



2017 ANNUAL REPORT

FISCAL YEAR ENDING DECEMBER 31, 2017





Welcome.

National Eczema Association President & CEO, Julie Block, welcomes you in this brief video.



President & CEO, Julie Block
2017 Annual Report
Introduction

Mission

The National Eczema Association (NEA) is a nonprofit, 501(c)(3) organization with a mission to improve the health and quality of life for individuals with eczema through research, support and education.





Founded in 1988, NEA is governed by a national volunteer board of directors, comprised of people with firsthand experience of eczema. Our board includes patients, parents, doctors and nurses — all dedicated to helping to make the world better for people with eczema.

Our volunteer Scientific Advisory Committee is made up of the top researchers and clinicians in eczema. The advisory board guides us in research, patient and professional education and everything else related to eczema science and medicine.



2017



A TRANSFORMATIVE YEAR

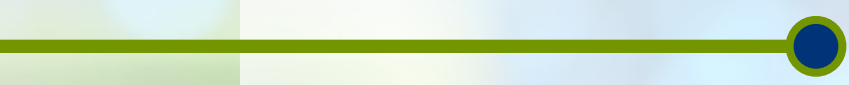
2017 marked the third year of our strategic plan to usher in a new era of care for all those impacted by eczema entitled “The Decade of Eczema: Roadmap to Advocacy.”

As you will read on the following pages, we made phenomenal progress on the five transformation keys. The specific areas of focus are as follows:

- Raise awareness about the seriousness of eczema and how it truly impacts lives.
- Educate medical providers to address the “whole” patient experience to improve health outcomes and equip them for a new era of care.
- 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.
- Focus research grants that establish the burden of disease and contributes to the evidence necessary to drive change.
- Advocate for accessible and affordable treatments.

Awareness Achievements





From Eczema Awareness Month to in person events, raising awareness is the first step to better understand the seriousness of this disease.

It was a banner year in 2017 as we grew our social media strategies, served as exclusive partners in national campaigns, and elevated the conversation surrounding the mental and emotional impact of eczema on our community's quality of life.

ECZEMA AWARENESS MONTH



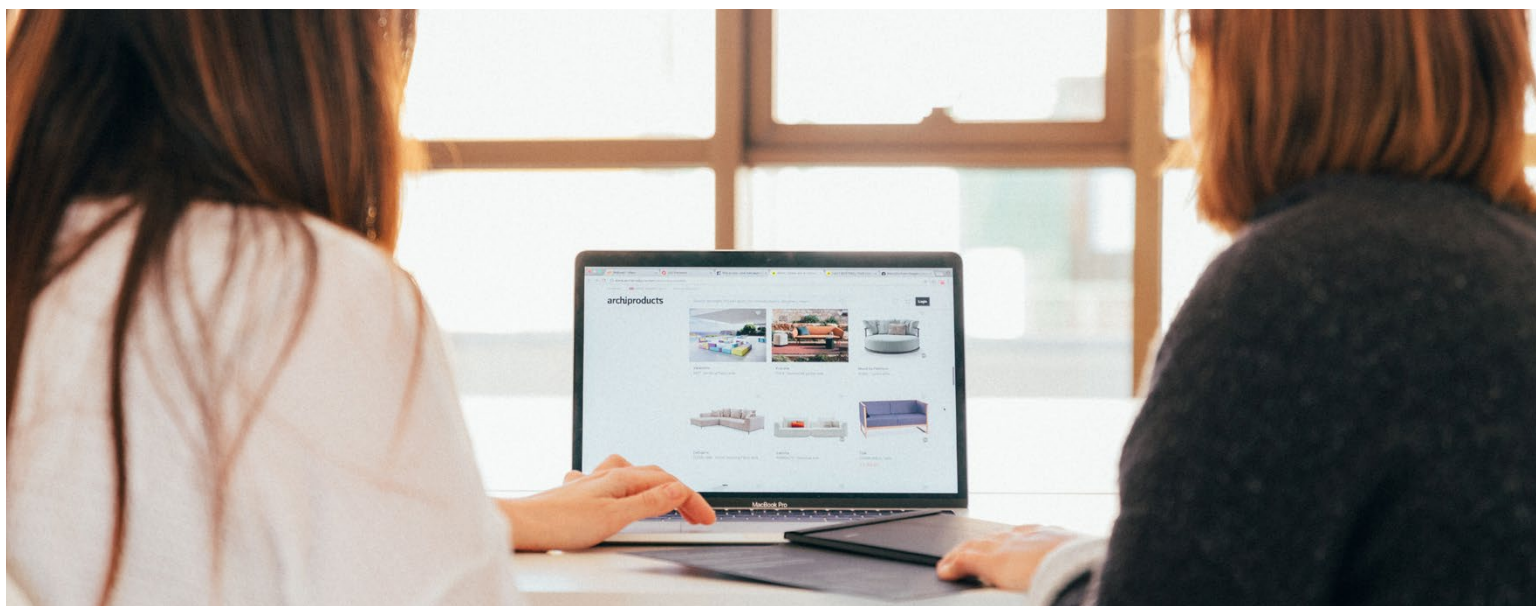
Our favorite part of Eczema Awareness Month was seeing members of the eczema community join the conversation and help spread awareness about eczema on Facebook, Twitter and Instagram using the hashtags #eczemamonth, #nationaleczema, and #bewellmindandbody.

