



**NATIONAL**  
**Eczema**  
**ASSOCIATION**

# *The* **ADVOCATE**

VOLUME 28 | NUMBER 2 | YEAR 2016

A QUARTERLY PUBLICATION OF THE NATIONAL ECZEMA ASSOCIATION

BUILD CONFIDENCE IN KIDS WITH ECZEMA

*IN YOUR WORDS:* ROLE OF DOCTORS  
IN THE TREATMENT OF ECZEMA

ITCHING FOR A CURE — WALK WITH US!

ALTERNATIVE TREATMENTS THAT WORK

SLATHER UP: SUMMER SUNSCREENS





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*The Advocate* 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.

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



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National Eczema Association is a national nonprofit patient-oriented 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. The association is supported by individual and corporate donations.

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# A new era of better eczema care

I'm thrilled to share some fantastic news:

**In April we got one step closer to a new treatment for moderate to severe atopic dermatitis (AD).** Recent clinical trials for the first biologic therapy for AD have shown it to significantly clear skin, reduce itch, and improve quality of life factors such as mental health for adult participants. And last January, a New Drug Application (NDA) was submitted to the FDA for a non-steroidal topical anti-inflammatory for mild-to-moderate AD in children and adults.

As new treatments are gaining ground, so is advanced research in prevention, basic skin care, and evidence about the burden of eczema on individuals and families. This important information means that, with your help, NEA will be able to share a comprehensive understanding of the seriousness of eczema with stakeholders like the FDA, legislators, researchers, and other thought leaders to create a sense of urgency around developing better care models and prioritizing access to more and better treatment options for adults and children with eczema.

**NEA will share many of these exciting advances in eczema understanding at our 2016 *Leaders in Eczema Forums* series.** These 1-day educational events replace NEA's bi-annual conferences, and provide information about eczema innovations and tools to help individuals with eczema and their families to lead full and empowered lives. Presentations will cover basic skin care, new research and treatments, eczema and mental health, and state-of-the-art treatments for children. As one parent who attended a 2015 Forum shared, "This 1-day forum has given us more than a year's worth of doctor's visits."

**Our next forums will take place this fall in Houston, Texas and the San Francisco Bay Area.** More information and registration will be posted on the NEA website ([nationaleczema.org](http://nationaleczema.org)) as soon as it is available.

There are many ways to get involved with NEA even if you can't make our 2016 forums. October is Eczema Awareness Month, which we will kick-off with **our annual Itching for a Cure walk on Sunday, October 2<sup>nd</sup> on the UCLA campus.** This fun event brings all our eczema community together to raise awareness of eczema as a serious disease and funds to support eczema research and education. Start planning now to host an Itching for the Cure team! Visit our website to learn more about how to get involved, register, and volunteer.

We have also launched a new survey series, ***In Your Words***, to learn more about the challenges you face with eczema. Your responses to the surveys will shape a greater understanding about the impact eczema has on you and your loved ones, define our national policy priorities, and allow NEA to develop meaningful actions so, together, we can effectively advocate for better eczema care. You can read more about this exciting opportunity to engage by helping build a stronger voice for eczema on page 10 of this issue.

It's an unprecedented and hopeful time for all living with eczema. Together, thanks to your support, courage, and participation, we will continue to advance a new era of better eczema care.

Thank you for all you do to support NEA.



Julie Block  
President & CEO



# SLATHER UP: SUMMER SUNSCREEN

Summer is upon us and protecting your skin from the sun is more important than ever. Skin cancer is the most commonly diagnosed cancer in the United States. The good news is that with proper skin care, many cases of skin cancers can be prevented.

People living with eczema are even more vulnerable to the sun's damaging rays and have more challenges finding sunscreen products that work for their skin. Factors including chemicals in the sunscreen, preservatives, and the base can affect people in different ways.

The National Eczema Association (NEA) includes a number of sunscreen products in its Seal of Acceptance™ program to help you find the best products for you and your family. Sunscreens that have been awarded the Seal of Acceptance™ must meet the following criteria:

- Mineral-based sunscreen ingredients: Titanium Dioxide (TiO<sub>2</sub>) and Zinc Oxide (ZnO)
- Alcohol-free
- SPF 30 or greater
- “Broad spectrum” protection from both ultraviolet (UVA) A and UVA B rays

Below are sunscreens that have received NEA's Seal of Acceptance™:

- AVEENO® Baby Natural Protection Lotion Sunscreen
- AVEENO® Baby Natural Protection Face Stick Sunscreen
- AVEENO® Natural Protection Lotion Sunscreen
- CeraVe® SPF 50 Sunscreen Body Lotion
- CeraVe® SPF 50 Sunscreen Face Lotion
- CeraVe® Baby Sunscreen SPF 45
- Neutrogena® Pure & Free® Liquid Sunscreen
- Neutrogena® Sensitive Skin Sunscreen Lotion SPF 60+
- Neutrogena® Pure & Free® Baby Sunscreen Lotion SPF 60+
- Neutrogena® Pure & Free® Baby Faces Ultra Gentle Sunscreen
- Neutrogena® Pure & Free® Baby Sunscreen Stick SPF 60



