawi, a small country in southeastern Africa wedged between Tanzania, Zambia and Mozambique. Born in Malawi and raised in Edmonton, Canada, Munthali-Mphande has never been free from eczema.

She has had AD, seborrheic eczema and dyshidrotic eczema, sometimes sequentially and sometimes concurrently. She said she has suffered greatly from the stigma that attaches itself to those who have the severe scarring and outbreaks associated with the condition.

"There were many sleepless nights when I'd cry, 'Why me, God?' A so-called friend once said, 'Chawa, you have snake skin, and your kids are going to have it too!'" But, like Henriquez, she embarked on a path to greater selfesteem. "Either you let it get you down or you work on your self-confidence."

For someone as outgoing and bubbly as Munthali-Mphande (you can hear it in her voice!), self-confidence comes more easily for her than it might for others. That's why she decided to create a motivational page on Instagram, called C.C.M. Motivationals.

"I've always had a passion for helping and motivating people to get to a better place," she said. "My Instagram gives me a way to share life experiences, motivational quotes and success stories with people all over the world."

•••

Married for eight years and the mother of three children, Munthali-Mphande sees her own life as a success story despite (and beyond) her battle with eczema. ►

## Pamper yourself with self-care

And speaking of success stories, Adam Simpson, a 30-year-old insurance broker from Ipswich, U.K.-a small town about an hour outside London-weighed in on the link between self-care and romantic success.

"Two weeks before going out to a club or a dance, I'd pay extra attention to my diet and my skin routine," he said. "I'd feel better, and then I'd get more attention from girls. Doing right by myself gave me the extra boost in self-confidence that I needed, not only in terms of dating but in every part of my life, from work to friendship to going to the gym."

Sometimes, Simpson's AD is so bad that he can't even stand up, he said. But his girlfriend, Zoey, who has a mild case of eczema, "gets" him. The couple recently bought a house together. Simpson said he's "incredibly comfortable" with the relationship, thanks to Zoey's empathy and understanding.

Adam Simpson

Self-care also made all the difference for Jennifer Troyer on her wedding day. Unlike most of the others interviewed for this article, Troyer has adult onset eczema. A hospice social worker from Columbus, Ohio, she developed the condition in 2014 shortly after completing graduate school and remembers all too well what life was like before eczema came along.

In the weeks before her wedding, Troyer started taking prednisone. She had experienced side effects from the medication in the past, but wanted to make sure she'd be able to enjoy the crucial weeks before, during and after the ceremony, including her week-long honeymoon in Ireland. After calculating the risks and benefits, she opted to try it again.

Thanks to prednisone, Troyer said, she was able to feel beautiful in her wedding gown, endure the rigors of overseas travel and be "in the  $\blacktriangleright$ 





moment" the whole way through. "On my wedding day, I wore makeup, hairspray and even proper undergarments," she said. "Normally, I can't tolerate any of these things.

"We've been married for seven months, and by now, we're past the honeymoon phase, but we're totally intertwined," she said. "Sometimes I don't want him to kiss me when my lips are cracked, and sometimes I don't want to be touched, and that can't be easy for him to take. But then we'll have a meaningful conversation, and we find our way back to each other."

## Loving yourself with eczema

Without exception, the interviewees said they felt lucky to find a partner who accepts them as they are, but choosing the right partner also depends on knowing what to look for. Openness, honesty and authenticity rated high with all the interviewees as the most desirable qualities in a spouse or partner.

Just as important as your partner's character, said Munthali-Mphande, is the ability to cultivate patience and tolerance in yourself. "Everyone has problems or knows someone who does," she said.

"My husband has bipolar disorder, so in our marriage, acceptance works both ways. As tough as it can be to deal with eczema, I realize that often I'm the one who needs to do the accepting. We work together as a family to get through the hard times, supporting each other all the way." >

## Eczema's role in sex and intimacy

Gawron couldn't agree more that the key to a successful relationship is mutual acceptance. He also believes that truly accepting each other is the basis for a satisfying intimate life.

"Sex can easily become a sore point for couples," he said. "Who's in the mood first? If you're a guy who has eczema, the mood may strike, but then you have to get undressed, shower and moisturize-and then an hour has gone by, and it's been a long day, so the mood fades. And what if she's not in the mood?" After nearly 25 years of marriage, the Gawrons have gotten past all that, he added.