Our theme for Eczema Awareness Month (EAM) 2017 was ***“Be Well: Mind + Body.”*** All month long, we gave our community the tools needed to live their best life with eczema, starting from the inside-out. After all, what’s a healthy body without a happy mind?

Special activities for EAM included:

- **WEEKLY EMAILS** detailing the connection between eczema and mental health and ways to support it. Starting with week one — Eczema: It’s more than skin deep — we look at the mental impact of eczema. Week two — The Science behind feeling lousy — we looked at the connection between inflammation and depression. Next up week three encouraged — Do try this at home — with tips for how to lower inflammation while boosting mental health. Our final week stated — It’s time to take action — calling for our community to step up and spread awareness of the impact of eczema.
- **A WEBINAR** featuring licensed clinical social worker Jennifer Moyer Darr titled “How to Be Well When You Don’t Feel Well: The brain body connection” helped us understand the impact eczema can have on mental health, and some coping techniques for managing the emotional component.
- **A FACEBOOK LIVE CHAT** with the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) with other National Institutes of Health (National Institute of Allergy and Infectious Diseases and National Center for Complementary and Integrative Health) spurred national conversation across fields of study.
- **LIVE FROM NEW YORK** it’s your eczema gurus! Direct from our Forum at Mount Sinai we went live with Emma Guttman, M.D. regarding the importance of engaging in clinical trials, Peter Lio, M.D. on complementary medicine with a specific acupressure point to help with itch, and Jennifer Moyer Darr, LCSW on psycho-social emotional coping and specifically what you can say instead of “Stop scratching!” There were over 6,000 views between the three live videos.
- Our **RAISE YOUR VOICE ADVOCACY CAMPAIGN** had 73 advocates send 457 letters to their representatives to tell them why eczema is important to them and asking them to name October as Eczema Awareness Month in their respective states.
- With **DAILY SOCIAL MEDIA POSTING** across channels NEA had nearly double our normal monthly new followers, and nearly triple the engagement.





IN YOUR WORDS SURVEY SERIES

2017 saw the continuation of our survey series “In Your Words” where we set out to learn more about the challenges people living with eczema face every day. While there were several highlights, one in particular struck our community, and was the basis for a national press release. Nearly one-third of people with atopic dermatitis report a diagnosis of anxiety/depression. This is over 20 percent higher than that of the general US population.



ITCHING FOR A CURE VIRTUAL WALK

For the first time in NEA history, our annual walk “Itching for a Cure” was held entirely virtually. With 166 virtual walkers registered and over \$17,500 raised throughout the month, it was a huge success. Many community members also hosted their own community walks from Hawaii to New York.