In addition to selecting the product that works best for your skin, it's also important to practice proper skincare. It's common for people to not use enough sunscreen and don't reapply often enough, which can mean you're not getting the full SPF protection indicated on the label. Be generous in your application and keep in mind the following tips:

- Apply sunscreen evenly to all uncovered skin, especially your lips, nose, ears, neck, hands, and feet.
- Apply 15 minutes before going out in the sun.
- If you don't have much hair, apply sunscreen to the top of your head, or wear a hat.
- Reapply at least every two hours or immediately after swimming.
- Give babies and children extra care in the sun. Ask your health care professional before applying sunscreen to children under 6 months old.
- Never apply sunscreen to damaged or broken skin.

Finally, if you are using a product for the first time, test the product first. Apply a small amount, about the size of a pea, to the pulse of your wrist or the crook of your elbow. Don't wash that area for 24–48 hours and watch for any allergic reaction such as redness, a rash, any form of breakout on the skin, itchiness, pain, flaking, etc.

With the proper precautions, you, too, can have a safe and happy summer! ●







## NEWS ROUNDUP

*Recent news and articles about eczema, eczema research and treatments, and the lives of people with eczema and their families*



### London areas with hard water linked to babies getting eczema

*Evening Standard*, May 23, 2016

by Ross Lydall

This article reports on a study from King's College London that infants living in areas with hard water have an increased risk of developing eczema. This was the first study to explore the link between eczema and water hardness in infancy. This study will be followed by a clinical trial to assess whether using water softeners at home could cut the risk.

<http://www.standard.co.uk/news/health/london-areas-with-hard-water-linked-to-babies-getting-eczema-a3254341.html>

### I have three seconds before she draws blood: life with extreme eczema

*The Guardian*, May 21, 2016

by Maggie O'Farrell

Novelist Maggie O'Farrell writes about the impact of eczema on her daughter, who was diagnosed as an infant. She writes poignantly not only of her daughter's suffering and the rigorous regimens they have practiced to try to control her symptoms, but also of the hope they have found in treatments that are working for them.

<http://www.theguardian.com/society/2016/may/21/life-with-extreme-eczema-maggie-ofarrell>

### Association between AD and attention deficit hyperactivity disorder in US children and adults

The National Center for Biotechnology Information, April 23, 2016

by Strom MA, Fishbein AB, Paller AS, and Silverberg JI

This abstract describes the author's research which explores the association between atopic dermatitis (AD) and attention deficit disorder (ADD) attention deficit hyperactivity disorder (ADHD) in children and adults. The study concluded that AD is associated with ADD/ADHD in both children and adults.

<http://www.ncbi.nlm.nih.gov/pubmed/27105659>

### Penn study suggests changes in skin "microbiome" during canine atopic dermatitis could lead to antibiotic-free therapies for human and canine disease

Penn Medicine, Perelman School of Medicine and Penn's School of Veterinary Medicine, University of Pennsylvania, April 26, 2016

by Daniel O. Morris, Shelley C. Rankin, Christine L. Cain, and Ana M. Misisic

This study, which was conducted with dogs and which appears in the *Journal of Investigative Dermatology*, revealed that during flare, there was a decrease in the diversity of the skin bacterial population as certain bacterial species proliferated, along with a decrease in the skin's protective barrier.

[http://www.uphs.upenn.edu/news/News\\_Releases/2016/04/grice/](http://www.uphs.upenn.edu/news/News_Releases/2016/04/grice/)

### Burden of sleep and fatigue in US adults with atopic dermatitis

The National Center for Biotechnology Information, April 27, 2016

by Yu SH, Attarian H, Zee P, and Silverberg JI

The objective of this study was to determine the burden of sleep disturbance and fatigue in US adults with AD. While the study revealed no significant association between having AD and having a diagnosed sleep disorder, adults with AD had higher odds of sleep disturbance, including less sleep, difficulty falling asleep, and awakening early. The conclusion was that AD does negatively impact sleep and that sleep disorders may be underdiagnosed among adults with AD.

<http://www.ncbi.nlm.nih.gov/pubmed/26983091> ●



# COMING TOGETHER

*Eczema Champions Gather to Share Advances in Care*



The energy was palpable as health care professionals, scientific researchers, industry partners, and patient advocates convened at two annual dermatology conferences earlier this year. While the presentations at the *American Academy of Dermatology* and the *Society for Investigative Dermatology* differed in scope, the take-away from both was the same: **better care for individuals and families living with eczema is on its way.**

## American Academy of Dermatology

NEA joined as many as 25,000 health care professionals and advocates at the 74<sup>th</sup> annual *American Academy of Dermatology* (AAD) Annual Meeting March 4–8, 2016 in Washington, DC. This year's conference included multiple presentations on the burden of eczema and atopic dermatitis on individuals and families, ground-breaking research on the causes, and new treatments in development.

