



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

# *The* **ADVOCATE**

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A QUARTERLY PUBLICATION OF THE NATIONAL ECZEMA ASSOCIATION

LEAKY GUT

1-DAY FORUMS

ECZEMA DRUGS IN DEVELOPMENT





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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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**EDITORS NOTE:** Dr. Aaron Drucker was erroneously written as Dr. Adam Drucker in the article, "NEA's Latest Research Award" from the Fourth Quarter 2015 issue of *The Advocate*. Please accept our sincere apologies.



# Thank you!

Dear NEA Friends:

What a year! If you've been following us on our journey, you know NEA has been busy launching our new strategic vision, The Roadmap, which exponentially expands awareness of eczema and its impact on your lives, seizes opportunities brought to us by new scientific findings, and readies our community for the new treatment access issues we know are coming.

Never before has it been as imperative for us to band together and raise our voices to ensure we get the treatment and support we need to live quality lives with eczema. **Thanks to your generous past support, we have made great strides to meet the challenges ahead, including building a strong team that has advanced multiple goals on the Roadmap. In 2015, we jointly:**

- Raised the profile of eczema from “just a rash” to a serious, life-altering disease.
- Engaged national leaders, including the FDA leadership, in eczema drug development, access, and affordability issues.
- Funded “burden of disease” research to more fully understand the impacts of eczema on the lives of individuals and their families. This work is essential so we can address the needs of the “whole” person; eczema is not just a skin condition.
- Funded research on new potential therapies to relieve the itch of eczema, and alternative therapies to treat eczema.
- Built new connections with individuals and families during our October Eczema Awareness Month, resulting in 7 million message views, 350,000 video views, and nearly 5,000 new Facebook “friends.”

- Engaged more than 500 participants in our 2015 Itching for a Cure walks in Chicago and Los Angeles, raising awareness and \$120,000.
- Shared emerging eczema knowledge and treatment options with nearly 100 people at our Leaders in Eczema One-Day Patient Forums.
- Reached more than 25,000 people in our end-of-year giving campaign.
- Engaged with National Health Council Committees—including the Healthcare Reform Action Team, the 21st Century Cures/PDUFA Team, and the Grassroots Action Team—to advocate for increased access to new treatments for eczema patients.

In 2016, NEA will continue to implement innovative strategies to increase research, education, and advocacy. We plan to launch a national public awareness campaign that explains what it's really like to live with eczema, we will fund research to find real solutions, and we will work within our community to improve the quality of life for everyone who is impacted by eczema.

**Thank you for all you do to make this work possible. As they say—and as I hope you know—we can't do it without you!**

With deep appreciation,



Julie Block  
President & CEO



P.S. Save the date! NEA will host our 2016 Itching for a Cure walk on Sunday, October 2, at UCLA. Watch for updates in our publications and online. ●





## YOU RAISED YOUR VOICE *and* RAISED YOUR

Thanks to you and the rest of the eczema community, 2015 Eczema Awareness Month was our most successful yet. You raised your hands, raised your voices, shared your eczema stories and helped NEA spread the word that eczema is a significant burden on the lives of many who are affected, and deserves to be recognized as a serious disease.

"I am standing in awe of the power that our eczema community holds in its hands," said Julie Block, President and CEO of NEA. "The amazing success of Eczema Awareness Month 2015 was just the beginning. We need to raise our voices even louder to advocate for affordable and accessible treatments and we know now that we can. Stay tuned for what you can do help in 2016."

Our campaign to spread the word on social media took off like never before. More than 7 million people were exposed to our messages about eczema through their Facebook and Twitter feeds and our videos were seen by almost 350,000 people. Our main video alone had over 138,000 views. Almost 5,000 new people joined our Facebook community and 3,700 people left comments such as these:

*"I have suffered from eczema for 6 years now. I have always been embarrassed of it. And being a 17 year old girl attending a public school I got a lot of rude remarks. I have about 5 people, on a daily basis, ask me what's on my arms, neck, and cheek. This page has taught me that I don't need to be ashamed. So I'm raising my hand."*

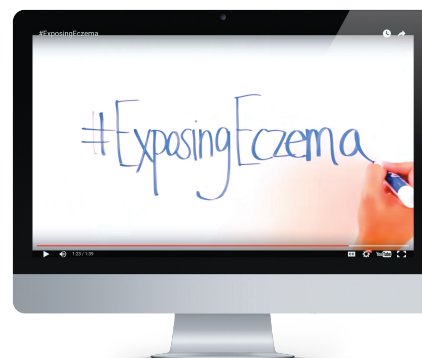
– AB 10.21.15

*"Thankful to have mostly outgrown this painful skin condition. Anyone who knew me as a young kid, knows just how bad mine was. Even as a kid, it affects your self-confidence. People typically don't understand it or even know what it is. I remember other young kids my age wouldn't touch me because they thought it was contagious. I believe Eczema Awareness is SO important. Seeing this video made me so happy that someone is trying to spread the word."*

*#ExposingEczema #EczemaAwarenessMonth"*

– AG 10.8.15

There's never been a more exciting, hopeful time in the history of eczema treatment. There is a new understanding of the disease and many new treatments on the horizon. NEA is leading the charge to turn this rare intersection of hope and opportunity into a new era of care and we cannot achieve our goals without you, the eczema community. Thanks for raising your voices and sharing your stories. We will be in touch in the coming months with more opportunities to take action! ●



The National Eczema Association extends a special thank you to our 2015 Eczema Awareness Month Sponsors

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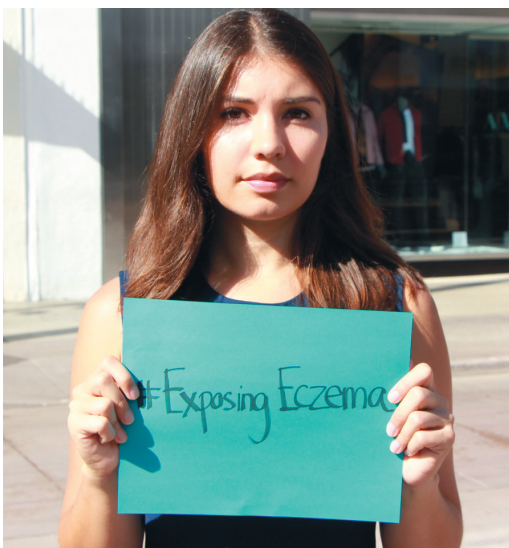
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# YOUR HANDS *to* PROMOTE ECZEMA AWARENESS





## WHY I CONTRIBUTE

*to the National Eczema Association*

We asked Nathan, a member of NEA's Board of Directors, Co-Leader of the Chicago Support Group, and longtime NEA supporter why he joined the National Eczema Association. Here was his response:



*Nathan lives in Chicago where he is a medical student. He was diagnosed with eczema at two months old and suffered from severe eczema in grade school and high school. Through treatment, great doctors and avoidance of triggers he has been under control since graduating college.*

### How did you first learn about NEA?

I first learned about NEA from my dermatologist, Dr. Peter Lio, who is a member of the NEA's Scientific Advisory Committee. Several years ago, Peter mentioned that the mother of one of his patients wanted to start a NEA support group. Dr. Lio asked if I wanted to help and I jumped on board. We launched the Chicago-area NEA support group in early 2013.

### What inspired you to raise funds to support our mission to improve the quality of life for individuals with eczema?

I am excited about the next chapter in the care of eczema patients. Over the next several years biologic medications will expand and improve the treatment tool-belt exponentially. At the same time, sophisticated treatment modalities will be disseminated to care providers across the medical landscape.