Abbey Lewellyn and her boyfriend, John St. Clair, both students at the University of Louisiana at Lafayette, are at the start of their romantic relationship. Offering a quick peek into their intimate lives, Lewellyn described the way her beau rubs cream on her back...his sweet, protective attitude toward her...and best of all, their bath ritual.

"We try different bath products to see which ones we like and which ones don't trigger an allergic reaction," she said. "Taking a bath together does wonders for my skin and my mentality. And it has brought us much closer too."

St. Clair feels that being involved with someone with eczema has helped him change for the better. "You're with a person, not a disease! Sure, you have to travel outside your comfort zone, but we're happy and hopeful. I plan to be with Abbey for a long, long time."





## Newly Diagnosed with Atopic Dermatitis? What You Need to Know

If you or someone you love was recently diagnosed with atopic dermatitis (AD), don't worry. NEA is here for you! In a recent webinar, Dr. Craig Teller discussed the basics of atopic dermatitis: what it is, how it differs from other forms of eczema, conditions related to AD, available treatments and how to best manage your disease. Please note that portions of this Q&A have been edited for clarity and brevity. Watch the full webinar at nationaleczema.org/resources/webinar-wednesday-archives/.

## How do you know when to treat for a staph infection, which is a common comorbidity of eczema?

Your skin is colonized, so this means that if you have eczema – and literally, 100 percent of patients with eczema have staph already on the skin – when it becomes infected, that's when you start to see scabbing, redness and pain. If you start to have areas that feel more tender, uncomfortable or sensitive, but it's not itching as much – that's the hallmark feature of a staph infection. That's the time to start your topical antibiotic, whether over-the-counter or prescribed, which is the most effective method of targeting Staphylococcus aureus.

#### Are there any beneficial numbing sprays for itchiness?

There are. Look for an ingredient called Pramoxine 1 percent. It's over the counter. It creates a changing sensation in the skin, a numbing effect, and for most patients with eczema, it doesn't irritate. Another one that's readily available over the counter is called Sarna lotion. There are also prescription numbing creams that can be used as well. Play around to find what works for you to get that numbing, counter sensation. And if you want the cheapest numbing agent? Ice. Not only can it help numb the area, it also acts as an anesthetic.

## For people who are on allergy injections, how does that help with eczema?

When you receive patch testing or prick testing that reveals you have an environmental allergy, such as ragweed or mold, what they do with the weekly allergy shot is they start giving you small doses of what you're allergic to. Gradually, over time, your body will begin to build up a resistance so that you stop reacting to that allergen. How does that help with your eczema in particular? Well, if you can stop overreacting to allergies and other things that irritate you and set you off, your eczema will likely stay a whole lot calmer. It won't cure it. We wish it would, but it won't cure it.

## Can you speak to hand eczema and how that may or may not be atopic vs. contact dermatitis?

I feel your pain. That is one of the more challenging and uncomfortable areas to have eczema. Hand eczema is often a sign of atopic dermatitis. The classic teaching was if you had eczema as a child, often times, into adulthood, it moved toward the hands. Now we know that is not always the case. So how do you know if your hand eczema is from a contact allergy?

One of the telltale signs is when you start to see it on the back of the hand, as opposed to the palm side of the hand, it's a contact allergy. When you put medication on and get a painful reaction – and 2-3 percent of patients are allergic to their topical steroid, for instance – it might be contact dermatitis. It's a great question, but the answer is we don't always know. Luckily, there are ways to figure it out. Bring it up to your doctor if you think you have contact dermatitis, and they may conduct some patch testing.

## Can you talk about scalp eczema, what it is and how to treat it?

Scalp eczema can be atopic dermatitis in the scalp, or you can have seborrheic eczema – what we commonly call dandruff – with redness, itching and flakiness in the scalp. So there are a lot of different forms of eczema in the scalp. The scalp is one particular area that tends to be played into by stress. It's one of those unconscious things you notice if you're working at the  $\blacktriangleright$ 

### ASK A DOCTOR

computer or studying, you don't even realize you're scratching. It's that same itch mechanism, and this is one of the worst areas to have it. If you itch or scratch the scalp, it creates more itching. You'll notice the area gets thicker and flakier. When that starts to happen, you get into a horrible cycle.

