



NATIONAL
Eczema
ASSOCIATION

2016

ANNUAL REPORT

FISCAL YEAR ENDING DECEMBER 31, 2016



Dear NEA Friends,

The year 2016 marked the second year of our five-year plan to usher in a new era of care for all those impacted by eczema. And what a year it was! Science continues to evolve at a rapid pace, and NEA is working every minute of every day to capitalize on the coming sea change these advancements will bring in the treatment of the disease.

Thanks to your support, we made phenomenal progress on the five transformation keys as outlined in our plan entitled ***The Decade of Eczema: Roadmap to Advocacy***. Our accomplishments are highlighted throughout this report. It bears reminding our community exactly where NEA activities are focused:

1. Raise awareness about the seriousness of eczema and how it truly impacts lives.
2. Educate medical providers to address the “whole” patient experience to improve health outcomes, and equip them for a new era of care.
3. Promote a new model of care that takes place outside the medical provider’s office to embrace the real experience of eczema patients and caregivers at home, in schools, workplace, and in their communities.
4. Focus research grants that establish the burden of disease and contributes to the need for data and evidence.
5. Advocate for accessible and affordable treatments.

One essential and deepening quality of our NEA community that is difficult to report is the courage, inspiration, and knowledge you share with one another, as well as the myriad of stakeholders making decisions that affect you and your families. These include the FDA, pharmaceutical companies investing in new eczema therapies, researchers and scientists, insurance companies, and over-the-counter product manufacturers. It is testament to your ever-present hope, and investment in our mission to improve the health and quality of life for everyone with eczema.

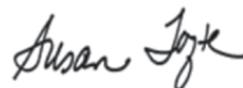
Thank you for all you do to make NEA shine!

With deep appreciation



Julie Block
President & CEO





Susan Tofte
NEA Chairwoman of
the Board of Directors



KEY ACCOMPLISHMENTS

GIVING ECZEMA PATIENTS A VOICE

With over 60 new treatments in development for eczema and atopic dermatitis, and the approval of the first new therapy in 15 years, advocacy efforts have never been more important. New treatments don't mean much if our community does not have access to them.

Our efforts to ensure these new therapies (as well as current ones) are **accessible and affordable** include engaging with the Institute for Clinical Effectiveness Research (ICER) as they review the cost effectiveness of Dupixent and Eucrisa.

NEA is working closely with ICER to include the patient experience in their evaluation of new and emerging therapies for atopic dermatitis. Because ICER's findings influence health plan coverage, it is imperative that the true impact of eczema on quality of life, and how the disease affects individuals, families and society, is factored prominently into the review.



DEVELOPING STRATEGIES TO IMPROVE ECZEMA CARE

Late 2015, NEA recruited a multi-disciplinary group of national medical experts to equip medical practices for the latest in eczema care so patients can best manage their symptoms and potential comorbid conditions.

Known as the Coalition United for Better Eczema Care (CUBE-C), this group represents dermatologists, allergists, immunologists, pediatricians, family practitioners, and psychologists. They are charged with developing the curriculum to provide medical practitioners education on new models of care and emerging therapies.

This physician education initiative is progressing at a rapid pace. Our multi-disciplinary health care leaders have completed a holistic, patient-centered, physician education curriculum. The goal of CUBE-C is to train medical professionals to deliver cutting-edge eczema care, which in turn, improves the care you receive in the doctor's office.



KEY ACCOMPLISHMENTS

LIVE BEYOND THE SCRATCH

Eczema Awareness Month had us launching an intensive media campaign aimed at raising a national recognition of eczema as a serious disease, build our community, and develop the boots on the ground needed to advance advocacy efforts state by state to ensure access and affordability of care.

This Eczema Awareness Month, we encouraged you to look beyond the scratch to live happy, healthy and comfortable lives, with our first ever Start from Scratch Challenge!

Throughout the month of October, we challenged you and your loved ones to complete weekly Start from Scratch Challenge activities to show that you're not defined by the limitations of eczema. Each Challenge activity aimed to empower you and your loved ones with tools to live your lives free from the limitations of this disease.

Over 1200 community members joined us in the Start from Scratch Challenge across social media channels to show others how they thrive beyond the scratch.



NEA'S 2016 ITCHING FOR A CURE WALK — A GREAT SUCCESS!

More than 100 people across the US joined NEA either virtually or on the UCLA campus to raise over \$65,000 to drive research and funding toward a cure for eczema. By stepping together, participants sent a powerful message that no one living with eczema is alone, support and community are available through NEA, and thanks to new therapies in development, a healthier and happier future is finally within reach.

The superstar IFAC fundraisers of 2016 who helped us reach our goals include: *Ashley Blua*, *Keith Heeley*, *Diane Eggerman*, *Srobono Mitra*, *Jarrett's Jam Squad*, and *Peyton for a Cure*.

We also want to congratulate our 2016 Spirit of the Walk winners who helped lead the pack at UCLA — way to go, *Jayden's Red Hot Chili Scratchers*!