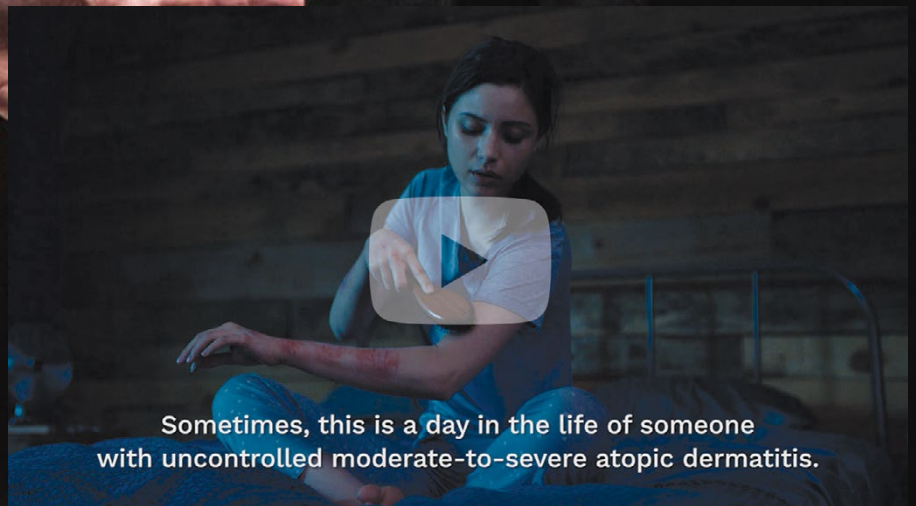
The NEA team brought their own weekly walks with NEA President and CEO Julie Block live on Facebook. Garnering over 3,600 views the live videos covered topics from advocacy to the importance of social media.

UNDERSTAND AD: A DAY IN THE LIFE

In its second year, Understand AD is a disease awareness campaign sponsored by Sanofi Genzyme and Regeneron. NEA served as the exclusive partner in this campaign for 2017, with the highlight being the video series Understand AD: A Day in the Life. Written and led by famed screenwriter Peter Moffat, this series is a powerful video and visual reminder of what daily life is like inside the home for people with AD.

By bringing AD out of the shadows, Moffat's goal was to start an important conversation that would shake up the status quo so that no one will continue to underestimate the disease or stigmatize the people who have it.

Moffat envisions this new conversation will change minds and hearts by engaging the media, schools, health care establishment, our elected officials and the public at large. The conversation Moffat has started is like a tapestry woven out of many disparate threads. The larger story is made up of countless small details that burden the lives of people with AD. NEA is proud to have been a part of this watershed moment.



Sometimes, this is a day in the life of someone with uncontrolled moderate-to-severe atopic dermatitis.

Education Accomplishments

To serve our mission of improving the health and quality of life of people living with eczema, it is foundational that we educate both medical providers and the patients themselves. From ensuring providers know about the latest treatments and best practices for treating eczema, to empowering patients to own their eczema care, NEA seeks to embrace the truth of living with eczema in the real world.





ECZEMA MATTERS MAGAZINE

You spoke. We listened. Our community told us they wanted more stories, more lifestyle articles and more tips for living with eczema. After taking these requests to heart and updating our website and e-newsletter in 2016, we applied the same efforts to our print magazine in 2017.

The magazine was rebranded from The Advocate to Eczema Matters and features a friendlier feel with more lifestyle information and community stories. Additionally, we launched our online magazine by the same name, ensuring all articles from the magazine, e-newsletter and more, are available on our website. Check it out at EczemaMatters.org!





COALITION UNITED FOR BETTER ECZEMA CARE (CUBE-C)

NEA has created a network of cross-specialty leaders to equip clinicians to succeed in the new era of eczema care, offering education and standards on effective treatment and disease management. We are exceedingly proud of NEA's education initiative, entitled Coalition United for Better Eczema Care (CUBE-C).

In 2017, eczema clinical and research leaders representing dermatology, allergy, immunology, pediatrics, family care and psychology, along with patient representatives, developed a holistic, patient-centered clinician education curriculum. A one-of-a-kind opportunity to improve health outcomes.

This patient-centered, up-to-date curriculum will be disseminated nationwide through a series of conferences and events in coming years. This is also an opportunity to diversify NEA's revenue as we enter the world of providing continuing medical education to healthcare professionals.

