

# 2015

## ANNUAL REPORT



PHOTO



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Cure  
October 11, 2015 - Los Angeles  
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Comment



Dear NEA Friends:

As we reflect back on 2015, what we've accomplished in such a short period of time is nothing short of amazing. We're especially excited to see NEA's strategic plan, ***The Decade of Eczema: The Roadmap to Advocacy***, come to life and build the path toward a new era of eczema care.

**Thanks to your support, NEA made ground-breaking inroads into launching patient-centered initiatives by expanding our education, research, and community engagement activities.** In 2015 that included leading 4 successful *Leaders in Eczema* Educational Forums across the US, hosting 2 record-breaking *Itching for Cure Walks*, providing testimony in front Federal Drug Administration (FDA) to advance new guidelines for clinical research involving children, and funding essential research to learn more about the burden eczema has on you and your families.

These are only the first of many steps on our path toward building a new era of eczema care together. 2016 promises even more advancements, including exciting opportunities for you to raise your voice and help define how NEA can improve the health and quality of life for everyone with eczema.

**Thank you for all you do to support our work.**

With deep appreciation,



Julie Block  
President & CEO

Susan Tofte  
NEA Board Chair





Stephanie and Paige Knox

*“It’s so important  
to shine a light on  
what eczema is and  
how it affects people.”*

# Stephanie Knox

**Living with eczema** has been an ever-changing journey for Stephanie Knox and her daughter Paige, who was diagnosed with eczema when she was about 10 months old. Paige had what Stephanie calls “super eczema,” impacting her entire body.

“Eczema is like any chronic disease,” said Stephanie. “You deal with issues with the disease when you’re an infant, when you’re a toddler — with Paige, she’s in middle school now, and adolescence. She doesn’t want to bring attention to herself. She is doing well, managing her eczema, and learning this lifestyle. Yet, she’s also more self-conscious about her eczema.”

As parents who have a child with eczema know, there are multiple ways families have to adjust their lives, from rigorous management routines, to household cleaning regimens and frequent doctor visits. Most people who don’t live with eczema themselves don’t really understand, even if they are empathetic. “We have a pet-free home, we have our nightly routines, we have an action plan to treat hot spots,” said Stephanie. “It has become our lifestyle.”

Stephanie has been a powerful advocate for Paige and likewise for the National Eczema Association (NEA). While already engaged in activities for other organizations in her home town of Asheville, NC, Stephanie wanted to do something not only to bring attention to eczema and raise money for research, but to bring people living with eczema together. So she reached out to NEA, offering to organize and host the inaugural *Itching for a Cure* walk in Asheville in 2012. The tradition endures today, and includes people throughout the country forming their own walk teams and participating as “virtual walkers,” raising awareness, money, and support in their own local communities to support NEA’s mission.

“Eczema can be such a dark disease,” says Stephanie, “and it’s so important to shine a light on what it is and how it affects people. Being connected to other eczema sufferers, parents, and caregivers is important, too.” she continued. “You share your ideas, you share your stories, and you even cry a little in frustration and laughter. It goes beyond just having eczema in common.” Even though life with eczema continues to be a journey for her family, *Itching for a Cure* has become the beacon of hope and community-building event Stephanie hoped for all those years ago. “It’s my heart and my soul,” she said.

# ITCHING FOR A CURE

**Thank you to the NEA community for helping make our 2015 Itching for a Cure walks our most successful yet!**

In 2015, more than 550 people joined NEA on two IFAC Walks: one in Chicago, IL, and one in Los Angeles, CA. Together, we raised nearly \$120,000 through individual donors and industry sponsorships to support our mission to improve the health and quality of life for individuals with eczema through research, support and education.

Congratulations and a heart-felt thanks to our 2015 fundraising superstar awardees who helped advance eczema research, education and outreach through their IFAC fundraising efforts:

**Chicago, IL:** Chicago Eczemaniacs, Ditch the Itch, Thad Czopkiewicz, Sheila Prutsman, and Kelly Cirrintano.

**Los Angeles, CA:** Rosenblum's Rousers, Jarrett's Jam Squad, Hugo's Eczterminators, Keith Heeley, Ashley Blua, and Marie Parmer.

“The funds raised through IFAC will advance eczema research, so that no parent has to explain to their child why their skin is so different, why it may hurt to take a bath, why it may burn to put on moisturizer.”

—2015 IFAC participant





Nathan Jetter

# Nathan Jetter

**Nathan's journey began in childhood.** Just two months old when he was diagnosed with eczema, his symptoms were severe. "I don't remember thinking about it as a problem when I was very young, I had no other expectations for how things should be," he said. "But when I was five or six years old, and school started, that was when I began to realize I had some unique challenges."

