



NATIONAL  
**Eczema**  
ASSOCIATION



# 2013 ANNUAL REPORT

FISCAL YEAR ENDING DECEMBER 31, 2013

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VOICE *of the* ECZEMA PATIENT

# VOICE *of the* ECZEMA PATIENT

## Dear NEA Friends and Supporters,

We couldn't be more pleased with the momentum and accomplishments achieved in the year 2013. We have stayed laser-focused on our Mission:

**Improving the health and quality of life of individuals with eczema through research, support, and education.**

On the research front, 2013 was a record year for our investments. We funded \$124,600 for 4 diverse research subjects. Some of the topics included improvements in skin barrier function and better understanding how changes in the immune system can lead to skin disease. Additionally, we funded some investigations that address topics such as improvement in eczema through meditation, and using the power of patient-driven data to assist in guiding research.

We are proud of the increased support and education NEA has given to our patient community. We've fully embraced social media to allow us to touch more people. Our Facebook site has grown to reach over 12,000 NEA Facebook Friends weekly. It's so rewarding to see our eczema community sharing and educating one another on best practices, products that work for them, new clinical trial information, and tips they've learned through care of their skin. Just seeing the interchange among our friends convinces us that lives are improving daily due to these conversations. If you haven't liked us on Facebook, please do!

One area of particular note in 2013 is the growing leadership role of NEA as the "Voice of the Eczema Patient." We speak with eczema patients and families every single day. We understand eczema and the challenges that are both physical and emotional. This knowledge has allowed us to be YOUR voice with many different stakeholders such as large pharmaceutical companies developing new therapies, physician associations, and government agencies. Advocating for you and pushing for greater improvements in eczema care is front and center to all our efforts. We want others to know that eczema has a severe impact on our lives, and that it's "not just a rash." Through our advocacy, we have seen dramatic growth in public understanding of eczema, and in investments to bring new eczema therapies to market. These future therapies offer real hope that we can both better treat, and ultimately cure, eczema.

We thank you for your continued support of NEA and encourage you to stay in close touch with us. The future has never been brighter!

Warm Regards,



Julie Block  
President & Chief  
Executive Officer



Elizabeth Hoff  
Chair,  
NEA Board of Directors

"NEA has had a significant impact on my life and the way I look at my condition."

*-longtime NEA supporter*

"Words will never be adequate enough to express my gratitude to you, NEA, and what you've given my family... The only way that I feel that I can adequately say thank you is by doing my best to educate others about eczema."

*-2013 Itching for a Cure participant*



# SPEAKING UP *for* ECZEMA PATIENTS



## KEY ACCOMPLISHMENTS FOR 2013

Our second annual **ITCHING FOR A CURE WALK** — the only dedicated walk for eczema — was held with much success in New Jersey. 256 walkers and 30 corporate partners participated in person, with many more “virtual” walkers taking part. *The result? \$85,000 in walk donations, increased eczema awareness, and immeasurable fun!*

We increased the number of **NEA DONORS** by 10%.

The CEO, staff, and board members met with 7 **PHARMACEUTICAL COMPANIES** developing new eczema treatments (20 total meetings) to ensure that eczema patient voices are heard. Discussions revolved around quality of life, current limitation of treatments, how to reach eczema patients when new therapies are launched, and NEA's role in getting information out about ongoing clinical trials. *We're proud to represent you in discussions about new, exciting therapies, and cures.*

NEA was active at 10 **MEDICAL MEETINGS** around the world that focused on eczema and skin diseases. At these meetings, the NEA staff and board members **MET WITH TOP PHYSICIAN LEADERS WHO SPECIALIZE IN ECZEMA** to discuss how to better educate community dermatologists, allergists, and other health care professionals on eczema care. *We recognize that many doctors treat patients with eczema and one of our goals is to spread the word to community physicians about the best, most recent treatments.*

NEA has been advocating for a smallpox vaccine that is safe for people with compromised immune systems, including people with eczema. *We are pleased to note that **DELIVERY OF A SAFE VACCINE** has now been added to the national stockpile of emergency vaccines and other drugs.*