PHRMA CHALLENGE GRANT AWARD

NEA received the top prize of \$50,000 from the PhRMA Foundation's Value Assessment Challenge Award program. The submission, entitled "Improving Value for Eczema Patients," outlines NEA's leadership in the important area of patient care called Shared Decision-Making (SDM).

SDM is a model of care that recognizes patients as foremost experts in their own condition, and healthcare providers as experts in treatment and management of those conditions. With SDM tools and resources, these two experts can more effectively collaborate before, during and after patient appointments to improve health outcomes.

WEBINAR WEDNESDAYS

Our very popular Webinar Wednesdays feature medical experts discussing the latest in disease management, research, treatments and related information to live well with eczema. Each webinar is an hour in length, which includes time for participants to submit questions to the expert. Webinars are archived on the NEA website.

The six Webinars held in 2017 had over 6,000 registrants and included a range of topics including complementary and alternative treatments for eczema, introduction to biologics, the brain-body connection and newly diagnosed, to name a few.

LEADERS IN ECZEMA FORUMS

The Leaders in Eczema Forum series continued for its third year and included two daylong forums in Denver, Colorado and New York City. These one-day events provided an opportunity for individuals or caregivers of children living with eczema to come together and learn best practices for eczema management from experts, get coping strategies, understand new developments in eczema research, and meet other patients, caregivers and clinicians.

Forum speakers included a diverse range of experts and advocates including dermatologists, researchers, social workers and individuals living with eczema. We enjoyed meeting nearly 200 community members between these two local events.

SEAL OF ACCEPTANCE PROGRAM

Helping Eczema Patients Find Suitable Products For Over Ten Years

Appropriate skin care is the cornerstone of eczema care.

People with eczema, and those that care for them, often struggle to find products appropriate for their unique condition. NEA's Seal of Acceptance program is designed to help navigate the ocean of products available in a typical store. For over 10 years the Seal of Acceptance program has helped identify a variety of personal care and household product options created for people with eczema.

The program encourages and recognizes product innovations that provide benefits and improve the quality of life for people with eczema and sensitive skin. Through the program NEA is influencing the development of products for eczema patients.

The program got its start evaluating moisturizers and has since expanded to include a variety of product categories including cleansers, clothing and fabrics, hair care products, disposable wipes, household products and more recently sunscreens. At the end of 2017 over 200 hundred products have been accepted, with a renewal rate of 99 percent. Products are listed on the NEA website at EczemaProducts.org.



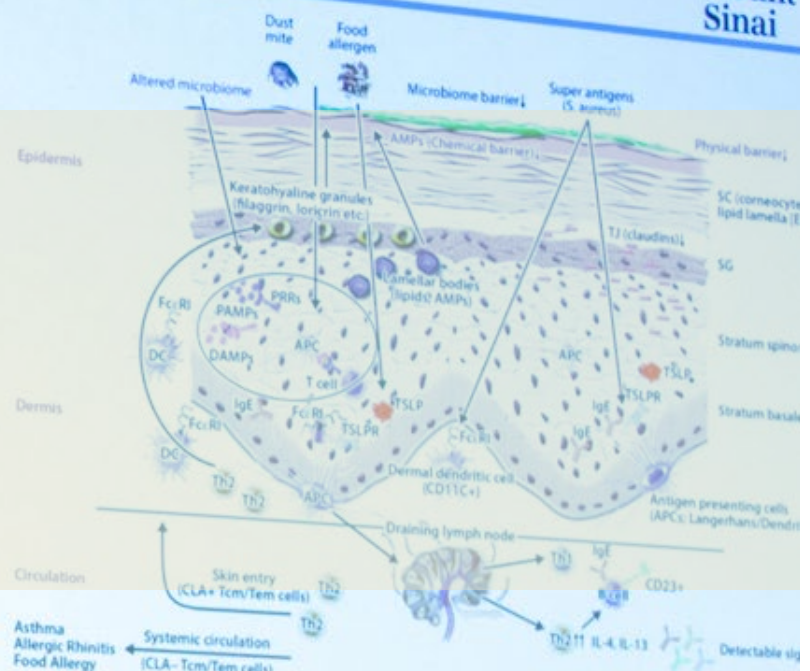
Research Accomplishments

The groundswell of scientific advancement related to eczema is growing, bringing with it a need for stewardship and support for research that will yield new scientific insights of importance from the patient perspective. **For the millions of individuals with eczema and their families, research is the foundation of hope for a better tomorrow, and empowering knowledge for today.**



What happens in AD?