NEA's work is critical to ensure these things happen. Two focus areas from the NEA's Roadmap to Advocacy speak to my personal interests and passions:

- Establish cross-specialty leadership to educate and equip medical practitioners so that they are better able to effectively manage eczema care

- Advocate on behalf of patients so that new and emerging eczema treatments are accessible and affordable

***We can come together as a community through NEA so that the next chapter of atopic dermatitis is about thriving, not just surviving.***

### What do you think the greatest challenges are for people with eczema and their loved ones?

Finding a doctor with expertise and passion for treating eczema has been a major challenge in the eczema community. Fortunately, more dermatologists and allergist seem to be taking an interest in atopic dermatitis. I also think it is easier to find an eczema expert than it used to be thanks to the NEA's patient conferences and social media.

Expense is another problem. Many insurance plans cover Elidel but not Protopic. Both are good medications, but personally Protopic helps me more, and I imagine there are other people out there who feel the same. Co-pays for phototherapy can also add up quickly. The problem of expense will increase as new biologics come to market.

### How has NEA's work personally touched your life?

First and foremost has been the Chicago-area support group. The walks have been important to me too. We did a virtual walk here in Chicago at the same time as the Los Angeles walk in 2014. Moreover, we had the Itching for a Cure walk in Chicago last year. It was also great meeting people from around the country at the Boston conference two years ago and listening to such a dedicated group of researchers and physicians.

### If you could share any information or advice with other individuals who suffer from eczema, what would it be?

I enjoy watching the survival expert Bear Grylls on TV. One of things he said during his show really resonated with me and I think is good advice for living with eczema: "Survival can be summed up in three words — never give up. That's the heart of it really. Just keep trying." ●





# Thank you Los Angeles!

NEA's Itching for a Cure Los Angeles walk on October 11 was a great event with over 300 individuals showing their Itching for a Cure spirit. Thank you donors, sponsors, volunteers, and walkers!



## Congratulations and Thank You to our Top Fundraisers

### Teams

Rosenblum's Rousers  
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### Individuals

Keith Heeley  
Ashley Blua  
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### Honorable Mentions

Christopher's Itch Warriors  
Sawyer the Warrior  
Boz Borowiecki

### Spirit of the Walk Award

Jayden's Red Hot Chili  
Scratchers



## Special Thank You

Debbie Byrnes  
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Keith Heeley  
Stephanie, Scot,  
and Paige Knox  
Palace Beauty College  
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## *Itching for a Cure*

**Thank you for helping make NEA's 2015  
Itching for a Cure walks in Chicago and Los Angeles  
our most successful yet!**

Last year, more than 550 people joined NEA as walkers and virtual walkers. Together, we raised nearly \$120,000 through individual donors and industry sponsorships.



NEA had over 87 teams between the two walks. Congratulations and heart-felt thanks to our 2015 fundraising superstar awardees who helped advance eczema research, education and outreach through their IFAC fundraising efforts.





2015



**Thank you to everyone  
who helped make 2015 a great success!**

*And be sure to save the date for our 2016 IFAC  
walk in LA: Sunday, October 2, 2016.  
We look forward to seeing you then!*



## Thank You Sponsors

The National Eczema Association extends a special thank you to our 2015 Itching for a Cure Sponsors, totaling nearly \$35,000



## LEAKY GUT:

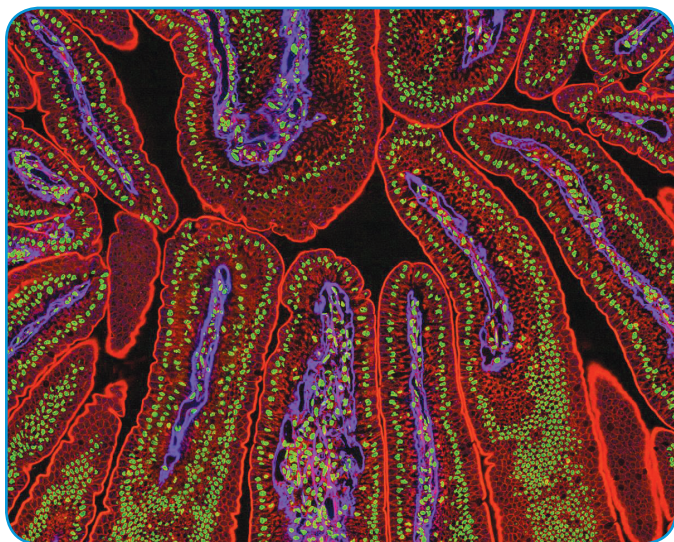
### *Does the Concept Hold Water or Is It Full of Holes?*

*Increasingly, the concept of leaky gut is being touted by alternative and holistic practitioners as being fundamentally important in many chronic illnesses.*

By Peter A. Lio and Karan Lal, MS-4

It is now well accepted that skin barrier dysfunction is implicated in a variety of important inflammatory skin diseases including acne, atopic dermatitis, and psoriasis.<sup>1</sup> Following the epidermis as it rounds the lips and becomes the lining of the oro-digestive tract, it does not seem unreasonable that barrier impairment could continue internally as well. In fact, similar to the function of the cutaneous epithelium, the intestinal epithelium separates luminal contents from the interstitium, and impairment of this function leads to increased intestinal permeability, sometimes called “Leaky Gut.”<sup>2</sup>

Increasingly, the concept of leaky gut is being touted by alternative and holistic practitioners as being fundamentally important in many chronic illnesses.<sup>3</sup> Though it has perhaps not yet garnered much conventional medical attention, many patients seem aware of this entity and are asking questions about it. In this brief review, we examine the science behind the idea and its potential clinical relevance to dermatology.



*The small intestine is where most of our nutrients from the food we eat are absorbed into the bloodstream. The walls of the intestine contain small finger-like projections call villi which increase the organ's surface area, enhancing nutrient absorption*

### The Gut

Far more than a simple tube for absorbing nutrients, the gut has three major constituents: luminal microbiota with an outer mucus layer, an inner mucus layer, and finally the epithelial layer. The luminal microbiome within the gut has around one thousand grams of bacteria that digest nutrients to produce hormones and vitamins, inhibit growth of pathogenic organisms, and assist in the metabolism of drugs and toxins.<sup>4-6</sup> The intestinal cells known as enterocytes ultimately prevent substances from coming in contact with the blood and adaptive immune system through their tight intercellular junctions.<sup>4</sup> When functioning normally, this barrier is highly selective, allowing nutrients to pass but still protecting against foreign molecules and pathogens.