Every step we take together helps improve the health and quality of life of anyone living with eczema.



KEY ACCOMPLISHMENTS

KNOWLEDGE IS POWER — LEADERS IN ECZEMA FORUM SERIES

The Leaders in Eczema Forum Series included two day-long forums which took place in San Francisco and Houston. These one-day events provided 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.

We covered topics you let us know were important, including basic skin care, the emotional impact of eczema, alternative treatments, and research on itch. Speakers included a diverse range of experts and advocates including dermatologists, researchers, social workers, and individuals living with eczema. Community members came from near and far for both events.

It was a powerfully educational and emotional day for all of us in attendance. We were honored to have our community come and share their stories and hope that all attendees learned valuable information and made positive connections with others in the eczema community.

A NEW LOOK FOR NEA ONLINE

In our commitment to foster a greater understanding of eczema to improve the well-being of those diagnosed, we recognize the importance of staying current with technological trends. In an effort to do this, we refreshed our website and publications to provide the best information and resources we can based on responses from our members.

NEA's website is now more mobile friendly, easier to navigate, and encourages those who are new to us to sign up for our e-newsletter.

Speaking of our e-newsletter, our monthly publication has a new name. E-Insights has become Eczema Matters. We will continue to use it to bring you all matters that are eczema related, from new research discoveries, to community stories.

BUILDING STRATEGIC PARTNERSHIPS THROUGHOUT THE ECZEMA COMMUNITY

NEA continued developing strategic partnerships with attendance at the annual American Academy of Dermatology and the Society for Investigative Dermatology conferences. We hosted receptions with many of the key opinion leaders in the eczema community at both conferences.



KEY ACCOMPLISHMENTS

FDA APPROVED NEW ECZEMA DRUG

For many years there were few treatment options available for people with eczema, including for those with a severe and chronic form of eczema, atopic dermatitis (AD). Today, there are more than 60 new therapies in development, and new clinical trials are getting underway on a regular basis.

Late December, the U.S. Food and Drug Administration approved Eucrisa (crisaborole), a topical treatment for children and adults with mild to moderate atopic dermatitis (AD). Eucrisa works differently than other topical treatments on the market. It is a non-steroidal topical that has performed well in multiple phase 3 clinical trials, including with children as young as 2 years old.

IN YOUR WORDS PROGRAM — WE ASKED, YOU ANSWERED.

The “*In Your Words*” survey series was designed to help us learn more about the challenges people living with eczema face every day. Survey responses shape a deeper understanding about the impact eczema has on people with eczema and their families, define our national policy priorities, and allow NEA to develop meaningful actions. Together we can effectively advocate for better eczema care.

Surveys included:

- ▶ **Patient satisfaction survey:** Evaluated patient satisfaction and the role of doctors in the treatment of a chronic and serious form of eczema, atopic dermatitis (AD)
- ▶ **Caregiver survey:** Examined how eczema impacts school-age children with eczema and their families
- ▶ **Adults with atopic dermatitis survey:** Asked adults with atopic dermatitis to share how AD impacts their day-to-day lives

The results of these surveys are called patient reported outcomes. That is, information given by patients on their experience with having a particular disease or set of symptoms. Understanding the patient experience provides critical information to physicians, health insurance companies, government agencies (such as the FDA or CDC), drug manufacturers, clinical researchers, and even patients on how to manage their condition.

This was the first year of our ongoing survey series, that will help us better understand the challenges people living with eczema face. We will continue to ask and share patient reported outcomes about eczema and AD. We are also putting this data into action by using it to define new models of care, to define patient outcomes, to develop physician education programs, and to develop better, more patient-centered ways to manage symptoms outside the doctor’s office or clinic.

Look for additional surveys from NEA to continue deepening our knowledge of the experience and needs of the eczema community.



NEA RESEARCH ACCOMPLISHMENTS

RESEARCH GRANT AWARDS 2016

With current unparalleled and extraordinary scientific advancement in eczema, comes a more urgent need for leadership, and for a body of data and evidence to inform the understanding of gaps and needs from the patient perspective. A critical area of focus for NEA is fostering and disseminating research proving that eczema is serious and matters. NEA is becoming the steward of burden of disease research.

In 2015, we commissioned an audit of the existing burden of disease peer-reviewed literature on both pediatric and adult atopic dermatitis (AD). Several areas were identified in the audit as research gaps: quality of life, itch, pain, sleep, psychosocial impact, marital status, social life time, economic burden and academic/occupational impacts.

MEET OUR 2016 GRANTEES:



Lisa Meltzer, Ph.D. National Jewish Health, Denver, CO

Impact of Atopic Dermatitis Treatment on Sleep and Functioning

This study looks at changes to subjective sleep quality (self-reported) and objective sleep quality (measured by a sleep device) for children following treatment for moderate to severe atopic dermatitis (AD). The sleep quality of the parents will also be tracked.