NEA participated with other members of the Coalition of Skin Diseases at the **AMERICAN ACADEMY OF DERMATOLOGY'S LEGISLATIVE DAY ON CAPITAL HILL**. NEA raised its voice to US Policymakers asking for more funds to be allocated for skin disease research. *Our CEO, Julie Block, met with many congressional representatives advocating for research toward skin disease cures and therapies.*

October 2013 was our 10th annual **ECZEMA AWARENESS MONTH**. During the month an impactful *Eczema: Spread the Word* campaign focused on helping individuals share how they feel about eczema to increase understanding of this disease and help eczema patient voices be heard. *The campaign reached millions of Americans, spreading understanding about what it's like to live with eczema and increasing eczema awareness.*

NEA launched a new, complete kit of **ECZEMA: TOOLS FOR SCHOOL** to help parents and educators give children with eczema the best possible school experience. *Guides for educators and parents are available to help children navigate the very challenging school-age years. Visit [tfs.nationaleczema.org](http://tfs.nationaleczema.org) to request a copy.*

NEA partnered on the new **ECZEMA APP** that was launched allowing patients and parents to track symptoms, flares, triggers, and keep summaries to share with their doctors.

The **NEA SEAL OF ACCEPTANCE™** has become THE recognized standard for products which have the most accepted, least reactive ingredients for eczema patients. In 2013, 28 additional products underwent our rigorous review and were awarded our Seal of Acceptance™. *Due to our breadth and review of products most suited for eczema, we have been in discussions with large retail pharmacies to better serve eczema patients — including Eczema Care Centers. Very exciting!*

# MAKING *the* ECZEMA VOICE HEARD

## 2013 BY THE NUMBERS

256

number of participants in the New Jersey Itching for a Cure walk held in June



1,296

individual donors in 2013

18

drugs that are currently in US clinical trials to treat eczema

4

new research grants funded in 2013

\$85,000

funds raised from the 2013 Itching for a Cure walk



\$166,380

dollars raised by individual donors in 2013... a 29% increase over last year



19

physician experts who sit on NEA's Scientific Advisory Committee

96

products that have been granted and bear the National Eczema Association Seal of Acceptance™

60,000

readership of NEA's award-winning quarterly magazine, *The Advocate*



60+

meetings with pharmaceutical companies and eczema product manufacturers to represent YOU!

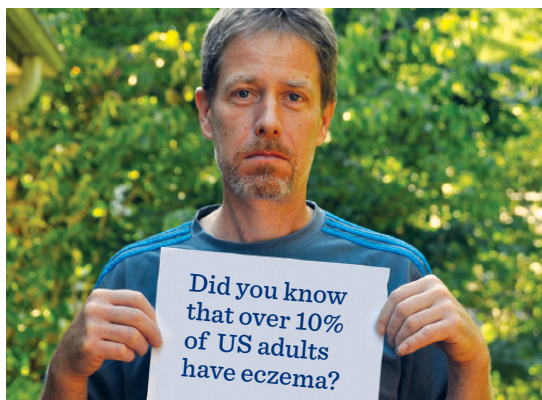


5

dedicated NEA staff members who get up every day wanting to make a difference in eczema patients' lives

15

cities where active support group leaders are helping people cope with eczema



### ***Thank you to our Donors!***

Annual giving provides NEA with critical financial support to meet its annual operating needs. We rely on annual giving to fund our operating budget, and those unrestricted dollars support every aspect of NEA, from patient conferences, to building rental and utilities, to vital program needs that further our mission to support and educate our eczema family. Annual giving is the single most important way for our friends and those interested in our mission to help sustain the National Eczema Association. Thank you!

# VOICING THE NEED *for* ECZEMA RESEARCH

## NEA'S CONTINUED COMMITMENT TO RESEARCH IN 2013

The National Eczema Association (NEA) provides grants for patient-oriented eczema research and serves as a catalyst for millions of dollars of additional eczema research. NEA first began to directly fund eczema research in 2004.

**NEA has awarded approximately \$500,000 to research that is focused on topics important to the eczema patient and their loved ones:**

*itch • infection • skin barrier • prevention*

NEA's research program offers hope for better treatment and a cure.