Certain triggers and stresses are thought to cause dysbiosis and cellular junction disruption allowing for increased intestinal permeability, which has been implicated in the pathogenesis of many disease states including inflammatory bowel disease, celiac disease, hepatic fibrosis, food intolerance, and small intestinal bacterial overgrowth.<sup>7-9</sup> Interestingly, there are also non-gastrointestinal diseases on this list, including fibromyalgia, chronic fatigue syndrome, and, relevant to dermatology, atopic dermatitis.<sup>10</sup>

### The Evidence

The exciting developments in understanding of filaggrin and related proteins in atopic dermatitis (AD) have led to a deeper understanding of the central importance of barrier function in this disease.<sup>11</sup> Along with skin barrier dysfunction, it has been postulated that there is compromise of the intestinal permeability barrier in AD as well. Many clinicians employ elimination diets—ostensibly in hopes of avoiding food allergens or triggers—and often report positive results from their afflicted patients despite fairly convincing evidence that dietary exclusion does not seem to benefit unselected patients.<sup>12</sup> Directly or indirectly, the implication of the gut in AD has been very difficult to shake, with patients often insisting diet is the “root cause.”<sup>13</sup>

One of the ways that the intestinal barrier can be tested is to administer a mixture of sugars orally, frequently lactulose and rhamnose or mannitol, and examine their urinary excretion. These water-soluble, non-degradable





molecules are instructive as the larger molecules (lactulose) are thought to permeate between the cells only when there is significant gut barrier impairment, while the smaller molecules (rhamnose or mannitol) are absorbed transcellularly, relatively independent of the barrier function. Therefore, by examining what is excreted in the urine, one can determine a lactulose/rhamnose ratio, which is elevated in proportion to gut barrier dysfunction.<sup>14</sup>

Compellingly, a study from the United Kingdom identified significantly increased lactulose to rhamnose excretion ratios (leaky gut) in children with AD when compared to controls, and were particularly greater in children under the age of eight years old.<sup>15</sup> To examine the relationship between leaky gut, atopic dermatitis, and cow's milk allergy, one study consisting of 35 infants under the age of one year with AD examined the urinary concentrations of end-products in children with cow's milk allergy

and AD compared to children with AD alone. Perhaps as one might expect, children with both cow's milk allergy and AD had higher levels of the end-products, indicating greater intestinal permeability, compared to children with AD only.<sup>21</sup>

Another very recent study found a strong correlation between a gut bacteria called *Faecalibacterium prausnitzii* and AD, and that these patients had markers of gut epithelial inflammation, which can lead to barrier impairment.<sup>10</sup> While these represent correlative data, they raise the important question of the clinical implication of leaky gut in these patients, particularly as we learn more about the role of transcutaneous sensitization in AD, secondary to what might be dubbed "leaky skin."<sup>16</sup>

### Interventions

Armed with these fundamentals, we now move into the more clinically relevant realm: If leaky gut is indeed involved in the pathogenesis of AD, can it be treated? The answer seems to be "yes," although with qualifications.

Diet has been implicated in the development of both leaky gut and AD and is a provocative place to start. Parents often note an association between certain foods and flares of AD.<sup>17</sup> When tested, some 39 percent of families recognized improvement in their children with AD following an elimination diet, although this remains a confusing and controversial area.<sup>18</sup> Historically, the thinking has been that food allergies (present in about 30 percent of children with AD versus only 10 percent in non-atopics) may be driving the skin disease.<sup>19</sup>





Indeed, food allergies have been shown to cause inflammation within the gut, altering the complex intestinal barrier. One small study evaluated 15 children with atopic dermatitis and subjected them to a two-week elimination diet where they were only allowed to consume a highly restricted group of foods. Interestingly, nine of the 15 patients had a significant reduction in clinical eczema scores and mean intestinal permeability in responders was lower when compared to that of non-responders.<sup>20</sup> While studies suggest that only 40 percent of children with atopic dermatitis that are food sensitized actually have specific signs and symptoms of food allergy, these findings raise the idea that perhaps there are other mechanisms at play beyond simple IgE-mediated allergic responses.<sup>17</sup>

While many questions remain unanswered about diet and AD, there is hope that better understanding will help sort what types of dietary modifications could be helpful and in what settings.

Greater knowledge of the gut-skin connection has led to introduction of probiotic therapy in the management of AD. This concept relies on gut biodiversity and/or the presence of certain beneficial organisms as critical components to immunologic well being.

Perturbations in gut microbacterial diversity may inhibit the maturation of the T-regulatory cells causing Th1 and/or Th2 induced inflammation.<sup>22,23</sup> While the overall body of data on probiotics and AD remains somewhat unclear, the consensus currently states that probiotics are not effective for the treatment of established AD but may be helpful in prevention. However, there is the suggestion that the non-uniformity of the results from the many studies belies a more complex answer: not as simple as “probiotics are not effective”, but that there may be different phenotypes of the disease which respond more favorably than others; depending on the preponderance of the phenotype studied, the results could vary greatly.<sup>24</sup>

One double-blind placebo controlled crossover study administered two different strains of lactobacilli probiotic to 41 children with moderate to severe AD for six weeks. Ultimately, 14 patients had lactulose-mannitol excretion tests after placebo, and after active treatment to assess intestinal permeability. Median lactulose excretion decreased by 50 percent following treatment with probiotics, suggesting a significant improvement in gut barrier.<sup>24</sup> Another study of 39 infants with AD were randomized to receive lactobacillus rhamnosus GG for three months, and

the major groups of gut and skin bacteria were characterized using PCR along with several immune indices. At one month, the proportion of IgA- and IgM-secreting cells decreased significantly in the treatment group, thought to indicate an improved gut barrier function in those patients who received the probiotic.<sup>26</sup>

It is important to note that many unknowns remain here: the appropriate strain, dose, and duration of probiotics for AD still require a great deal of elucidation, but there is certainly promise in probiotic therapy.

Newer physical modalities may also be of benefit in conditions that result from possible compromise of the gut barrier. Gelatin tannate is one such agent that, through its chemical structure, may be able to form bonds with mucin within the mucus layers of the gut barrier.<sup>4</sup> In addition to its physical activity in preventing contact of commensal organisms with the adaptive immune system, gelatin tannate acts as an astringent and can complex pro-inflammatory mucus-related proteins for elimination.<sup>25</sup> This may prove to be a viable option for treating impaired barrier function, perhaps akin to a topical moisturizer for the skin.<sup>29</sup>

### Verdict

Atopic dermatitis remains a complex, multi-faceted disease. Despite its increasing prevalence and concomitant growing scientific interest, there are still many unanswered questions. Leaky gut represents a thought-provoking notion that has diagnostic and therapeutic ramifications, but raises many questions. More studies are required to determine if leaky gut is universal in AD or if there are specific subtypes/phenotypes for which it is relevant, and what approaches will yield the most improvement. Until then, as with all poorly-understood entities, we must keep alert for connections and observations that will guide future questions and research directions, and perhaps most of all, keep listening to our patients.



*Peter A. Lio, MD is Assistant Professor of Clinical Dermatology and Pediatrics-Dermatology at Northwestern University Feinberg School of Medicine and Director of the Chicago Integrative Eczema Center. Dr. Lio is also a member of the National Eczema Association Scientific Advisory Committee.*





*Karan Lal, MS-4 is at New York Institute of Technology College of Osteopathic Medicine.*

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Original article written by Peter A. Lio and Karan Lal, MS-4 for Practical Dermatology. Republished with permission.

*The National Eczema Association extends a special thank you to Paul Winnington, Editorial Director, Dermatology, Aesthetics, Neurology. ●*