As for ways to help with it: 1) Recognize that if you can do anything to eliminate scratching, whether it's ice cubes or lotions with menthol, that will help. 2) This is one of those situations where you do want to shampoo on a daily basis. Look for shampoos brands with ingredients such as zinc pyrithione and salicylic acid. These can help calm down the redness and minimize excessive flaking. One of my favorites is P&S Solution. Leave it on the scalp overnight, and then use P&S Shampoo to rinse it out. If you can't get a handle on your scalp eczema with over-the-counter products, you can get prescription shampoos with concentrated topical steroids to help reduce itching very quickly. Just because you're using a medicated shampoo, don't forget to use conditioner as well to help moisturize the scalp.

## Someone used a topical steroid for two months, and then their eczema got worse. Is this a rebound effect?

That's a rebound effect. There are three things that can happen. 1) When you use a topical steroid, it constricts the little capillaries and blood vessels so the itchy chemical can't leak out into the skin. When you stop using them, eventually those capillaries start to dilate back again. That's why I don't see topical steroids as a long-term solution, but more of a short-term, stop-the-itch solution. 2) There is a phenomenon called tachyphylaxis. If you use the highest potency of a medication day in and day out, your body develops a resistance to it, and the medication stops working. Then you'll start to experience a rebound effect. 3) The last thing to remember is you can have a topical steroid allergy. So the exact thing you've been prescribed to make it better can actually make it worse at times.

## Can you talk about ways to treat face eczema, including eczema around the eyes?

We typically think of the skin on the face as being thinner, particularly around the eyelids. There is a propensity for people with eczema to have involvement of the eyelids. The easiest thing to do for eyelids at nighttime is to use Vaseline on the upper and lower eyelids. It can safely get into your eyes. It is the most cost-effective and calming thing to do. It can seal in moisture. If you're not having problems with acne, then you can use mild topical steroids on the face and seal it in with moisturizer. You'll want to use lower strength. If you are prone to acne, topical steroids can make you break out more, particularly around the mouth. That's when you want to go with nonsteroidal medicines, which are extraordinarily safe to use on the face.





### JOIN US FOR WEBINAR WEDNESDAYS!

NEA Webinar Wednesdays feature worldclass medical experts discussing the latest in disease management, research, treatments and related information you need to live well with eczema. Each webinar is an hour and includes time for Q&A from the audience. View archives of past webinars and register for upcoming events at nationaleczema. org/nea-webcasts.



Dr. Craig Teller is clinical instructor of dermatology in family medicine at Baylor College of Medicine, clinical instructor of dermatology at the University of Texas Medical School and a dermatologist at Bellaire Dermatology in Houston, Texas.

## WHAT'S HAPPENING AT THE NATIONAL ECZEMA ASSOCIATION

By Karey Gauthier, MS

## Live your best life, Eczema Warriors!

n the decades since NEA's founders officially declared war against eczema, we've fought on your behalf to end stigmatization, raise public awareness and fund the research necessary to develop safe, affordable and effective treatments.

We know that living with eczema can be a battle. We understand the trial and error of finding the right products for your skin, the frustration that you never outgrew your eczema like the pediatrician said you would, the long sleeves or pants in summer months to cover your flares, and always wondering if you're the only one ... We want you to know that you don't have to fight this battle alone! There are millions of people across the U.S. who share the same thoughts, feelings and experiences as you. Join our troop of Eczema Warriors at Eczema Expo '18 in Chicago from June 21-24, and let NEA introduce you to the friends you never knew you had!