Researchers will also explore how severity of a child's AD may affect behavior, mood, reasoning, memory, ability to pay attention, and quality of life for the child and parents.

The study is the first to look at how atopic dermatitis impacts the sleep and daytime functioning of both the parents and the affected child and how AD treatment may change these dynamics.



NEA RESEARCH ACCOMPLISHMENTS



Katrina Abuabara, M.D.

University of California, San Francisco, CA

The Association Between AD and Sleep Throughout Child and Adolescence: A longitudinal cohort study

Adequate sleep is critical for health and well being. Sleep disturbances are common in people with atopic dermatitis, yet little is known about how AD impacts sleep at different stages of a child's life.

This study will look at data from infancy to adolescence of more than 14,000 people with atopic dermatitis. Researchers want to understand how AD may affect a child's sleep at each developmental stage and if certain patterns in disease activity relate to poor sleep over the long-term. This information may help identify which children with AD are most likely to suffer from poor sleep and therefore would benefit from medical care.



Aaron Secrest, M.D., Ph.D.

University of Utah, Salt Lake City, UT

Understanding Pain in Patients with Atopic Dermatitis

Stepping off from recent findings showing pain as a symptom of atopic dermatitis, this study seeks to determine how severe the pain is for people with AD, and how this pain affects other areas of their lives.

To determine the scope of pain from atopic dermatitis, study participants complete health assessments at each doctor's visit — completing questions on pain, itch, sleep and quality of life. These patient-reported outcomes will be analyzed to determine how common and important pain is to people with AD. Armed with this information, researchers will conduct focus groups to explore the reasons for pain and how it affects the person with AD and their loved ones.

The NEA Research Grant program provides seed funding to scientists with innovative research leading to an increased understanding of eczema and its impact on those with the condition and their families.

This program is supported through donations by our community members.





We couldn't do it
without you.

For all of the work that NEA has accomplished throughout 2016, it wouldn't be possible without the engagement and support of our amazing community. From the events that you attended, to the donations made, to the people who participated in clinical trials — we are finally looking at hope, and it is all because of you.

FINANCIALS

Statement of Activities Year Ended 2016

The support and goodwill of our community of supporters has allowed NEA to accelerate our reach to patients, caregivers, medical providers, policy makers, and I'm excited about our prospects in the years to come. NEA will help more individuals, and provide a strong voice on the national stage 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

ASSETS

Current assets:

Cash and cash equivalents	\$ 590,341
Investments	\$ 683,555
Accounts receivable	\$ 159,573
Prepaid expenses & other current assets	\$ 17,156

TOTAL CURRENT ASSETS \$ **1,450,625**

Fixed assets, net of accumulated depreciation	\$ 23,363
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TOTAL ASSETS \$ **1,473,988**

LIABILITIES & NET ASSETS

Current liabilities:

Accounts payable	\$ 35,508
Accrued vacation payable	\$ 13,957

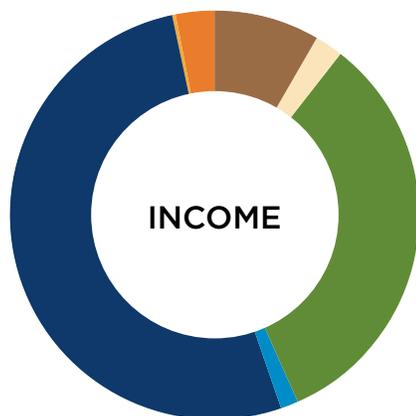
TOTAL CURRENT LIABILITIES \$ **49,465**

Net assets:

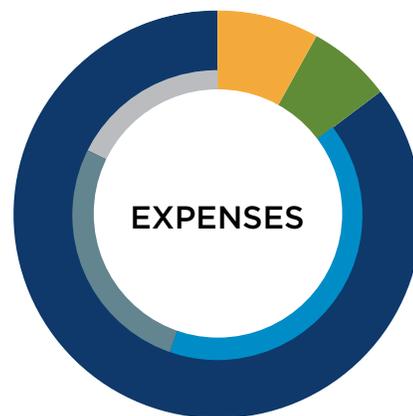
Unrestricted	\$ 1,424,523
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TOTAL NET ASSETS \$ **1,424,523**

TOTAL LIABILITIES & ASSETS \$ **1,473,988**



Individual Contributions/Grants	\$ 150,929
Grants	\$ 42,000
Service Program	\$ 595,304
Awareness Events	\$ 23,042
Forum Registration Fess	\$ 2,672
Alliance Partners	\$ 934,780
Brochures	\$ 5,045
Other	\$ 55,185
TOTAL INCOME	\$ 1,808,957



Administration (8.2%)	\$ 155,308
Fundraising (6.6%)	\$ 125,313
Programing (85.3%)	\$ 1,623,538
Support & Education (40.7%)	\$ 774,238
Awareness (26.9%)	\$ 511,400
Research (17.7%)	\$ 337,900
TOTAL EXPENSES	\$ 1,904,159



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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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