Research topics NEA has funded include\*:

- The Role of the Skin Barrier in the Development and Prevention of Atopic Dermatitis
- The Effect of Visual Stimuli on Itch Perception Intensity
- Why Do Subjects with Atopic Dermatitis have a Barrier Defect in the Skin that Makes them More Susceptible to Skin Infections?
- Topical Calcineurin Inhibitors for Atopic Dermatitis: Balancing Clinical Benefit and Possible Risks
- Do Alopecia Areata and Atopic Dermatitis Share HLA Alleles and Cytokine Profiles?
- A Genome-wide Analysis of Atopic Dermatitis
- Supraspinal Processing and Quantitative Assessment of Sensory Features of Itch in Atopic Eczema

*\*For a full listing of NEA Research Grants and final reports, please visit our website at [nationaleczema.org](http://nationaleczema.org)*

NEA is committed to advancing eczema research at every turn. Throughout the year, NEA consistently works in different areas to support eczema research advancements to make a difference in your life:

- Advocates for more funding at the National Institutes of Health (NIH)
- Provides you with the latest eczema research news from around the world
- Collaborates with a variety of research groups, including the Pediatric Dermatology Research Alliance (PeDRA), Harmonizing Outcomes Measures for Eczema (HOME), and the World Congress on Itch

Thank you to our NEA community for making this progress possible!



NEA-funded researcher Pranab K. Mukerjee, PhD in his lab



NEA-funded researcher Nelissa Perez-Nazario, PhD working with a patient in her clinic



# VOLUNTEER VOICES MAKING *a* DIFFERENCE



## THANK YOU TO ALL NATIONAL ECZEMA SPECIAL VOLUNTEERS FOR 2013

We are blessed with the best volunteers. Our volunteers this year have gone above and beyond and have made such a difference to our eczema family. The following is not everyone who has volunteered but we wanted to call out Support Group Leaders, Itching for a Cure walk participants, and select individuals who have embodied the spirit of giving through their events and activities in 2013. Thank you for your commitment and for spreading the word!



Barjes Angulo  
The Batten family  
Lauren Bendiksen  
The Blanton Family  
Chelsea Bolton  
Donna Bost-White  
The Boyon Family  
Linda Cardinale  
Kim Cee  
Mikey Chapman  
Lisa Choy  
Irene and Phil Crosby  
The Czopkiewicz Family  
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Gabi Mehta  
The Munge Family  
Dr. Sonal Patel  
Amanda Roland  
Jack Selden  
The Silver Family  
Melodie Tao  
Viviane Theodorakis  
GwenDolyn Yarborough-Hall



## 8 WAYS YOU CAN HELP NATIONAL ECZEMA BE A LOUDER VOICE!

1. Like us on Facebook.
2. Join us for the October 5th, 2014 Itching for a Cure walk in Los Angeles.
3. Ask your doctor if you can place/replenish NEA Patient Brochures in their waiting room.
4. Donate to help support more research and education.
5. Try products which proudly display the National Eczema Seal of Acceptance™.
6. Host an Itching for a Cure fun walk in your community.
7. Become a local NEA Support Group Leader.
8. If you're a Federal Employee, you can support NEA through payroll deductions. NEA's CFC number is 66644.

# YEAR ENDED DECEMBER 2013

## STATEMENT *of* ACTIVITIES

### ASSETS

#### Current assets:

Cash and cash equivalents	\$ 459,180
Marketable securities	89,118
Prepaid expenses	30,458
<b>TOTAL CURRENT ASSETS</b>	<b>578,756</b>

Fixed assets, net of  
accumulated depreciation: 28,571

<b>TOTAL ASSETS</b>	<b>\$607,327</b>
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### LIABILITIES AND NET ASSETS

#### Current liabilities:

Accounts payable	\$ 0
Research Grants payable	5,000
Accrued vacation payable	8,146
<b>TOTAL CURRENT LIABILITIES</b>	<b>13,146</b>