- Skin barrier is compromised
- Allergens and irritants (including staph proteins) can thus readily penetrate into deeper layers of the skin
- Activation of the immune system
- More damage to the skin barrier
- Immune cells accumulate in the skin (Th2, Th22 and some Th1, Th17) and migrate to other organs to initiate the atopic march



Czarnowicki T, Krueger JG, Guttman-Yassky E. JACI 2017

NEW BREAKTHROUGHS IN ECZEMA TREATMENT

For many years there were few treatment options available for people with eczema, including those with a severe and chronic form of eczema, atopic dermatitis (AD). After more than a decade without any new therapies, in mid-December 2016, and then again in March 2017, the U.S. Food and Drug Administration (FDA) approved two new drugs for the treatment of AD.

Eucrisa® (crisaborole), is a new topical non-steroidal treatment for adults and children age two years and older with mild to moderate AD. Dupixent® (dupilumab) is the first biologic medicine approved for the treatment of adults with moderate to severe AD.

The approval of these two new drugs signals the beginning of a new era with a focus in eczema research and clinical trials. With more than 100 new potential therapies currently being investigated, additional future treatment options for eczema are promising.

DRAFT GUIDANCE FOR PEDIATRIC ATOPIC DERMATITIS CLINICAL TRIALS

In March 2015, NEA participated in a U.S. Food and Drug Administration (FDA) hearing regarding the inclusion of children in atopic dermatitis (AD) clinical trials. Because of the testimony NEA provided at this hearing, the FDA recognized the unmet medical need for children with moderate to severe AD and unanimously supported future inclusion of these children in clinical trials.

In response to this groundbreaking decision, and in partnership with the Pediatric Dermatology Research Alliance (PeDRA) and the International Eczema Council (IEC), NEA contributed to the development of a draft guidance document for industry. Submitted in June 2017, this document will foster and guide the development of safe and effective drugs for infants, children and adolescents age three months to <18 years of age.





A woman with short grey hair and glasses is speaking into a microphone. She is wearing a dark jacket over a white top and a patterned scarf. Her right hand is holding the microphone, and her left hand is open and gesturing. She is standing behind a dark podium. On the podium, there is a laptop and a gooseneck microphone. The background is a light blue wall.

PEOPLE ENGAGED IN ECZEMA RESEARCH (PEER)

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

PEER connects patients with research by keeping an up-to-date list of current trials on our website, sending location-specific recruitment emails when participants are needed, sharing articles on the current research results, and providing the patient voice to the companies engaged in eczema research.

Today, hundreds of people living with eczema and their caregivers are working to further eczema research through the PEER program. Participants directly impact the future of eczema research by participating in clinical trials, submitting confidential surveys, partnering with industry to create patient-centered clinical trial protocols, and joining our advocacy efforts. Keep your eyes out for the PEER logo on emails and the NEA website to let you know when and how you can get involved.

NEA'S RESEARCH GRANT PROGRAM: INVESTING IN KNOWLEDGE AND HOPE

Through the NEA Research Grant program, the hope and desire for heightened awareness is channeled into seed funding for researchers with innovative efforts that will increase our scientific and clinical understanding of eczema, as well as its many impacts on individuals and their families.

In 2017 NEA awarded two innovative grants whose findings will foster a deeper appreciation of the diversity of people with eczema, the burden of the condition, and identify opportunities to improve patient health and quality of life.

MEET OUR 2017 GRANTEES

**Junko Takeshita,
M.D., Ph.D., MSCE**

University of Pennsylvania, Perelman
School of Medicine

*The burden of atopic dermatitis
among the medically underserved*



Atopic dermatitis (AD) is common across different races and ethnicities; however, little is known about AD among minorities, and few opportunities exist to study it in minority and medically underserved populations.