NEA joined the conversation by hosting the first-ever NEA AAD reception for more than 100 supporters. Drs. Mark Lebwohl, Larry Eichenfield, and Eric Simpson, along with NEA CEO Julie Block, spoke about the renewed focus on eczema, and how NEA is partnering with patients and

national leaders to advance eczema research, patient and physician education, and ensure access to better eczema care for individuals and families—all goals included in NEA's strategic plan, the Roadmap to Advocacy.

## Society for Investigative Dermatology

The Society for Investigative Dermatology (SID) hosted its 2016 Annual Meeting in Scottsdale, AZ. This meeting highlighted a vast array of research focused on dermatology, including eczema and atopic dermatitis. NEA's evening reception at SID served as both a celebration and call to action, as the work to propel new treatments through drug development and into the hands of deserving patients will require collaboration for success.

Speaking to more than 60 attendees on behalf of the National Eczema Association were Drs. Amy Paller and Eric Simpson, and NEA CEO Julie Block. Great hope and possibility were the reception's main themes: hope around the current research and innovations; and possibility that patients with eczema, regardless of their age or disease severity, will have the treatments necessary to improve their health and quality of life. ●





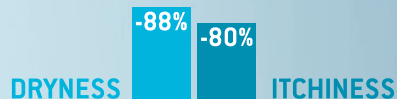
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## GET A HEAD START!

*Build Confidence in Kids with Eczema*



*Excerpted from the blog [It's an Itchy Little World](http://It's an Itchy Little World), [itchylittleworld.com](http://itchylittleworld.com)*

By Jennifer Moyer Darr, LCSW, National Jewish Health in Denver, Colorado.

Confidence comes from within and builds over time as children master new skills and develop a sense of competence. While we can't give our kids with eczema confidence, there are some things we can do to help them become more confident and self-assured.

### Words Matter

From an early age, children pick up on our words, tones, and emotions and often incorporate them into their world view. This means we can help shape their eczema story before they even begin talking. Take a moment to think about how you describe your child's eczema. Is it a "burden" or "battle" that you have to "endure" or an "illness"

that "fosters strength" and "encourages organization?" Is it "just eczema" or "a horrible rash?" While all those statements may be true, reframing negative thoughts/language can help not only us cope more effectively but our children as well.

### Be an Educator

Typically, between ages 3–4, children become more aware of differences. Educating their peers as early as preschool can be helpful in removing the curiosity and help them understand and support your child. Keep things brief, age-appropriate, and involve your child as much as they are comfortable. Maybe they only have one line at first but this empowers them to begin advocating for themselves and creating their eczema story. Being able to identify "it's just my eczema — you can't catch it" or "you can help me by..." allows them to engage peers and adults alike, and having peer support early on will help set the stage for later transitions.



## Encourage Strengths

Eczema care can be daunting, and for some children so much attention goes to eczema care that this begins to define them. What does your child enjoy? What do they do well? Encourage these activities and help your child find their passion. Encouraging them to try new things and take risks not only helps them build confidence but it can be the difference between “I’m Joe and I have eczema” and “I’m Joe. I play basketball, have a pet gecko, love science and oh, yeah I have eczema.”



## Use Behavior Specific Praise

We all like to hear “nice job”, but using behavior specific praise really highlights what someone has done well. Hearing “well done” at the end of unwanted skin care is good, but hearing “I know you didn’t want to do the wet wraps, but I really liked how you just took a deep breath

and got it done quickly” provides more engagement and a clear emphasis on the behavior(s) you would like to see more of.

## Provide Choices When Possible

No one likes to be told what they “have to” do all the time and this can diminish confidence and decision-making ability while increasing opposition. Unfortunately, having eczema often comes with a lot of have to... have to take a bath, have to put on lotion, have to do wet wraps, have to take medication. Giving choices and empowering kids with eczema to evaluate their needs can help minimize this and encourage increased independence as they get older. As small children, choices may only be about which pajamas they want to wear over their wet wraps or which toys they want in the tub. As they get a little older, choices may include “Do you want to rub in your moisturizer or do you want mommy/daddy to do it?” As they get older ask them to assess their skin and help decide what level of care is needed. As teens they can better assess cause and effect and may sometimes choose options you disagree with. It can be helpful to discuss their thoughts and choices. Ask cause and effect questions such as: “If you skip your bath tonight what do you think the result will be?” or “Would it be more helpful to be a little late to school and do some skin care now or be on time but itchy?” Although your teen will likely test the boundaries, offering a supportive approach may help them get back on track faster than telling them they “have to.”