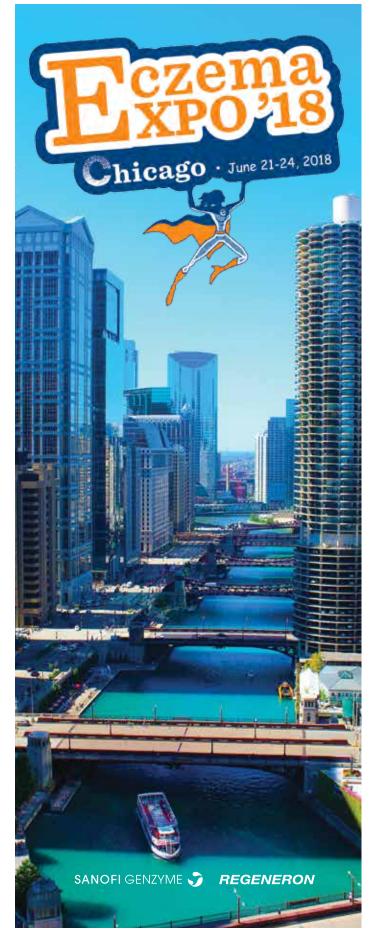
Eczema Expo , generously sponsored by Sanofi Genzyme Regeneron, is a weekend gathering of patients, caregivers, medical providers and industry professionals in the eczema community. Expo '18 will focus on empowering people to live their best life, with an emphasis on eczema education, holistic health and wellness, and advocacy. ►

## In Memoriam – Carolyn Watson Reese

It is with deep regret that we announce the passing of dedicated board member Carolyn Watson Reese. Carolyn's enduring passion for the National Eczema Association began over 20 years ago in support of her husband Tom's journey with eczema. By Tom's side throughout his term on the NEA Board of Directors beginning in 2003, Carolyn served on the Board from 2012-2017. Carolyn's unwavering commitment to NEA's mission was best expressed in her greatest passion – ensuring all families can attend the patient conference, regardless of financial barriers. Carolyn's significant contribution will continue through The Carolyn and Tom Reese Scholarship Fund.

We will miss our friend and board colleague. Our thoughts are with Tom and their children. Donations in Carolyn's memory may be made at: **nationaleczema.org/donate/**.





The Expo will provide attendees with comprehensive tools to live well with eczema. Guiding us through the weekend are world-renowned health professionals, including:

• **Peter Lio, MD**, will present patient-powered treatments, such as gut health and cannabis.

• **Susan Tofte, RN, MS, FNP**, will speak on the latest eczema treatments and best practices for topical medications.

• Jonathan Silverberg, MD, will share current research and what makes this the "Era of Eczema."

• **Ruchi Gupta, MD**, will discuss food allergies vs. sensitivities, and how this impacts eczema.

• **Gil Yosipovitch, MD**, "The Godfather of Itch" will discuss the mechanisms and management of itch.

• **Lisa Meltzer, PhD**, will share research on how eczema affects sleep, and offer tips for getting a better night's rest.

• Jennifer Moyer Darr, LCSW, will teach coping techniques to be well, even when you don't feel well.

• **Richard Aron, MD**, a name familiar to many eczema patients around the world, will be in attendance to speak about the Aron Regimen.

• **Amy Paller, MD**, will speak on ways patients can get involved in eczema research, including how and why it is important.

• Vivian Shi, MD, will help you get the care you need with shared decision-making, and complementary and alternative treatments.

There also will be support groups led by professionals and peers to address all aspects of life with eczema from infancy through young adulthood to midlife through the golden years, including discussions on grooming, intimacy, fitness and allergy-friendly diets.

There will be fun for the whole family, so don't forget to bring the kids!

Our superhero-themed Kids' Camp supports our eczema youth by nurturing self-esteem with a focus on empowerment. Kids' Camp (age 5-12) will include age-appropriate, expert-led educational sessions about basic skincare and the emotional burden of living with eczema. Teens' Camp (11-17) will include basic skincare, emotional coping techniques, exercise, beauty & grooming, and storytelling for healing.

Kids' Camp is a place that reminds children with eczema that they're not alone. They'll meet and have fun with new friends who understand eczema, while enjoying arts and crafts, playing games, and learning a bit about eczema and skincare in the process. All campers will be invited to join our bowling outing on Friday, June 22, and around-the-town scavenger hunt on Saturday, June 23.

Expo '18 will undoubtedly be our best conference yet! When you leave on Sunday afternoon, June 24, you will be armed with new information, new tools for managing eczema and a new community of friends. Register today **EczemaExpo.org**! >

## Isn't it time for YOU to join the Era of Eczema?

Jenene Chesbrough has a story so many in our community can tell. She was born with atopic dermatitis (AD), managed bullying as a child, faced the challenges of young adulthood with the added complications of skin flares, and experienced worsening symptoms throughout her 30s.

What sets Chesbrough apart from many is her choice to get involved with eczema research. After delivering her first baby, she experienced a full-body eczema flare. She tried many treatment options before landing with Dr. Emma Yassky-Guttman's group at Mount Sinai in New York City.