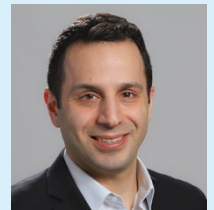
As a result, these individuals are underrepresented in the scientific literature and our understanding of AD among them is poor. To address this barrier, this research aims to identify individuals with AD from a racially and ethnically diverse, socioeconomically disadvantaged, and medically underserved population in North Philadelphia.

These residents will be surveyed to better understand and compare their AD disease and quality of life burdens, and the medical care received for AD by race and ethnicity. The information from this work will further our understanding of AD in minority and underserved populations and identify any disparities in the burden of and care for AD, with an overall goal of improving the lives of an underserved group of individuals with this chronic skin disease.

**Aaron Drucker,
M.D., Ph.D.**

Women's College Hospital, Ontario

*Risk of suicide associated
with atopic dermatitis
in Ontario, Canada*



Atopic dermatitis (AD) has a tremendous psychosocial burden, and has been associated with various mental health conditions, including depression and anxiety. No studies to date have looked at the relationship between AD and suicide in North America and no studies have included youth, despite AD being more common in young people.

This study will investigate the risk of death by suicide associated with AD among people aged 15-55 in Ontario, Canada. This study will use available coroner data to compare a group of patients who committed suicide with a control group that did not, and evaluate them for a diagnosis of AD, as well as frequency of physician visits.

The results from this work will allow an estimation of if, and by how much, AD increases the risk of suicide, as well as potentially identify an important opportunity for intervention.

Advocacy Accomplishments

The objectives of NEA's advocacy program are to increase awareness of the seriousness of eczema among policy makers and improve eczema patients' access to the medical interventions and services that they need to improve their health and quality of life. 2017 was the inaugural year of NEA's advocacy program entitled "Raise Your Voice," during which we made solid progress in each of the three main advocacy domains that comprise our overall strategy: Policy Development, Direct Advocacy and Grass Roots Advocacy.





POLICY DEVELOPMENT

NEA's policy development goals for 2017 were to establish the internal mechanisms for evaluating and adopting formal positions on public policy initiatives impacting the health and welfare of eczema patients. To this end, NEA took several significant actions.

NEA's board of directors adopted policy positions related to increasing awareness of eczema among policy makers.

- NEA supports initiatives that propose to increase federal funding for eczema and related research.
- NEA supports initiatives that document eczema's disease burden on individuals, public health and the economy in general.
- NEA's board of directors also adopted policy positions on four policy issues impacting eczema patients' access to health services and interventions.
- Step-therapy — Insurer cost control measures that require patients to fail on drugs before being able to access the medicine prescribed by their physicians.
- Out-of-pocket expenditures — The costs that patients have to pay at the doctor's office and at pharmacy counters for prescription and over-the-counter medications.
- Prior authorization — The processes insurers can make patients go through before agreeing to cover medications.
- Network adequacy — The standards governing the balance of providers that insurers must offer to patients.

DIRECT ADVOCACY

NEA conducts direct advocacy through its participation on issue-based coalitions, by directly testifying on public policy initiatives, and speaking to public officials. During 2017 NEA took the following direct advocacy actions:

- NEA joined five national coalitions and six state coalitions.
- The five national coalitions focus on step therapy, prior authorization, out of pocket costs, and federal funding for eczema research.
- The six state coalitions focused on step therapy initiatives in Texas, Iowa, Virginia, and New York; and prior authorization initiatives in Minnesota and Kansas.
- Step therapy initiatives passed in Texas and Iowa.
- NEA submitted written and oral testimony to the Institute for Clinical and Economic Review (ICER) concerning the value of Dupixent. ICER reviewed and published a report on the value of two new drugs for the treatment of AD in May 2017.
- Dupixent is the first in a class of medications called biologics to be FDA approved for moderate to severe atopic dermatitis. This "value assessment" determined that Dupixent's cost, though significant, provides sufficient quality-of-life improvements for patients to justify its coverage by insurers.