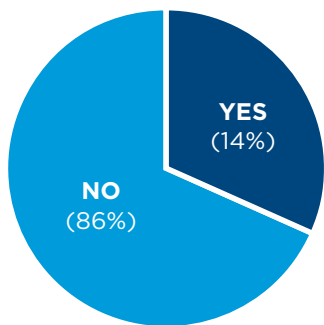
*Jennifer Moyer Darr, LCSW is the Manager of Outpatient Behavioral Health Services at National Jewish Health in Denver, Colorado. For the past 12 years she has provided clinical services to children and families living with eczema, asthma, food allergies, and other chronic illnesses.* ●

# WE WANT TO HEAR FROM YOU!

*In Your Words*

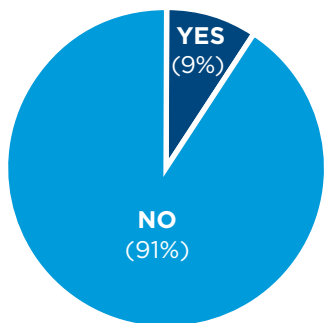
In 2016, the National Eczema Association (NEA) launched a survey series, *In Your Words*, to learn more about the challenges you face with eczema. Your response to the surveys will shape a greater understanding about the impact eczema has on you and your loved ones, define our national policy priorities, and allow NEA to develop meaningful actions so, TOGETHER, we can effectively advocate for better eczema care.

We kicked off *In Your Words* this past January with a 6-question online survey to evaluate patient satisfaction and the **role doctors of doctors in the treatment of the most serious form of eczema, atopic dermatitis (AD)**. Here's what we learned from you (251 U.S. respondents):



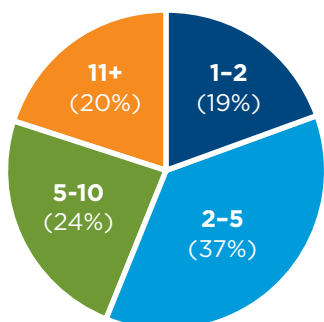
**Overall, are you satisfied with the treatment of atopic dermatitis?**

**86%** reported they were **not** satisfied with the treatment of atopic dermatitis (AD)



**Overall, do you think doctors know how to treat atopic dermatitis?**

**91%** responded that they think doctors **do not know** how to treat AD



**How many doctors have you seen for this problem?**

**More than half, 56%**, reported having **seen up to 5 doctors** for their or their child's AD

When asked what their opinion or suggestion about the role of the doctor in the treatment of AD was, **participants responded overwhelmingly that they want more information — and more options:**

*“Compassion, being a good listener, responding to the patient’s questions, having up-to-date knowledge of the research and which treatments are most likely to be useful vs. not useful (including alternative medicine approaches) for a particular patient are all important roles for the doctor.”*

*“Last year when I was in the midst of an eczema flare that was difficult to get under control, I appreciated my current doctor asking me what MY goal was at that point.”*

*“Doctors need to provide more education to patients about managing eczema beyond ointments. Also, they should refer severe sufferers to physicians who specialize in advanced therapies. Most patients feel hopeless when traditional treatments fail.”*

*“I realize that not all doctors can or will have first-hand experience living with such conditions, but there is an emotional and psychological piece that goes along with the physical part. I’m not sure of the answer, but there is a definite problem that is not being served.”*





**What is NEA doing in response?** We are educating physicians about the patient experience and concerns around eczema and atopic dermatitis care. We've presented the results to our Scientific Advisory Committee, and at the Society for Investigative Dermatology and International Society for Investigative Dermatology conferences this spring.

We're also putting this data into action by using it to: Define new models of care to improve patient outcomes, develop physician education modules to advance those new models of care; and, apply these learnings to **develop better coordinated patient-centered care outside of the doctor's office**. This work is happening in NEA's two new strategic committees focused on improving patient care: *Coalition United for Better Eczema Care (CUBE-C)* and *Partners in Eczema Care (PIE-C)*.


As we continue, the *In Your Words* survey series will be utilized to:

- Create patient-identified educational resources about eczema treatments and care options for you and your loved ones
- Advance research on the burden of eczema and models of care that help address its impact on you and your family
- Educate health care decision makers about the importance of treating eczema early and effectively
- Provide educational in-person or recorded forums so you can learn more about emerging research, treatments, and support opportunities

*In Your Words* will continue with a more comprehensive second survey to our eczema community this summer – together we will build a picture of patient and family needs that will impact national policy priorities and advocacy work.

## What Can You Do? Be a part of the solution!

Thank you for all who participated in our inaugural survey! We want to hear from you again — and from more of you. You can participate in NEA's *In Your Words* survey series by signing up for our monthly electronic newsletter, *eInsights*, on our website: [nationaleczema.org](http://nationaleczema.org).

You can also watch for information about *In Your Words* surveys and what we learn by following NEA on Facebook: [facebook.nationaleczema.org](https://facebook.nationaleczema.org) 

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The image displays a variety of exederm products designed for sensitive skin. From left to right, there are bottles of baby shampoo, baby oil, baby lotion, body wash, and several jars of cream. Each product features the exederm logo and a small illustration of a baby. The products are arranged in two rows, with some standing upright and others lying down. The background is plain white, highlighting the products.

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The National Eczema Association logo is located in the bottom right corner. It consists of a circular seal with the words "ACCEPTED NATIONAL ECZEMA ASSOCIATION" around the perimeter. Below the seal is a rectangular box with the words "NATIONAL Eczema ASSOCIATION" in bold, capital letters.

# INTEGRATIVE APPROACH TO ECZEMA

*Bringing together the best of both worlds*

By: Fatima Lakhani, BS and Peter A. Lio, MD

Adapted, with permission, from original publication in *Practical Dermatology*.