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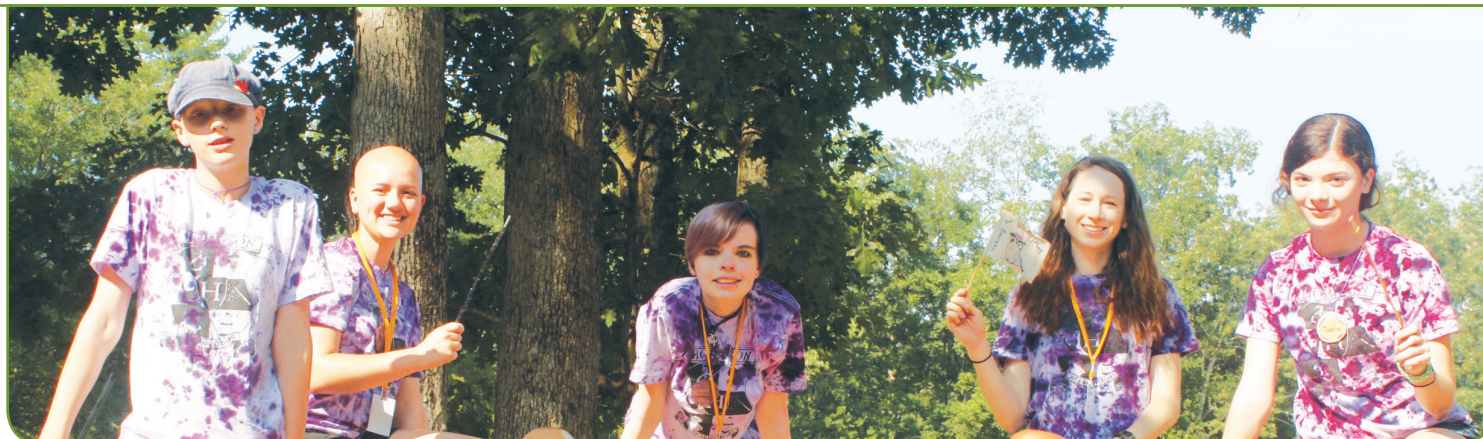
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## AAD CAMP DISCOVERY



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For more information about attending, volunteering or donating, please visit [campdiscovery.org](http://campdiscovery.org) or contact Janine Mueller at [jmueller@aad.org](mailto:jmueller@aad.org). ●



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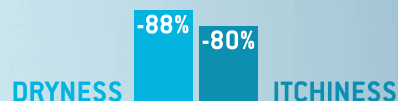
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## MY FORUM EXPERIENCE



*Dear National Eczema Association,*

I attended the Nashville forum, and I am writing to express my appreciation to the National Eczema Association for hosting a wonderful 1-Day experience.

The past year has been difficult for me and my wife, trying to find ways to alleviate our daughter, Mae's, eczema. Between her second birthday and the forum, my wife and I have had some time to slow down and reflect on the past year. It has been a long, confusing, and heartbreaking year of watching her itch; learning the in's and out's about food allergies, environmental allergens, and other kinds of triggers; trying all sorts of steroids, antihistamines, creams, soaps, and moisturizers; and negotiating conflicting advice from pediatricians, allergists, and dermatologists.

At the forum, I learned that (1) eczema is not food-driven per se, though food can certainly be an irritant; (2) eczema is cyclical and multi-factorial; any viable treatment plan should therefore implement a range of medicines, moisturizers, and alternative treatments (such as sunflower oil) to

identify what works; (3) skin is permeable; (4) since there is technically no cure for eczema, a more constructive question is not to try and identify the precise cause of a flare up, but to become more and more sensitized to what factors or conditions to avoid moving forward; (5) laugh and avoid stress; (6) given the severity of Mae's eczema, and the fact that my mother and my wife's mother both have very mild forms of eczema, this may be a long-term health concern for Mae.

These are not easy lessons to come by, particularly the last one. But I am very grateful for them. I am also hopeful to hear that there are many new medications and alternative treatments that are currently in development. Most importantly, I am glad that there are competent and compassionate people who are leading the way. My entire family is grateful for NEA. This 1-Day forum has given us more than a year's worth of doctor's visits.

*Best wishes,*  
*Gideon ●*







# LEADERS *in* ECZEMA

## ROAD TO A BETTER FUTURE

### Two Educational Forums in 2016

The National Eczema Association invites you to **LEADERS IN ECZEMA**, one-day educational events for adults, in Texas and California.

**LEADERS IN ECZEMA** will provide you with information, resources, and opportunities to meet patients, caregivers, and clinicians

- Learn from eczema experts
- Receive coping strategies
- Understand new developments in eczema research

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**DATE TBD**  
California



**Discover how you can be an Eczema Leader and how we can create a better future together!**

Stay tuned and join us on Facebook, NEA's online support forum, and sign up for NEA's eInsights for more information.



Peter Lio, MD, is the Medical Director of the Leaders in Eczema forums. Dr. Lio is an Assistant Professor of Clinical Dermatology and Pediatrics at Northwestern University's Feinberg School of Medicine and Director of the Chicago Integrative Eczema Center. Dr. Lio is also a member of the National Eczema Association Scientific Advisory Committee.



## ANACOR PHARMACEUTICALS

*Partnering with the National Eczema Association*

**We asked Anacor Pharmaceuticals, a proud sponsor, why they support the National Eczema Association. Here was the company's response:**



Founded in 2000, Anacor is a biopharmaceutical company headquartered in Palo Alto, California focused on discovering, developing, and commercializing novel small-molecule therapeutics derived from its boron chemistry platform. To learn more, please visit [www.anacor.com](http://www.anacor.com).

### **What is NEA's role to advance eczema care for millions of Americans?**

The National Eczema Association (NEA) is a national non-profit organization dedicated to improving the health and quality of life of millions of individuals with eczema through education, research, and raising public awareness of the disease. Already the world's largest non-profit serving those affected by eczema and atopic dermatitis, the organization's established online community is large, and growing.

Anacor Pharmaceuticals is proud to help support the NEA and the important work it undertakes to help individuals of all ages with eczema. Like NEA, we believe that more innovation is needed, given the lack of long-term prescription treatment options for this chronic condition.

### **Do you believe NEA's new strategic direction as outlined in the Roadmap to Advocacy will make an impact?**

NEA's Roadmap to Advocacy is an important manifesto. The organization's Five Transformation Keys provide a step-wise approach to addressing unmet needs of eczema sufferers. This roadmap is consistent with Anacor's belief in the value of disease state education and ensuring that our medications are accessible to those who need them.



### **How can eczema patients impact new treatment developments?**

The first step for patients is to find engagement that works for them, be it through NEA's social media and online communities, or by attending local events.

This is where the momentum begins to build, the patient voice gets elevated, and patient needs are heard.

### **Why does your company choose to support the NEA?**

Eczema is often a debilitating condition, the stigma of which often adds to the burdens of those suffering from the condition. Anacor believes in the NEA's mission to improve the health and quality of life of those suffering with eczema through research, support, and education. ●





## WHAT'S IT LIKE TO PARTICIPATE *in a* CLINICAL TRIAL?

### *Patient Perspectives*

*We all play an important role, especially patients, in bringing new treatments to those that need them. Research is like a relay race that scientists can only take so far, and at some point, they must hand the baton to patients to engage in clinical trials to help bring the treatment to reality. The National Eczema Association asked two NEA supporters about their first-hand experiences as participants in clinical trials. Both people are adults with eczema who have had the disease throughout their lives.*



### MEET ASHLEY

*Ashley lives in California and works in the public relations industry. Now 28, her eczema began when she was two years old. In addition to her eczema, she also suffered from asthma as a child, and continues to battle severe allergies, all of which run in her family. Ashley started the clinical trial in June of 2015, and is still a participant.*

### Why did you participate in a clinical trial?

As a lifelong eczema sufferer, I thought I had the disease under control. I'd spent 20 plus years perfecting my excuses, "Oh, I had an allergic reaction to something" or my favorite as a kid, "My dog scratched my legs when we were playing." But as many people know, the disease is unpredictable, and in the summer of 2014 it evolved into something that a simple excuse could no longer cover. I began trying the standard and alternative therapies such as topical steroids, oral medication, allergy testing, trigger avoidance, various diets, bleach baths, hypnosis, acupuncture, supplements ... you name it. I tried it. And was left with no tangible results. It was disheartening and this condition wasn't getting any better. My eczema was now showing up in places on my body that it had never been before, creeping up from my legs, to my arms, shoulders, neck — and eventually, my face.