Nathan's severe eczema symptoms persisted throughout his school years. It wasn't until college that he began to get his eczema under control. Today, Nathan's symptoms are well managed, and he is a third year medical student at the University of Illinois who has served as President of the dermatology interest group for his student body, lead free clinic days, helped launch a National Eczema Association (NEA) support group, and currently serves on the NEA Board.

Nathan first learned about NEA through Dr. Peter Lio, a member of NEA's Scientific Advisory Committee. With encouragement and support from Dr. Lio, Nathan teamed up with nurse Erika Czopkiewicz, and launched the NEA Chicago Eczema Support Group in 2013. One of NEA's most active support groups, they meet throughout the year to share information, resources, and experiences with people facing the same challenges.

"One of the most powerful aspects of the support group is when people start to tell their stories and you can see on their faces that they realize they're not alone," says Nathan. "The importance of that became apparent at a recent meeting, when a family brought their child and someone asked him why he wanted to come to the group. He told us, 'I wanted to know if there was anyone else like me.' And then he climbed into the lap of one of the attendees and stayed there."

Building a community of empowered patients and physicians is a key focus of Nathan's. "Much of what motivates me," said Nathan, "is going through a tough experience and discovering how much of a difference really good care makes." A member of NEA's Coalition for Better Eczema Care, Nathan is also helping develop medical curriculum with a patient focus and promoting a patient-centered approach to care. Thanks to Nathan's leadership, commitment and support, excellent eczema care will become a reality and help improve the health and quality of life for individuals with eczema.

*"Much of what motivates me is going through a tough experience and discovering how much of a difference really good care makes."*

# ITCHING FOR A CURE

“Jarrett’s Jam Squad is dedicating the Itching for a Cure walk to those who have countless days where they feel like there is no hope — both sufferers and caregivers.”

—Jarrett’s Jam Squad Team





Dr. Eric Simpson, OHSU

# Can Eczema be Prevented?

## Ask Dr. Eric Simpson

**For the first time in decades,** new drugs and therapies that may provide real relief for anyone living with eczema are close to being available. For many, this is a time of unprecedented hope.

But what if there were a way to prevent the very first flare, to stop eczema from even starting?

Frustrated by seeing patients with eczema and atopic dermatitis (AD), and realizing the treatments he had to offer had many limitations, Dr. Eric Simpson began to wonder if eczema prevention was a possibility.

Simpson specializes in dermatology at Oregon Health & Science University (OHSU), and is the director of the clinical studies unit. He has been funded by the National Institutes of Health (NIH) to study eczema treatment and prevention. His early research in this area was funded by NEA, where he currently serves as Co-Chair of NEA's Scientific Advisory Committee.

"My original inspiration was Jon Hanifin — my mentor since I was a young resident in dermatology," said Simpson. Dr. Hanifin, whose research helped better understand the cause of AD is one of the founders of NEA, and currently sits on the NEA Board of Directors.

Hanifin also noted something else. "Dermatologists have suspected for many years that eczema is due to a barrier problem in the skin, as we have seen numerous cases of babies with severe eczema everywhere on their bodies except in the diaper area which stays surprisingly smooth," said Hanifin. "The reason is that the constant moisture in the diaper area keeps the skin from cracking. That is why we encourage parents to treat eczema in infants as early as possible and continually moisturize the skin."

This idea led Simpson to wonder whether it would be possible to

*"What drives my passion is seeing how you can change someone's life when you clear up their understanding of the disease and empower them to manage it."*

stop eczema from starting by practicing early skin care. In 2008, Simpson applied for and was awarded a NEA grant to fund a pilot study of emollient therapy for the primary prevention of atopic dermatitis (AD), which is the most common and chronic form of eczema. 22 babies considered to be at high risk for developing AD (those with at least one parent or sibling who has, or had, AD) participated in the study. Parents applied an emollient cream at least once a day over their baby's whole body, except for the diaper area and scalp, preferably within three minutes of bathing. All babies treated did not have eczema, and they followed them over time to see if this approach prevented the development of eczema.

The result? Of the 22 babies, only 3 babies developed AD within the follow-up period of 547 days. The rest of the babies showed no signs AD during the study period, and also did not experience any adverse effects from their skin care regimen. Previous studies of similar high risk subjects revealed that the risk of developing AD by 2 years of age to be between 30% and 50%<sup>1</sup>.

This original pilot study has led to more studies, and to more questions. Simpson is currently in the planning phase to conduct a population-based study that he hopes will help answer some of these questions.

"What drives my passion," said Simpson, "is seeing how you can change someone's life when you clear up their understanding of the disease and empower them to manage it. Eczema is such a mysterious disease, but when you're able to help people change their lives, it's amazing."