## Introduction:

Atopic dermatitis (AD) is a chronic itchy inflammatory disease that affects a large number of children and adults.<sup>1</sup> The suffering is not limited to the skin; patients have increased rates of ADHD, depression, and anxiety.<sup>2</sup> The most cutting-edge theories suggest that having eczema on skin may directly lead to the development of systemic food allergies as well.<sup>3</sup> This “leaky skin” concept means that treatment of this condition is essential.

Fortunately, we have at our disposal an impressive array of treatments that give most patients excellent relief. Unfortunately, however, there is a group of patients that is not well-served by these treatments: side effects, other existing conditions, personal preference, and even the fear of side effects can sometimes be insurmountable obstacles.<sup>4</sup> For some patients, it may be in their best interest to consider an integrative approach to treating AD.

Integrative medicine is a form of medicine that aims to marry conventional, evidence-based treatments with those that are perhaps less conventional and may not have widespread agreement among all physicians and healthcare practitioners, sometimes called “alternative” or “complementary” medicine.<sup>5</sup> Beyond this, however, the ideals behind integrative medicine are not only to address the medical issues, but also to include the emotional, social, and spiritual aspects of a patient’s life.<sup>6</sup> There has been a great deal of focus on the use of alternative therapies to treat conditions such as atopic dermatitis, which is often found to be resistant to conventional treatments, has no cure, and continues to defy easy explanation. Studies have indicated that roughly half of all patients with AD have tried at least one form of alternative medicine.<sup>7</sup> Thus, it is beneficial to know at least a little about these treatment options. In this article, we will touch upon some conventional and alternative therapeutic options that can be used for patients with AD.



## The Conventional Approach

The conventional treatment of AD includes a multi-targeted approach that aims to enhance the barrier function of the skin as well as to reduce inflammation and itch. Additional steps would be to avoid factors that trigger flare-ups and decrease bacterial colonization. These include contact allergens, detergents, and extreme temperatures.<sup>8</sup>

A primary goal of treating AD is to maintain adequate skin moisture. This can be addressed by the use of moisturizers. Generally, fragrance-free moisturizers with few ingredients are preferred in order to minimize allergic sensitization. Lotions, creams, and ointments may all be used, although ointments tend to have a higher lipid content which appear to lead to a more effective barrier.<sup>8</sup> Studies have demonstrated that the use of moisturizers decreases the need for topical steroids in infants with AD.<sup>9</sup> Perhaps the most exciting evidence suggest that early use of moisturizers can actually prevent the development of AD in high-risk populations.<sup>10-11</sup>

Topical steroids remain the mainstay of treatment for AD, for better or for worse.<sup>12</sup> While they have a rapid and powerful effect on AD, prolonged use can lead to numerous side effects including skin atrophy, pigmentation changes, and even topical steroid withdrawal.<sup>13</sup> Increasing recognition of these adverse effects has led to the widespread problem of corticosteroid phobia, which may also contribute to the desire for more integrative approaches.<sup>14</sup>

The non-steroidal topical calcineurin inhibitor tacrolimus has been shown to approximate moderate topical steroids



in its anti-inflammatory effect, and can be used instead of steroids or as a complement when needed.<sup>15</sup> Studies have indicated that application of steroids or calcineurin inhibitors to skin previously involved with AD may decrease future flares, and such “proactive therapy” is ideal, although can be more difficult for the patients to keep up over time.<sup>16</sup>

Patients with more severe disease may not respond to the above treatments, even when leveraged with powerful techniques such as “wet wrapping” and “soak and smear”.<sup>17, 18</sup> In these situations, phototherapy, particularly with narrow band UVB, is a possible therapeutic alternative that is relatively safe and can stave off the need for more potent systemic agents.<sup>19</sup>

If all of the above treatment options fail, patients may require systemic immunosuppressants such as cyclosporin. While off-label for atopic dermatitis, studies have demonstrated that 6-8 weeks of treatment with cyclosporin results in a roughly 50% decrease in the mean disease severity of AD,<sup>20</sup> providing much-needed relief and a chance to heal and recover. However, these are not curative: stopping the medications results in relapse.<sup>21</sup>

While there is currently great enthusiasm about the pipeline of upcoming medications for AD, some of these medications may be years away, and others may become held up during the process of development; it is not feasible to simply tell patients who are suffering to wait until we have something better.



### The Alternative Approach

Moisturizing oils are commonly used in the treatment of AD, and those that are plant-based have a place in alternative medicine. Sunflower seed oil has been found

to be desirable since it is able to induce the production of natural ceramides.<sup>22</sup> It also serves the additional benefit of directly enhancing the skin barrier and decreasing inflammation in the skin.<sup>23</sup>

Coconut oil is another natural oil that can be used to combat atopic dermatitis. In addition to serving as a moisturizer, it also possesses anti-microbial properties. One study demonstrated a 95% reduction in staphylococcus in AD patients compared with only 50% reduction in a control group.<sup>24</sup> This is highly promising given that the skin of AD patients is colonized by a greater abundance of *Staphylococcus aureus* than healthy patients and may be playing a very direct role in driving inflammation.<sup>25-26</sup>

Acupuncture has the potential to alleviate the itch associated with AD. Studies have demonstrated that acupuncture can reduce hive-like itch reactions,<sup>27</sup> and acupressure applied to the Large Intestine 11 point was also shown to significantly reduce itch.<sup>28</sup> Although the effect is generally modest, there may be a role for acupuncture or acupressure in some patients.