Once the condition became so severe that I was regularly missing work due to sleep deprivation, pain and overall embarrassment of how I looked, I started scouring the National Eczema Association's website for new therapies. I discovered information about a drug that was currently in the clinical trial phase. Thanks to the "clinical trials" section on the NEA's website, I was directed to ClinicalTrials.gov, where I inquired about the study and answered a handful of questions about my condition.

One of the questions was "How many dollar bills would it take to cover all of the eczema on your body?" Wow. I had never thought about it like that before. I quickly pulled a dollar from my purse and began counting. Let's just say the number was higher than the amount of dollar bills in my purse.



## MEMBER CONTRIBUTION

Once I was done answering the questions and hit the “submit” button, I cried. Hard. I cried because I was hopeful that there was something out there that would allow me to get my life back, and I cried because I was scared that I would be disappointed by another medication that didn't work.

To my surprise, within 24 hours a representative from the participating doctor had reached out to gather more details about my condition and less than a month after my initial inquiry, I was accepted into the study.

### What were the challenges?

The first challenge was dedicating the time to the study. For the first few months I was required to visit the doctor each week for blood tests, respond to survey questions about my physical and emotional health and to receive the “medication.” In the beginning, the hardest part was answering the survey questions, because I would often become emotional. For example “On a scale of 1 to 10, how



embarrassed/ashamed are you because of your eczema?” always seemed to get the water works going. I couldn't imagine ever answering anything other than a 10. If I could have answered 15, I would have written that.

Secondly, the routine blood tests were difficult because of swollen skin on my arms. There were a few times where the nurse had a difficult time finding a vein because of my inflamed, broken skin. I learned quickly to be extra hydrated before each appointment, and taking a quick walk before helped to get the blood flowing, and reduce the swelling.

The third challenge about participating in the clinical trial was not knowing if I was receiving the medication each week, every other week, or if I was on placebo. Some days my skin looked pretty good, and I was sure that I was receiving the medication, and then other days it was so severe, that I was positive I was on placebo. The process can easily mess with your mind, but the nurses and doctor were so encouraging and helped me remain hopeful by sharing other patient's success stories.

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Lastly, after many months in the first phase, the doctors allowed me to give my own injections. This was great because I didn't have to spend time in the doctor's office each week, and could do my injections at home. It was a challenge learning to give myself a pretty sizable shot in the stomach, but as soon as I did it once, the fear quickly diminished and I actually started feeling empowered by doing it on my own.

### What were the highlights (if any)?

One highlight from this experience is that it brought me closer to the National Eczema Association. I started volunteering, connecting with other people who have the disease, and started to feel like I wasn't so alone in my struggle. I'm now at a place where I'm not ashamed to hide a flare, and am happy to answer people's questions when they ask "Oh honey, what did you get in to? Was it poison ivy?"

While my eczema still isn't completely controlled, it's in a much more tolerable place than it was a year ago. I'm still participating in the clinical trial, and have stopped worrying so much about if I'm getting the medication or not. I feel lucky to be involved, and hope that if anything, all of my time, tears and blood samples will help the doctors and scientists to improve the medication so that it can help more people like me.

### What advice do you have for others regarding clinical trials considering your experience?

- 1. Do Your Research.** Lean in to the resources that are out there. Use the National Eczema Association and their support groups, events and news to stay informed on your options — that's how I learned about the study I'm in, which has been life changing (I'm no longer a 10 in regards to my embarrassment level, I get regular sleep, and now it only takes no more than three or four dollar bills to cover my eczema patches.)
- 2. Be Brave.** Yes, there can be risks associated with being involved in a clinical trial. I can't promise that there won't be days where you feel like a lab rat. But just remember, you can stop at any time, and the results just might be worth the risk.
- 3. Fight a Good Fight.** If you participate in a clinical trial,

there may be multiple phases in which you will have the opportunity to participate. If you think you may be on placebo for the first four months, don't give up. There may be an opportunity for you to be involved in the next phase. In my clinical trial, everyone will ultimately get the medication in the end, which gives me hope on the days I'm not feeling so great.

### MEET DEBBIE



*Debbie's eczema started when she was a baby. It continued to be a problem as a young child, but subsided throughout her teenage and young adult years. Unfortunately, soon after turning 40 and moving to San Antonio, Debbie's eczema returned with a vengeance. She also began suffering with seasonal allergies for the first time in her life. Her only family member with serious eczema is an aunt on her fraternal side. Debbie's siblings have had mild bouts of eczema, but her three children, ages 21-26, have not been affected at all. She and her husband, Mike, still reside in San Antonio.*

### Why did you participate in a clinical trial?

My atopic dermatitis (AD) has been something I've dealt with all my life. I don't remember how bad it was as a child, although my mom tells me my skin was never clear. For some reason, my disease improved during my high school, college, and childbearing years. But a decade ago, everything changed. Shortly after our family relocated to San Antonio from Houston, my skin issues started to worsen. My yearly trips to the dermatologist turned into monthly visits, but I soon realized we were getting nowhere. I spent so much money and time visiting numerous doctors, but it was to no avail.

On top of the endless amount of lotions and creams, I tried both topical and oral steroids, cyclosporine, CellCept, and phototherapy. Some of those treatments would work for a while, but nothing continued to work for me. As a happy-go-lucky individual, I struggled throughout the years trying to maintain a positive outlook. I wanted just one of those regimens to work so I could just get on with my life.

I became frustrated with my situation. My family didn't know what to do, and doctors seemed disinterested in helping me. While reading about eczema on the Internet one night, I discovered National Jewish Health (NJH) in Denver, Colorado. This hospital treats children and adults with severe eczema. At that time, I decided I had to go and began my crusade with the insurance company to get my visit covered. In October 2011, I spent 8 days at NJH. When I got there I was covered head-to-toe in eczema and had reached the end of my rope. During my visit, I underwent extensive laboratory tests, visited with a psychologist, and learned more about how to control my skin. The doctors and nurses showed me how to do wet wraps and soon thereafter I began to notice significant improvement.

It was shortly after my trip to NJH that I became involved with the National Eczema Association and began to build my support system. Both of those events were a turning point for me. Although I felt better while doing the wet wraps, I knew it wasn't something I wanted to do for the rest of my life. The wraps felt like the best remedy I had available at the time.

When the opportunity arose to get involved in the clinical trial, I gave it a lot of thought. I understood that there may be risks involved, but I didn't really look at it that way. Living with eczema is not easy. Chronic diseases such as this wear you down and make it hard to think about the future. I knew I wanted to try something to improve my quality of life. My decision to participate in the clinical trial was twofold. First, I felt I had exhausted all my resources and I needed a different approach. I wanted to be part of cutting edge treatments that would give me new hope. Secondly, I've decided that while I find ways to cope with my AD, it may not be that easy for the younger eczema patients and their parents. I want to help find a way to get closer to a cure for them as well as me. This is my way of doing my part.

### What were the challenges?

The biggest challenge for me has been missing work for the clinical trial appointments. As a teacher, I don't have the liberty to go into work a few hours late. I've had to take several half-day absences to make it to the

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appointments. When I started the trial a year ago, the appointments were weekly visits. Eventually I got to where I was going in monthly. No matter how many appointments it required, I was determined to make it work. The benefits of the trial definitely outweigh this challenge.

Another challenging part for me in the beginning was dealing with other illnesses while I'm participating in the trial. Most of the times I go in for my clinic appointments, the nurses draw blood for the trial. I became fearful that if I took certain medications, such as antihistamines for my allergies, it would affect my blood work in a negative way. If possible, I would refrain from taking other medications so it wouldn't jeopardize my participation in the trial. Every time I go to a clinic appointment, I am required to tell the nurses every change I've had in my health and how I was treated for it.