GRASSROOTS ADVOCACY

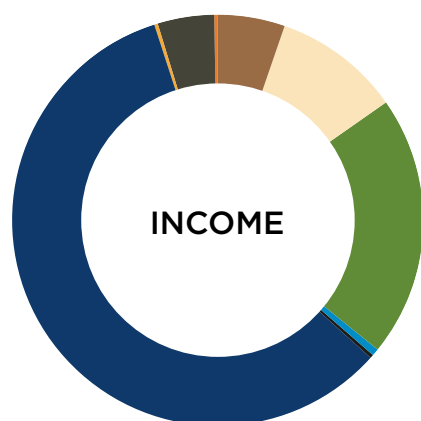
NEA involves its members in advocacy through its grassroots advocacy program. NEA made great strides in recruiting and activating members.

- One of NEA's grassroots advocates in the state of Louisiana successfully lobbied the Louisiana Legislature to declare October as Eczema Awareness Month. This exposure helped spread awareness that eczema deserves public attention and has a serious impact on the lives of patients and families.
- NEA recruited 343 grassroots advocates – 14.3 percent over target of 300 for 2017.
- “Raise Your Voice” supports our NEA grassroots advocates across the country as they engage their local, state and federal representatives in advancing public policy.
- NEA is poised to collect the data and evidence necessary to impactfully report the seriousness of the disease and ensure that payers cover new innovations as they come to market.

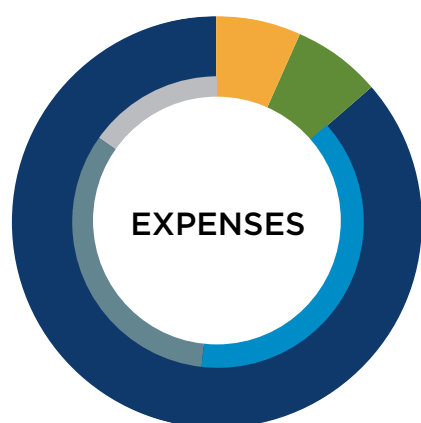


Financials

STATEMENT OF ACTIVITIES YEAR ENDED 2017



Individual Contributions/Grants	\$ 180,978
Grants	\$ 340,143
Service Program	\$ 683,027
Awareness Events	\$ 24,339
Forum Registration Fess	\$ 3,150
Corporate Sponsorships	\$ 1,878,750
Publications & Brochures	\$ 86,832
Investment Income	\$ 150,226
Other	\$ 6,138
TOTAL INCOME	\$ 3,353,583



Administration (6.8%)	\$ 132,099
Fundraising (7.0%)	\$ 136,938
Programming (86%)	\$ 1,689,633
Support & Education (38%)	\$ 746,352
Awareness (33%)	\$ 645,312
Research (15.2%)	\$ 297,969
TOTAL EXPENSES	\$ 1,958,670



President & CEO, Julie Block
2017 Annual Report
Financial Report

ASSETS

Current assets:

Cash and cash equivalents	\$ 1,262,312
Investments	\$ 1,420,538
Accounts receivable	\$ 160,450
Prepaid expenses & other current assets	\$ 12,689

TOTAL CURRENT ASSETS **\$ 2,855,989**

Fixed assets, net of accumulated depreciation \$ 12,827

TOTAL ASSETS **\$ 2,868,816**

LIABILITIES & NET ASSETS

Current liabilities:

Accounts payable	\$ 26,078
Accrued vacation payable	\$ 23,302

TOTAL CURRENT LIABILITIES **\$ 49,380**

Net assets:

Unrestricted	\$ 2,630,103
Temporarily Restricted	\$ 189,333

TOTAL NET ASSETS **\$ 2,819,436**

TOTAL LIABILITIES & ASSETS **\$ 2,868,816**

2017 NEA Board of Directors

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Emeryville, CA

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Accountant
Corte Madera, CA

CYNTHIA KIM, *Chief Financial Officer*
Financial Analyst
Burbank, CA

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THANK YOU

NEA Donors, January 1, 2017 – December 31, 2017

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\$25,000 to \$49,000

Elizabeth Hoff
Katherine & Sean Keenan

FOUNDATIONS:

The Gayden Family Foundation, Houston, TX

SILVER BENEFACTORS

\$10,000 to \$24,999

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\$2,500 to \$4,999

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Florence Lee
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Dinesh Shenoy
Don & Laila Young

THANK YOU

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\$1,000 to \$2,499

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\$250 to \$499

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