"NEA plays an important role in dispelling misinformation about eczema," Simpson continued. "But they are also actively working to uncover gaps in existing research to identify what we still need to learn."

Simpson understands that eczema can feel like an isolating disease and that it's important for patients, especially kids, to know that they are part of a wider community and that they are not alone. "Even though there is not yet a cure, there is hope that people with eczema can get their lives back. People at NEA and all over the world are working to support patients, research treatments, and advocate for access to medications."

In his own work, Simpson believes that skin barrier protection is important component of a combined approach to prevention that also includes immune triggers. His continued research and work on behalf of people with eczema is one of the reasons to believe this is indeed a hopeful time and that people can, and should, expect to be able to treat their condition and get their lives back.



1. Hoare C, Li Wan Po A, Williams H. Systematic review of treatments for atopic eczema. *Health Technol Assess* 2000;4:1-191.

# Research Grants Awards 2015

**Since 2004, NEA has been funding research** to improve the health and quality of lives of individuals with eczema. The NEA Research Grant Program is supported through donations by our community members. By focusing on research whose results can lead to direct impact on patient care, NEA has been helping to provide answers where there has previously been none.

In 2015 NEA awarded four grants, focused in the areas of quality of life, prevention, and alternative care, and itch:



Aaron Drucker, MD,  
Brown University

## Burden of Atopic Dermatitis

NEA awarded Dr. Aaron Drucker, Assistant Professor, Department of Dermatology at Brown University, a Burden of Atopic Dermatitis grant to discern where additional research was needed to fill in gaps in data around the quality of life impacts eczema and atopic dermatitis have on individuals and families.

“People with eczema and atopic dermatitis deserve care that will empower them to better manage their condition to improve their quality of life,” said Dr. Drucker. “Not only is this comprehensive audit important to help more people understand what we do know, but also because it will highlight research we need to do that will have a direct impact on patient care. I have great hope that as AD gets more attention, there will be more therapies than ever before that will be safe and effective.”



Ahsan Azamini, MD,  
Massachusetts General Hospital

## Itch

Itch is a cardinal symptom of atopic dermatitis (AD), but drugs that target specific itch receptors have not been effective for the treatment of itch. “Itch,” says Ahsan Azamini, MD, of Massachusetts General Hospital, “is one of the greatest challenges for people with eczema. The impact of itch on quality of life of patients is equal to that of pain, but the existing medications for itch have limited effectiveness, are not specific, and have many side effects. Better understanding of the mechanisms underlying eczema will contribute to the development of new treatments.”

Dr. Azamini’s study will build our understanding of the basic mechanisms of itch and targeting strategies for the treatment of AD and itch.

## Herbal Therapies



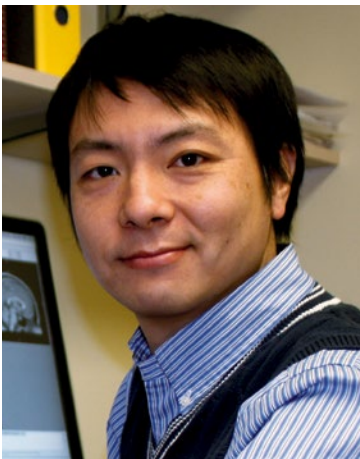
Peter Elias, MD, UCSF

Many physicians and patients have concerns about the side effects of current therapies to treat atopic dermatitis (AD). “Current therapies are not ideal because of physician and patient concerns about side effects,” said Peter Elias, MD, at University of California San Francisco (UCSF), about the impetus for his research into alternative therapies. “As a practicing dermatologist, I

have been challenged repeatedly in trying to treat severely affected patients.”

Dr. Elias’ grant will examine the herbal ingredient, apigenin, which is found in chrysanthemum, to better understand its benefits for barrier function and antimicrobial defense, and as an anti-inflammatory.

## Stress, Itch and Scratching



Hideki Mochizuki, PhD,  
Temple University

“Many patients with eczema suffer from itch, which significantly diminishes their quality of life, and exacerbation of itch caused by stress is one of the greatest challenges for patients with eczema,” says Hideki Mochizuki, PhD, at Temple University about his 2015 research study funded by NEA. “These issues can also greatly impact a patient’s family.”

Dr. Michizuki’s research will provide useful information to understand the mechanisms of how stress aggravates itch, which may lead to new therapies to manage acute stress and itch in eczema patients.





The Park's daughter enjoyed the Forums too!