### What were the highlights?

When I started this trial in January 2015, I understood there was a chance I'd receive the placebo. I thought about that all the time. I remember thinking to myself, "What if I can't tell what I'm getting?" "How will I cope if it is the placebo?" "How long would it be before I'd notice any improvement?" "Could I handle the fact that I'd never really know what I got?"

Even though I consider myself a low-key person, the anticipation was nerve wracking. I decided to focus on the positive thoughts and keep the hope.

Just five days after receiving my first treatment, I felt

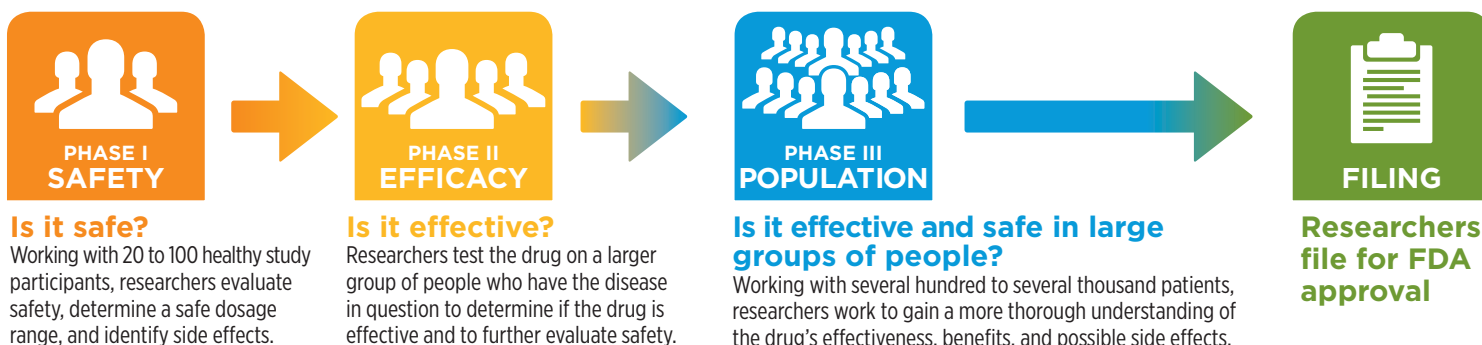
different. I will never forget the feeling I had that particular morning when I woke up. The feeling came from inside my body, not from my skin. My body felt at ease and relaxed. I have yet to find the right words to describe it, but I knew in my heart that something exciting was happening. That feeling continued and I began to heal. My skin looked better than it ever has. The itching stopped and I began sleeping through the night. I didn't dread showers anymore, because my skin didn't turn bright red from the water. My skin became less dry and required minimal work. I no longer needed all the creams, ointments, and oral medication. My monotonous skincare routine ended and my overall outlook on life changed. For the first time in a decade, I felt and looked normal. The medication I received through the trial didn't cure me, but I no longer felt like an eczema patient. For me it was almost 100% gone.

### What advice do you have for others regarding clinical trials considering your experience?

I would tell others who want to participate in a clinical trial to take charge of your own destiny. ***Do research on the available trials and decide which one is right for you.*** Once you make that determination, be persistent on how you get involved. Find out which doctors in your area are clinical trial sites, and call them often. If possible, stop by the office and talk with someone in person. I got on the list at three different offices waiting for the trial to begin. I called each site a couple times a week. Pursue all avenues to get into a trial, and don't give up. It could change your life in ways you can't even imagine. ●



# ECZEMA DRUGS *in* DEVELOPMENT



The research pipeline identifies drugs being tested for eczema/atopic dermatitis. The information in this pipeline chart comes from public sources and is as comprehensive as we understand it at this time.

The pipeline includes drugs that are in progress, listing: drug candidate (name of the drug), phase of study, mechanism of action (or how it works), route of administration, sponsor (drug company), and study location.

Sometimes a drug candidate has two names — the name that is used in the trial and then the brand name when it is approved. Often the name in the trial is a combination of letters and numbers to indicate the compound's name during development at the drug company.

Drug Candidate	Phase	Mechanism	Route of Administration	Sponsor	Study Location
BMS-981164	1	biologic (anti-IL31 monoclonal antibody)	Injection	Bristol-Myers Squibb	Non-US
CNTO 7160	1		Injection	Janssen Research & Development, LLC	Non-US
E6005	1	PDE4 inhibitor	Topical	Eisai Co., Ltd.	Non-US
FURESTEM-AD	1	Mesenchymal stem cells	Injection	Kang Stem Biotech Co., Ltd.	Non-US
OPA-15406	1	PDE-4 inhibitor	Topical	Otsuka Pharmaceutical Co., Ltd.	Non-US
Sodium Hypochlorite Solution	1	antimicrobial	Topical	Makati Medical Center	Non-US
XmAb*7195	1	biologic	Injection	Xencor, Inc.	US
Treatment of Chronic Itch with Oral Clonidine & Oral Naltrexone	1	Clonidine: reduces sympathetic system outflow. Naltrexone: opioid receptor antagonist.	Oral	University of Minnesota — Clinical and Translational Science Institute	US
GSK2894512 Cream	1	Non-steroidal anti-inflammatory	Topical	GlaxoSmithKline	Non-US
LEO 32731	1	Inhibits secretion of TNF- $\alpha$ , IFN- $\gamma$ , and IL-5 but increases anti-inflammatory IL-10.	Topical	LEO Pharma	Non-US
Pimecrolimus 1% vs Betamethasone dipropionate 0.05% vs Clobetasol prapionate 0.05% vs Glaxal Base cream vehicle	1		Topical	LEO Pharma	Non-US
AM1030-CREAM	1/2	5-HT2B receptor antagonist	Topical	AnaMar AB	Non-US
Apremilast (CC-10004)	2	PDE-4 inhibitor	Oral	Celgene Corporation	US/ Non-US
AQX-1125	2	Activates SHIP1 pathway	Oral	Aquinox Pharmaceuticals, Inc.	Non-US
CIM331	2	Anti-IL-31 receptor	Injection	Chugai Pharmaceutical	US
CT327	2	Anti-Pruritic	Topical	Creabilis SA	Non-US
DS107G	2	Derivative of an omega-6 fatty acid	Oral	Dignity Sciences, LTD	US/ Non-US
Dupilumab and Immune Responses	2	Biologic IL-4R Antibody	Injection	Regeneron Pharmaceuticals	US
IgE specific Immunoabsorption	2	removal of IgE		Universitaire Ziekenhuizen Leuven	Non-US
ILV-094	2	anti- IL-22	Injection	Rockefeller University	US
KHK4577	2	Interventional	Oral	Kyowa Hakko Kirin Company, Limited	Non-US
KM110329	2	Dietary supplement	Oral	Kyunghee University Medical Center	Non-US
MRX-6 Cream 2%	2	Anti-Inflammatory	Topical	Celsus Therapeutics PLC	Non-US
OC000459	2	DP2 antagonist	Oral	Atopix Therapeutics, Ltd.	Non-US
SB011	2	Cleaves GATA-3 mRNA	Topical	Sterna Biologicals GmbH & Co. KG	Non-US
QAW039	2	(PGD2), DP2 (CRTH2)	Oral	Novartis Pharmaceuticals	Non-US
Tralokinumab	2	anti-IL13	Injection	MedImmune LLC	US
VLY-686	2	anti-pruritic	Oral	Vanda Pharmaceuticals	Non-US