It has been hypothesized that stress-reducing methods such as hypnosis, massage, and relaxation therapies, could provide benefit to AD patients.<sup>29</sup> Stress has been implicated in weakening the barrier function of the skin in healthy individuals, and delaying skin healing in patients with AD.<sup>30</sup> One study demonstrated ten of twelve children had decreased itching and scratching 18 months after hypnotherapy treatment. These patients also had improved mood and sleep.<sup>31</sup> Additionally, one study found that interventions geared towards reducing stress levels in patients with AD were associated with significantly less itching.<sup>32</sup>

### Integration

Conventional medicine is often effective treating atopic dermatitis but does not always completely alleviate symptoms. The use of medications such as steroids may make patients feel uncomfortable or lead to long term side effects. In such cases, considering alternative and complementary approaches and thinking about the patient more holistically may allow for a truly integrative approach. Often this can mean a trial of phototherapy while using sunflower and coconut oils to help moisturize and decrease staphylococcal colonization, or identifying a patient who reports flaring with stress and encouraging a trial of a stress-relieving behavioral approach in addition to soak and smear. It can even mean

using acupuncture as an adjunct to systemic methotrexate or cyclosporine. Arguably, good clinicians do this naturally, at least to some extent: listening and adapting to the patient's concerns is at the heart of the patient-doctor relationship. Sometimes just bringing up these ideas may prove to be of great value for those unresponsive to or unwilling to consider the conventional approach. And, sometimes, that tiny connection can open the door to much greater understanding.



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## WELCOME REBECCA MCDONALD

*NEA's new Communications Director*



The National Eczema Association (NEA) is pleased to introduce Rebecca McDonald as NEA's new Communications Director. With so much attention being focused on eczema, from its impact on individuals and families to exciting treatment developments, it is more important than ever for NEA to provide up-to-date information on research, care, and opportunities for our community to get and stay connected. As Communications Director, Rebecca will ensure access to resources our community is seeking are easily found on our website and through NEA's social media channels, and will be reaching out to our community to share their stories to help raise awareness and understanding of what it means to live with eczema.

Rebecca is a recent San Francisco transplant from Brooklyn, New York. Her background includes traditional advertising agencies, digital marketing and web development, and nonprofit marketing and communications. Rebecca brings an ability to apply results-oriented strategy and metrics to advance NEA's mission through creative, multi-platform communications.

Rebecca found her passion for nonprofit communications through community service work including tutoring elementary and middle school students, and teaching writing to women incarcerated at New York area federal and state prisons. In her most recent position at the Episcopal Church Foundation, she created branding and identity to build national awareness and engagement among church leaders across the country.

Rebecca has a BA in English from Colby College in Waterville, Maine, and a MFA in creative writing from New York University. She is enjoying the access to the natural environment that living in the Bay Area affords and considers herself lucky to go hiking every day — a big change from Brooklyn! Both originally from the Boston area, she and her husband love to cook, travel, and spend time playing with their dog.

Please join us in welcoming Rebecca! ●





## Join us on the beautiful UCLA campus!

### Step toward a cure for eczema

Participate in the National Eczema Association's 2016 *Itching for a Cure* event by walking, donating, or sponsoring!



Walking with NEA ensures that **more than 30 million Americans affected by eczema** have access to research, support, and education that helps them live healthy and empowered lives.

***Thank you for your support!***





**Interested in learning more about hosting a  
NEA *Itching for a Cure* walk in your local community?**

Request information at [teamnea@nationaleczema.org](mailto:teamnea@nationaleczema.org)  
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## ***Thank You Sponsors***

The National Eczema Association extends a special thank you to our  
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## WALK WITH US ACROSS THE U.S.

*Organize a Virtual Itching for a Cure Team in Your Local Community*

If you can't be in Los Angeles to join us for our Itching for a Cure walk on October 2, you can still participate and make a big difference in your community by organizing a virtual walk team in your local community. You'll help us raise funds to help end eczema, build awareness of the impact eczema has on people's lives, and have fun with family and friends.

### Mikaela and Diana Jauregui

I've had eczema since I was a baby. When I heard about the Itching for a Cure walk, and I couldn't travel to participate, I decided to do a virtual walk in my hometown. I gathered my family and friends and they gathered their families and friends and organized the virtual walk. We had a great time and can't wait to do it again.

It's important to let others know what eczema is and how you can treat it, and that we do not have a cure yet. I have extreme eczema and sometimes people think it is contagious.

I want a cure, as does everyone who suffers with eczema. If everyone helps to raise funds for research a cure can be found. Together WE CAN!!!