Guttman encouraged Chesbrough to get involved in a clinical trial for a potential new eczema treatment. Although the first trial wasn't effective for her AD, being involved in research gave Chesbrough hope that there would be an effective treatment for her someday.

In early 2018, NEA put out a call for a speaker to share their experiences living with eczema to a pharmaceutical company that has treatments for atopic dermatitis under development. Chesbrough answered the call and spent the day sharing her story.

"I had a terrific experience speaking on behalf of NEA about my lifelong AD patient journey," she said. "I learned that my story truly transformed the way the audience looked at the disease and their work. It's essential to put a face to a condition and see how it impacts lives.

"I decided to share my story because I've been in two clinical trials - one that has completely given me back my life - and I am a big believer in drug research for AD," Chesbrough continued. "I want people to know that this chronic condition is more than just a vanity concern. It's serious and demands additional study."

With more than 100 treatments for eczema under varying stages of development, it is more important than ever for our community to participate in research. As a way to support these individuals, as well as the professionals running the research efforts, NEA created the People Engaged in Eczema Research (PEER) program.

PEER connects patients with research by keeping an up-todate list of current trials on our website, sending locationspecific recruitment emails when participants are needed, sharing articles on current research results, and providing the patient voice to the companies engaged in eczema research. Keep your eyes out for the PEER logo on emails and the NEA website to let you know when and how you can get involved.

To find a clinical trial appropriate for you or your child, visit: https://nationaleczema.org/research/clinical-trials/



Congratulations to our 2018 NEA Research Grant Awards recipients: Dr. Aron Drucker at the University of Toronto, who will study the risk of suicide associated with atopic dermatitis and Dr. Junko Takeshita at the University of Pennsylvania, who will study the burden of atopic dermatitis among the medically underserved. Our previous grant awards on pain and eczema, and the impact of sleep loss are ongoing.

## Bringing better eczema care to the medical community

NEA continues to advocate for better medical care as part of our mission to improve the health and quality of life for individuals with eczema through research, support and education. We are getting the word out on the holistic reality of eczema, the best ways for providers to treat eczema patients and emerging therapies to consider.

Eczema care in the current medical landscape is often fractured and uncoordinated. That's because many practitioners have not yet been informed about the best treatment protocols and emerging eczema medical research. As a result, there is both a great need and rare opportunity to develop a new health paradigm for eczema care providers - one that is aligned with best practices and based on an interdisciplinary model.

To answer this need, NEA established the Coalition United for Better Eczema Care (CUBE-C). CUBE-C is a network of cross-specialty leaders, patients and caregivers, constructing an educational curriculum based on standards of effective treatment and disease management.

Treatment protocols have been compiled to review the holistic reality of typical eczema patients, and address quality-of-life

considerations, patient and family preference, adherence and compliance issues, and evidence-based alternative and complementary treatments.

In fall 2017, eight articles covering the CUBE-C curriculum were published in *Seminars in Cutaneous Medicine and Surgery*. In 2018, 12 regional educational seminars will be held targeting dermatologists, pediatricians, allergists, mental health practitioners, nurse practitioners and physician assistants.

The entire curriculum is underpinned with the shared decision-making model (SDM), which is a model of care that establishes a partnership between patient and provider. SDM is built on the belief that patients are the foremost experts of their own condition, and providers are experts in the treatment of those conditions. Moreover, SDM contributes to enhanced patient satisfaction and reduced medical costs.

Later this year, NEA will launch a digital SDM platform that includes helpful tools for patients and providers, such as preappointment checklists and decision aids. The SDM platform will build trust between patients and their providers, while improving patient safety and health outcomes.



## CLIMBING CORPORATE LADDER WITH ECZEMA

Managing severe eczema flares in a busy corporate environment can be challenging. Here are my best survival tips.

BY HELEN PIÑA

y eczema exploded when I was 22, and it has been a significant part of my life since then, with consistent mild-to-severe flare-ups. Today, I am a 35-year-old eczema warrior with an exciting marketing career. Eczema impacts far more than a person's skin, including one's social life, sleep cycle and emotional health, to name a few. One of the most

challenging areas eczema affects me personally is in the business world.