*"I am glad that there are competent and compassionate people who are leading the way. My entire family is grateful to NEA. This one-day forum has given us more than a year's worth of doctor's visits."*

— Gideon Park

## HELP, HOPE, AND SUPPORT NEA *Leaders in Eczema Forums*

### **When Gideon Park's young daughter developed eczema,**

his family looked high and low for answers. "It has been a long, confusing, and heartbreaking year of watching her itch; learning the ins and outs of triggers, trying all sorts of steroids, antihistamines, creams, soaps, and moisturizers; and negotiating conflicting advice."

At NEA, we know managing eczema can be overwhelming. While there's a lot of information out there, some of it is contradictory, or confusing, and/or simply doesn't apply. So NEA asked our eczema community what *would* be most helpful — and, getting up-to-date information on the latest research and treatments came back as a top priority.

NEA *Leaders in Eczema Forums* are one way we're answering that call. These one-day educational events provide an opportunity for individuals or caregivers of children living with eczema to come together and learn best eczema management practices from experts, get coping strategies, understand new developments in eczema research, and meet other patients, caregivers, and clinicians.

Gideon was one of more than 100 people who attended NEA's 2015 Leaders in Eczema Forums around the US, and found some of the hope and help he was looking for. "I am glad that there are competent and compassionate people who are leading the way. My entire family is grateful to NEA. This one-day forum has given us more than a year's worth of doctor's visits."

Thanks to a grant from the Fondren Foundation, in 2015, NEA held forums in Minneapolis, MN, Nashville, TN, Orlando, FL, and Portland, OR. We covered topics you let us know were important, including basic skin care, the emotional impact of eczema, alternative treatments, and research on itch, eczema and allergies. Speakers included a diverse range of experts and advocates including dermatologists, nurses, social workers, researchers, and individuals living with eczema.

Next year, NEA will host Forums in Houston, TX and San Francisco, CA. Together, we can continue to improve the health and quality of life of all individuals with eczema.



## Leading the Way: Eczema Forums



**It's been an amazing journey** over the last five years at the National Eczema Association (NEA). Not only has NEA tripled its base of support, but we've also diversified and increased contributions in every category — general donors, major donors, community events, OTC product manufacturers, and industry partners. From Itching for a Cure to Seal of Acceptance to patient recruitment for innovative therapies, NEA is stronger than ever.

However, the journey is just beginning. The support and goodwill to date has allowed NEA to accelerate our reach to patients, dermatologists, and caregivers, and I am excited about NEA's prospects over the next many years to help more individuals, and provide a strong voice on the national stage to represent the millions of patients who count on NEA's advocacy. Thank you for all you've done, and for your ongoing support.



Dinesh Shenoy  
NEA Board of Directors, CFO

## Statement of Activities Year Ended December 2015

### ASSETS

#### Current Assets:

Cash and Cash Equivalents	\$963,202
Marketable securities	\$539,407
Accounts receivable	\$3,372
Prepaid expenses	\$14,128

**TOTAL CURRENT ASSETS** **\$1,520,109**

Fixed assets, net of accumulated depreciation:	\$30,250
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**TOTAL ASSETS** **\$1,550,359**

### LIABILITIES & NET ASSETS

#### Current Liabilities:

Accounts payable	\$14,206
Accrued vacation payable	\$15,930

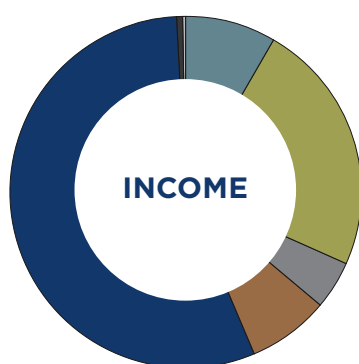
**TOTAL CURRENT LIABILITIES** **\$30,136**

#### Net assets:

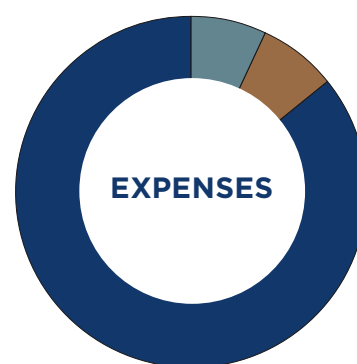
Unrestricted	\$1,519,723
Temporarily restricted	\$0

**TOTAL NET ASSETS** **\$1,519,723**

**TOTAL LIABILITIES & ASSETS** **\$1,549,859**



Individual Contributions/Grants	\$161,482
Service Program	\$441,708
Awareness Events	\$86,347
Magazine & Publications	\$139,060
Alliance Partners	\$1,056,957
Brochures	\$7,485
Other	\$4,081
<b>TOTAL</b>	<b>\$1,897,120</b>



Administration	\$96,240
Fundraising	\$98,664
Programming	\$1,160,967
<b>TOTAL</b>	<b>\$1,355,871</b>



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