### Angela Kelley-Green

Eczema is my cross to bear. I was born with atopic eczema. I didn't know anything was wrong with me until a girlfriend slept over my house and told me I was scratching the skin off the back of my neck. That comment stuck with me.

I remember a lot of things about growing up with eczema. My father yelling, "stop scratching," a boy telling me I "look like you kissed an iron," and people calling me ugly. I had a feeling of being different and "less than" and that's the reason I'm so eager to help people suffering with chronic persistent eczema.

Helping Renee Dantzler and GwenDolyn Hall organize the IFAC virtual walk of the District, Maryland and Virginia was a true joy. I wrote the story of the 3 Divas that introduced our team Believing in a Cure (BIAC) on the IFAC donor website. I also designed and printed out the signs we carried as we walked.

I believe we are all here for a purpose, and for me that purpose has to be helping others.



If you're interested in learning more about hosting a NEA Itching for a Cure walk in your local community, request information at [teamnea@nationaleczema.org](mailto:teamnea@nationaleczema.org) or call 415.499.3474. ●



# WHAT YOU'VE BEEN TALKING ABOUT

## Social Media Roundup

*Expert posts from our medical provider partners drive important online conversations. We love the information and stories our Facebook and NEA Support Forum communities share. We hope these highlights are helpful, and show how many of you are facing similar challenges.*

### Expert Post from Mary Williams, MD:

*Have you ever felt embarrassed about you or your child's skin condition? Or embarrassed by his or her appearance? Has he or she ever expressed feelings like this? How did you handle this? What worked for you or your child?*

**SB:** People think my 4 year old has a contagious skin condition and question why I'm out in public. I may not be able to fix her condition, but I make sure she sees her mom stand up for her.

**KL:** We have people ask us about our 3 year old, "is he ok?" And he gets strange looks when we go out. His flares cover most of his face. But now that he is getting older we talk a lot about his eczema and his allergies to try and empower him.

**RK:** I've never felt ashamed about my child!

### Expert Post from Enzo Finore, PsyD:

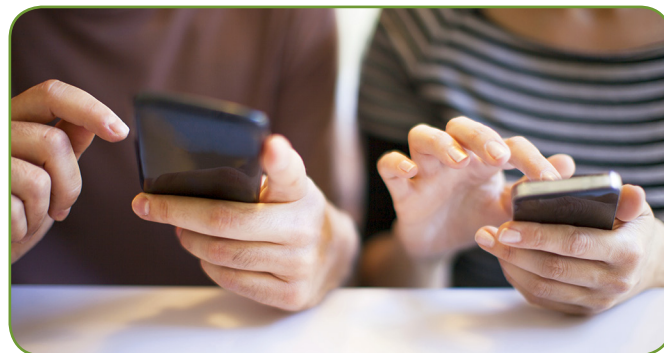
*The relationship between our biggest organ, the skin, and our psychological well-being has been widely acknowledged, both in scientific research and in anecdotal experience. Different emotions experienced through daily life have been reported by patients to trigger eczema flares. Do you find emotions such as sadness or worry make eczema symptoms worse for you?*

**ML:** My daughter's eczema has put a tremendous burden on her self-esteem. When she gets upset she almost always experiences a problem with her eczema.

**JK:** Emotions play a big role in our eczema. My son's first week of kindergarten was horrific! He was scared, anxious, stressed and worried about the whole "going to school" experience, and caused a huge flare up.

**VL:** Whenever my son gets upset or nervous, he tends to scratch which exacerbates his condition. I believe stress plays an important role in eczema.

**SS:** Although I don't believe stress is the cause of my eczema, I do believe it makes it worse. It's a vicious cycle — the more I flare the more stressed I get and the itching just gets worse. I have ice on my hands to sooth the itch.



### Expert Post from Margaret Lee, MD, PhD:

*One of my special concerns is that having a skin condition can affect your confidence enough that it influences your personality, your relationships, and even what jobs you get. In school, we know that visible differences including eczema can make you a bigger target for teasing or full-blown bullying. Does your child's school have an active anti-bullying program, and do you think it's helping? Do you feel like you have the resources and support to deal with bullies and make it stop? What are some ways to cope when someone is judging you unfairly by the way you look?*

**BF:** My six year old son has to explain that it's not contagious, happens a lot as younger kids tend to ask very open/personal questions. Thankfully at this age children have been kind, now if we could just get adults to stop staring and asking the inappropriate questions.

**KF:** I am reading this thru tears, I have it on palms and can relate all too well. Just keep on keeping on the best we can.

**CP:** I used to be really self-conscious about my eczema. Somehow, though, I've learned to not care anymore! Finding a partner who loves me no matter what eczema I have has definitely helped, along with my ever supportive family.