I am a marketing leader at a global tech company. I work at the company headquarters in Houston and interact with hundreds of employees, including the executive team. I work alongside an amazing marketing team, and together, we promote our brand and drive sales while tackling aggressive deadlines. I've had to handle my chronic eczema in this work environment, and it's not been easy.

## A flared-up face is so embarrassing

A face cannot be hidden. People are shocked, confused and made uncomfortable by a flared-up face - all feelings you don't want to trigger when walking into a room. Facial eczema is especially challenging because eczema is misunderstood by the general population. Most

people don't realize the extent to which eczema affects one's skin.

So how do you run meetings, present to an audience or walk by the CEO if your face looks unpresentable? By balancing a fine line between being antisocial, honest and indifferent. On my bad days, I avoid seeing my coworkers by working from home. That's not always an option, though, which is where honesty comes in.

When my skin is not well, I am open about my eczema with my peers and answer their questions, basically getting past the skin barrier to get back to business. You can't constantly be talking about your skin with everyone you come across though. So, there's a point where you have to stop caring what someone thinks when they see you. That is really hard to do, and I've not mastered it yet, but I understand its significance.

## Blood and skin flakes must be contained

Oh, the skin flakes and blood! Skin shedding and bleeding is embarrassing, unhygienic and definitely unprofessional, but it's very common for eczema warriors. During a shedding phase, I don't lose my entire skin layer all at once like a lizard. Eczema shedding is more like snow. At work, I walk from one meeting room to another, snowing onto the tables and chairs. Sometimes, I put my arm on a table and leave behind a little blood.

Bleeding and shedding might not be avoidable, but it must be contained. Be aware of your shedding and bleeding, then clean up as needed. As silly as it may seem to pile your skin flakes and throw them away after a meeting in a conference room (as if you just ate a crunchy

to asted sandwich), it's much worse for someone else to walk into a conference room with your leftover skin all over the furniture. It's just good eczema manners! ►

#### Itching is universal, scratching is personal

Eczema doesn't discriminate by body parts - it can show up anywhere. The inner thighs, feet and under arms are just a few itch locations that are a little too personal to scratch in front of coworkers. I'm no superhero; I've scratched all of these areas at work and hope nobody noticed. The reality is that scratching any area for too long is inappropriate.

I've lived through enough flare-ups to not be of the "never scratch" mentality. If I must scratch in the workplace, I tend to follow a few guidelines: scratch only when absolutely necessary, rub instead of scratch if possible, keep the scratching low key and keep minor itches untouched.

I keep a fun, unsharpened pencil at my desk for quick back scratches. If scratching is necessary for an inappropriate spot or for an extended period of time, I go to the bathroom. Bottom line, I'm at the office to work, not to scratch all day.

I do my best to block out my itchiness and concentrate on my priorities, diving into my work to keep my mind distracted. As difficult as it is, I do feel proud when I accomplish things at work. To achieve things while itchy is amazing. Eczema warriors should all receive a "worked while itchy" bonus at the end of the year, because we've definitely earned it!

#### Know when to put yourself first

Tips for working during an outbreak of eczema are great when a flare-up is bearable, albeit annoying. During these times, eczema warriors can prioritize their work and personal life over their body's dysfunction. But when it's beyond a bad flareup, we must put everything aside. There is just no other option.

When my eczema is severe and completely takes over, it is a very dark, emotional period for me. I try to get past my anger and blues by feeling compassion for my body and skin. It helps to have hope. My flare-ups eventually calm down, so I can always look forward to the recovery. During very severe eczema flare-ups, my advice is to take personal time off, if possible, to heal physically and emotionally.

I want to be represented by my strengths, not my eczema. I might need to work on overcoming the impression I believe my eczema has on people, but ultimately, I want my peers and leaders to think about the quality of my work, not my eczema, when they hear my name or see my face.

My advice for professionals with eczema: be so good at your job that your unhealthy skin is dwarfed by your accomplishments, no matter how bad your eczema may be. It's what I do every day. \*

Helen Piña is the creator of Itchy Pineapple blog and can also be reached on Twitter and Facebook.

**MY JOURNEY** 



4460 Redwood Hwy, Ste 16D San Rafael, CA 94903-1953 800.818.7546 or 415.499.3474 **nationaleczema.org** 