Drug Candidate	Phase	Mechanism	Route of Administration	Sponsor	Study Location
Omiganan (CLS001)	2	Cationic antimicrobial peptide	Topical	Cutanea Life Sciences	Non-US
ZPL-3893787	2	Histamine H4 receptor antagonist	Oral	Ziarco Pharma Ltd	Non-US
Asimadoline (To tx pruritis associated with AD)	2	Selective kappa-opioid receptor agonist	Oral	Tioga Pharmaceuticals	
Lebrikizumab	2	anti-IL13	Injection	Hoffmann-La Roche	US/Non-US
Lebrikizumab vs. Topical Corticosteroids in Adults	2	anti-IL13	Injection	Hoffmann-La Roche	US/Non-US (Canada)
Device: Immunoabsorptions with an IgE-specific adsorption column	2	Removal of IgE after apheresis of blood	Device	Universitaire Ziekenhuizen Leuven	Non-US
Q301	2	anti-inflammatory	Topical	Quriert Co., Ltd	US
VPD-737 for Prurigo Nodularis	2	Neurokinin-1 (NK1) Receptor Antagonist	Oral	Tigercat Pharma, Inc.	Non-US
Moisturizer + Subject's Own Antimicrobial Bacteria	2	Decrease <i>S. aureus</i> colonization and increase colonization by protective <i>Staph</i> species	Topical	Richard Gallo, University of California, San Diego	US
Ustekinumab	2	anti-IL12/23	Injection	Rockefeller University	US
Amino Acid Moisturizing Cream/Desonide Cream	3	hydrates skin/anti-inflammatory	Topical	NeoStrata Company, Inc.	US
AN2728 Topical Ointment, 2%	3	PDE-4 inhibitor	Topical	Anacor Pharmaceuticals, Inc.	US
Clemastine Fumarate + Dexamethasone	3	anti-Inflammatory	Topical	EMS	Non-US
Dupilumab Monotherapy Efficacy and Safety	3	biologic IL-4R Antibody	Injection	Regeneron Pharmaceuticals	US
Dupilumab + Topical Corticosteroids Long-term Safety	3	biologic IL-4R Antibody	Injection	Regeneron Pharmaceuticals	US
Holly Mangrove Shower Gel	3	Improves skin barrier function	Topical	Mahidol University	Non-US
Device: Non-medicated emollient plus Lyocell/Chitosan Sleeve		Ceramide embedded fabric	Device/Topical	University of Minnesota - Clinical and Translational Science Institute	US
Fluocinonide cream 0.1% in Reducing Itch		Corticosteroid; reduces inflammation		Wake Forest School of Medicine	US
3% Oregano extract cream		Natural product with antimicrobial, anti-inflammatory, and antiseptic properties	Topical	Rutgers, The State University of New Jersey	US
Photocil		Selectively delivers Narrow Band- Ultraviolet B (NB-UVB) therapy when exposed to sunlight.	Topical	Applied Biology, Inc.	US
Lactobacillus Paracasei (GM080)			Oral	Nestlé	Non-US
Bleach bath (sodium hypochlorite)		Alter skin microbiome and improve skin barrier and decrease expression of inflammatory proteins in the skin	Topical	University of Rochester	US
Xolair/Omalizumab in Severe Childhood Eczema	4	anti-IgE	Injection	Guy's and St Thomas' NHS Foundation Trust	Non-US (UK)
Runzao zhiyang capsule	4		Oral	Guizhou Tongjitang Pharmaceutical Co., Ltd	Non-US (China)
Ganoderma Tea	1/2		Oral	Hong Kong Baptist University	Non-US (Hong Kong)
Secukinumab	2	Antibody that binds to and neutralizes proinflammatory cytokine interleukin 17A (IL-17A)	Injection	Icahn School of Medicine at Mount Sinai; Novartis	US
MEDI9929	2	Antibody that blocks interaction of thymic stromal lymphopoietin (TSLP) with the TSLP receptor	Injection (SubQ)	MedImmune LLC; Amgen	US
Baricitinib (LY3009104)	2	JAK1 and JAK 2 Inhibitor	Oral	Eli Lilly and Company	US
Furoic acid loperamide hydrochloride cream; Mullite ointment; 3% boric acid solution; Zinc oxide	2		Topical	Shanghai Yueyang Integrated Medicine Hospital	Non-US (China)
Cetaphil Restoraderm Effect on Young Children with AD	4	Skin moisturizer with filaggrin breakdown products and ceramides	Topical	Galderma	Non-US (China, Philippines)
Combined Probiotics in AD in Children		Probiotics (Lactobacillus and Bifidobacterium)	Oral	Casa Espirita Terra de Ismael	Non-US (Brazil)
DSXS (Desoximetasone Topical)	3		Topical	Taro Pharmaceuticals	US
Dilute Acetic Acid (Vinegar) in Baths in Pediatric Atopic Dermatitis			Topical	Mayo Clinic	US
Trimethoprim/sulfamethoxazole vs Cephalexin vs Doxycycline vs Sodium Hypochlorite: Effects on treatments on Atopic Dermatitis		Characterizing microbiome alterations with drugs in column 1	Oral/Topical	National Cancer Institute (NCI)	US
Montelukast	4	Blocks binding of leukotriene D4 to its receptor	Oral	Murdoch Childrens Research Institute	Not Provided
Probiotics in Mild Atopic Dermatitis in Young Patients		Probiotic	Oral	Biopolis S.L.	Not Provided
Bacille Calmette Guérin (BCG) vaccine at birth for Allergy & Infection Reduction	3		Injection		Non-US (Australia)

**NOTE:** Although some drugs are not currently being developed in the United States, new studies might begin in the United States at any time. The online table on the NEA website will be updated to reflect any changes.



## INNOVATIONS IN ECZEMA CARE: THE ARON REGIME

*NEA's Chicago Support Group recently hosted a meeting, which included guest speakers Peter A. Lio, MD, NEA Scientific Advisory Committee member and Dr. Richard Aron. Dr. Aron is a South African dermatologist, specializing in Atopic Eczema, and he has created "The Aron Regime." Following the Chicago event, Dr. Lio shared his thoughts on "The Aron Regime."*

Several years ago I heard about a Dermatologist — Dr. Richard Aron — in London who was prescribing a combination of a topical steroid, a topical antibiotic, and a moisturizer with amazing results for atopic dermatitis. At the time, I simply thought that this was pretty much what we were doing already, and that it was not really worthy of much extra attention.

Fast forward to last year, when one of my more seasoned patients with pretty severe eczema approached me about it. She said that she had read a lot on Facebook and that his following was impressive, with very convincing stories. She had one of his recipes and asked if we could try it. Looking at it carefully — betamethasone valerate mixed with mupirocin in a Vanicream base — it seemed innocuous enough to try. It is important to note that this patient had severe eczema and was doing all of the right things already: using a potent-enough topical steroid correctly and in sufficient amounts, doing dilute bleach baths nightly, and applying moisturizer aggressively to protect and hydrate the skin. Things were better, but she still suffered and we continued to flirt with the idea of going on cyclosporine, the powerful immunosuppressant that can help to break the cycle, but carries with it a host of possible side effects. Suffice it to say that I was initially not very optimistic...