**LS:** We homeschool. My daughter has been left out, made fun of, bullied, talked down to... you name it. Public school is too hard for "different" kids. Homeschool has been a great decision for us. ●





# Scratch Pad

Dear NEA Scratch Pad,

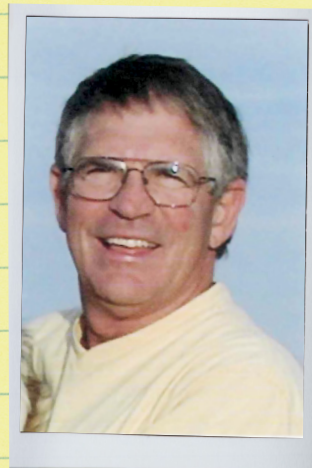
I have suffered with hand eczema for about 20 years but was only diagnosed about two years ago. It started when I worked in a hospital, but even after I left that job, I still would have flare-ups. My doctor prescribed an ointment, but it was ineffective. Through trial and error, I found a very effective combination: Benadryl Gel and Caladryl Clear Skin Protectant Lotion. For added relief, I sometimes include Gold Bond Ultimate Eczema Relief Cream. I mixed these together and then rub the mixture over the affected areas. Relief from pain and itching beings almost immediately. Hopefully this will be helpful to others toot.

Eric B.  
Stockbridge, GA

Dear NEA Scratch Pad,

I developed a sudden case of atopic dermatitis, from head to toe, about two years ago. I was tested for every known allergen (including the glue in my prosthetic knee) by multiple doctors and clinics. No topical prescriptions, antihistamines, or diet changes helped. My sanity was ebbing when my family doctor referred me to an allergist who suggested a low dosage of Methotrexate. 10mg, once a week, and my symptoms completely cleared! After a year, I discontinued the methotrexate and the symptoms soon reappeared. I have come to the resolution that I will probably take methotrexate for the rest of my life but I'm so grateful I found something that keeps my eczema clear!

Gary M.  
Greeley, CO



Dear NEA Scratch Pad,

I have suffered from eczema for over 51 years. I have been on methotrexate, cyclosporine, CellCept, and have various topicals most of my life. I have a very healthy lifestyle and I eat a vegetarian diet. In my research, I came across Dr. Brett King at Yale New Haven, who specializes in recalcitrant skin diseases. He prescribed a low dose (15mg) of Xeljanz and my eczema started to clear with little to no side effects. For the first time in a long time I felt comfortable in my own skin and the itching was all but gone. Xeljanz is a JAK-inhibitor that suppresses the immune system.

At first my insurance wouldn't approve of the medication, but with the support of Dr. King and my family, insurance finally covered it. While Xeljanz is not a cure, it is a lifeline and opportunity to live pain-free as we wait for new research and treatments come!

Cindy M.



# Scratch Pad

Dear NEA Scratch Pad,

I had a severe case of hand eczema, prominent on my left hand for a number of months. The small blisters and scratching would keep me up at night and I couldn't find something that would help. I felt like I had tried everything my dermatologist recommended, such as: counter creams, salt therapy, salt baths, swimming in the sea, Moo Goo, stone therapy, etc.



More out of desperation, I bought a natural Aboriginal bush medicine product called Sacred Grove Balm from a market stall and within two days, the blisters and itching completely cleared! Best of all, it never thinned out my skin! I recommend this product to anyone who hasn't found something that worked for their eczema!

Sarah E.

Dear NEA Scratch Pad,

I have eczema around my fingernails, which can be very painful. I fill an eye dropper with apple cider vinegar and place 1-2 drops of the vinegar under the edge of the nail. It's a pleasant surprise to see it actually healing!

Rose M.

Ann Arbor, MI

Dear NEA Scratch Pad,

Having dealt with atopic dermatitis for 70+ years I wanted to share tips that have helped me over the years. I order vegetable glycerin (which can be ordered by the gallon from homemade soap ingredient suppliers). Mixing 40% aloe vera juice and 60% vegetable glycerin, I apply the concoction over my body after I shower. I also apply after I wash my hands. This amazing mixture has essentially made my eczema non-existent and it's very reasonably priced.

M. H.

Vancouver, WA

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of the NEA Scratch Pad

The recommendations contained in the "Scratch Pad" are those of the contributors. NEA provides health information from a variety of sources; this information is not intended as medical advice. Persons with questions regarding specific symptoms or treatments should consult a professional health-care provider.

Email your "Scratch Pad" tip (along with a photo if you have it) to [info@nationaleczema.org](mailto:info@nationaleczema.org), so that we may publish it in an upcoming issue of *The Advocate* and help others!





# NEA SUPPORT NETWORK



A 5<sup>th</sup> grade NEA supporter did an amazing job spreading awareness for eczema as her class project. Hosting a table, she displayed information on eczema and the National Eczema Association and showed NEA's Eczema Awareness video. Not only did she raise awareness, but she also learned more about her eczema and knows that she's not alone in this fight. She was amazed at how many people came up to her and said that they either had eczema, too, or know someone else who has eczema.

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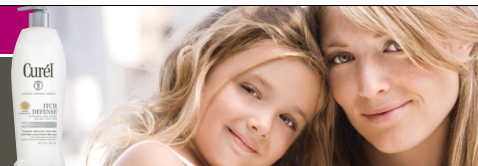
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