Let me pause the narrative to point out that there are really three innovations with the so-called "Aron Regime":

1. Mixing a topical antibacterial agent with the steroid, while not really a new idea, is important, especially as we are learning more and more about how the microbiome (the community of bacteria that normally reside on our skin) is abnormal in atopic dermatitis. In fact, a recent paper described a toxin (called "delta toxin") produced by the abnormal but ever-present

staphylococcus aureus bacteria on the skin that can actually induce eczema on healthy skin! (Nakamura, 2013)

2. Using a low-potency corticosteroid but with increased frequency of application. This is unconventional, and to my knowledge, not well-studied. In fact, there are studies that would suggest precisely the opposite: that once daily application of a corticosteroid may actually be sufficient. (Bleehen, 1995). However, there may be theoretical benefits to using a less-potent preparation more frequently, including the possibility that the skin barrier damage is decreased. Further studies are needed to assess this, but it certainly is thought-provoking.
3. Having only one thing to do rather than 3, 4, or even more steps. While there is no doubt that 5 or 6 daily applications is a lot, it is somewhat simpler than having a complex morning and evening routine. And it really only lasts for the first week, and then the tapering can begin, going down to 3 times daily application, then twice daily, then once, then ideally, off of the compounded cream. This compared to soaking, then patting dry, then apply the medicine, then a moisturizer, then a damp layer, then a dry layer, etc... which can become very tedious for some patients and families. Some have mentioned that part of the reason it may work so well is simply because patients are able to actually stick to the regimen because it is so straightforward.

Back to the story...

At the one-week mark, I called the patient to ask how things were going. She was ecstatic, saying that this was better than anything we had done before. In fact, she was sort of mad at me for "holding out" on this treatment for so long. Was she cured? No, not at all. But was she better? Absolutely. And it allowed us to avoid needing the cyclosporine, which I consider a big win. Were this the only story, I wouldn't be writing this. Some version of the above has now happened to about 2 dozen of my patients and I have to say that the results are generally very similar and very encouraging.







It has not been all roses, however; there have been some caveats as well:

- A few patients have found the cream base too irritating — in those cases, I've cobbled together an ointment version of the compound, sometimes with good effect.
- Several patients also simply did not respond to it sufficiently, and did end up needing to go on more powerful topical medications or immunosuppressants. I can say with confidence that it — at least the way I am using it — is not 100% effective by any means.
- It can be fairly expensive since it has to be compounded by a compounding pharmacy, and this adds a layer of complexity for the patient.
- There is some concern that mupirocin-resistant bacteria may emerge from such prolonged and widespread use. This certainly seems possible, but if we weigh this against the need for frequent oral antibiotics, it seems to be a rather small price to pay.
- There is some concern that increasing the application of steroids and the relatively prolonged duration of use could increase the risk of side effects. While this is certainly possible, Dr. Aron maintains that he has not seen many side effects after many years of using this approach. Still, this represents an off-label use for

these medications and caution is advised until further studies can validate his experience. We know that there are real risks to using topical steroids, and it is foolish to think that somehow this method is totally immune from them. That said, with close supervision and in the right context, the risks seem to be outweighed by the benefits.

In sum, I freely admit that while I am an eczema expert and very much devoted to understanding (and beating!) this terrible disease, I do not have all the answers. I need — we all need — new ideas, new approaches, creativity and innovation. I want to embrace and celebrate these things, *especially* when they are taking familiar and tested ideas and using them in new ways. *Especially* when no one has a conflict of interest to sell a product. And, perhaps most of all, especially when I get the sense that it is coming from someone who is truly dedicated to his or her patients. Fortunately, all three of these apply here.

Perhaps the Aron Regime will simply be a footnote in the long history of eczema, but perhaps it will be something more: a point of departure for new approaches in treating AD. The only way to know for sure is to study it and its principles, and to do that, we must first keep an open mind.



*Peter A. Lio, MD is Assistant Professor of Clinical Dermatology and Pediatrics-Dermatology at Northwestern University Feinberg School of Medicine and Director of the Chicago Integrative Eczema Center. Dr. Lio is also a member of the National*

*Eczema Association Scientific Advisory Committee.*

#### References:

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# Scratch Pad

Dear NEA Scratch Pad,

I developed hand eczema two years ago, shortly after going off all hormone treatments for my hysterectomy. I could not use Elidel or Protopic medication. Only strong hydrocortisone creams were somewhat helpful, but even those became less and less effective.

The skin on my hands became very fragile and looked burnt. They would crack open and occasionally bleed. Simple things like opening a screw top or playing the piano would injure my hands. The skin on my fingertips thickened and I lost feeling, making it hard to hold or pick up items. After two years, I decided I needed to be more pro-active and find something that would help me.



I started with eliminating certain foods from my diet, and at first, it would work! But then, after a short amount of time, my skin would revert back to its original bad state. After several months of trial and error, I found removing the following items radically helped my skin improve: citric acid and other acids found in food, sodium lauryl sulfate, and Cocamidopropyl betaine. I use the following products and they seem to work: CeraVe Hydrating Cleanser, Eucerin Original Cream, Vaseline, and mineral oil.

Luckily, I have found that I can eat almost anything but I cannot touch it with my hands. I hope this may help others with hand eczema.

Susan G.

Dear NEA Scratch Pad,

I have had chronic eczema since I was two years old. For me, sweat was a trigger, causing my skin to swell and sting. I wanted so badly to rid myself of eczema that I said yes to any and every medication. After years of experimenting, I realized no one product would work for a long time and I was building a tolerance. It only recently dawned on me how dependent on medication I had become. I had let my eczema rule my life, limiting time with friends and family. I realized I needed to figure out a way to accept living with eczema.

So, after 20 years, I decided to turn in my prescriptions for good old-fashioned gauze and for the first time in my life, I'm steroid free. While my skin is by no means perfect, I'm finding with the help of supplements and natural oils and lotions, it's tolerable. I have learned to ask for help when I need it but I'm nowhere near as embarrassed as I feared.

Cathryn S.  
New York, NY





# Scratch Pad

Dear NEA Scratch Pad,

I have to brag about this product. I saw it in *Good Housekeeping* magazine a couple of years ago and I have been a believer ever since. O'Keefe's Working Hands is the only thing that has made a difference in mine and my husband's life. The balm is not greasy or sticky, and has absolutely zero scent. I highly recommend this for hand eczema, as it works better than the steroid ointment I had tried before and it's much cheaper!

Heather K.  
Gainseville, FL



Dear NEA Scratch Pad,

I told my sister-in-law about my eczema and she recommended a new dermatologist to see. The doctor told me about a product, InfiniteAloe Cream, which I can say with a smile on my face, has worked wonders! I am finally able to sleep at night and has reduced my itch during the day. I use it on my legs and arms, along with CeraVe. I also bathe my legs with Grandpa's Pine Tar Soap. This has greatly helped with the scaly appearance on my legs so I don't even mind smelling like beef jerky for a little while..

Gina L.  
Labadieville, LA

Dear NEA Scratch Pad,

My family has had the enormous project of dealing with my son's eczema and asthma. It began as soon as he turned 3 months old (just like with my older son). However, his condition lasted way past 18 months of age that my pediatrician and I hoped for. We removed food dyes/colors, acidic foods, and azodicarbonamide from his diet and added probiotics (Lactobacillus & Bifidobacterium), Herpanacine, and Hydroxyzine. In addition, we found Scratch-Me-Not Sleeves to be a huge help. I feel like I have my son back and he is a much happier child with better sleep and fewer tantrums.

Vrinda N.  
Portland, OR

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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

NEA supporter, Mia, raised over \$605 in checks and cash at her birthday party to donate to the National Eczema Association. She wanted to help raise awareness and make a contribution towards eczema research that will someday help find a cure for eczema.

Thank you Mia for all your hard work in promoting Itching for a Cure!



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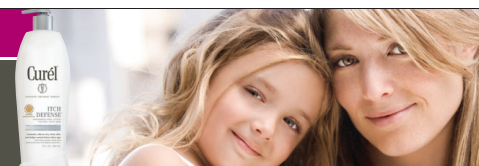
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