#### Net assets:

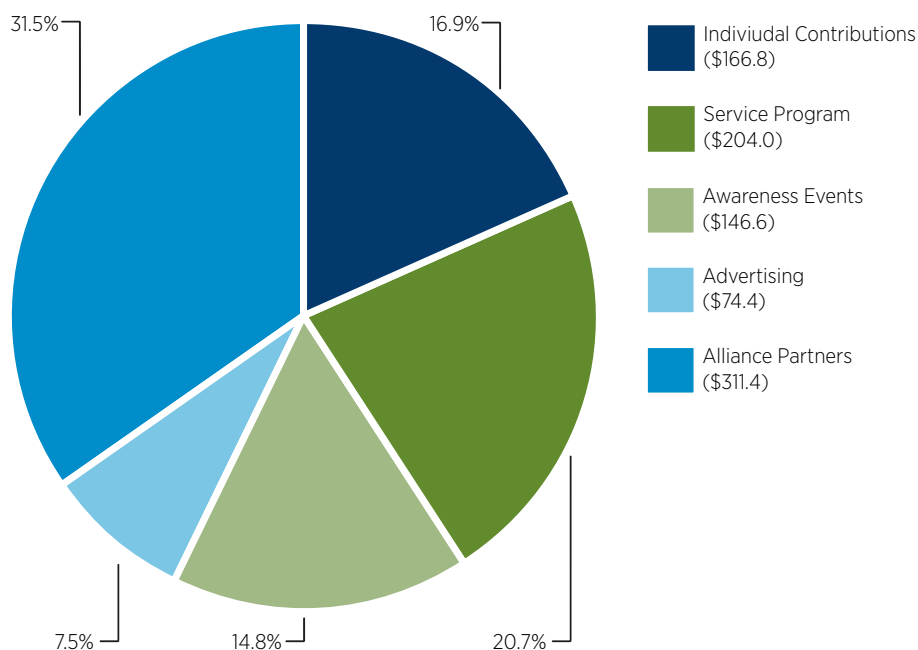
Unrestricted, undesignated	584,941
Temporarily restricted	9,240
<b>TOTAL NET ASSETS</b>	<b>594,181</b>

<b>TOTAL LIABILITIES &amp; ASSETS</b>	<b>\$ 607,327</b>
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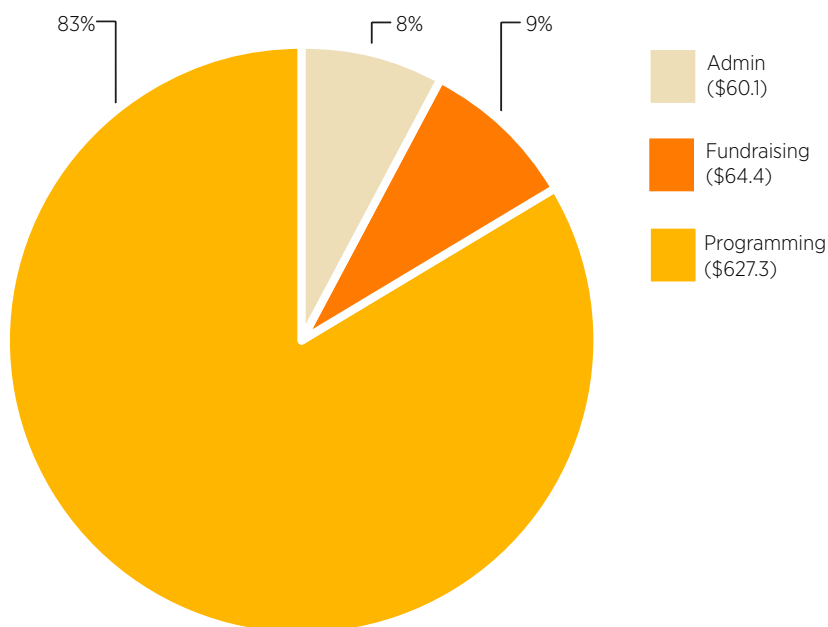
The National Eczema Association (NEA) experienced successful growth in 2013. Our wonderful Board members, volunteers, donors, Alliance partners, and staff worked together continuing to support NEA's mission.

Our partnerships with a variety of stakeholders in the eczema landscape provide support for NEA programming. It is testament to the advocacy reach of the eczema patient voice represented by NEA.

### INCOME



### EXPENSES



The Statement of Financial Position of the National Eczema Association as of December 31, 2013 was audited by R.J. Ricciardi Certified Public Accountants. A copy of the complete report, including notes, is available for public review from the National Eczema Association, 4460 Redwood Highway, Suite 16D, San Rafael, CA 94903-1953 or on the website at [nationaleczema.org](http://nationaleczema.org)



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**Scott Sanford** Seal of Acceptance Program Director

**Alexandria Lindsay** Program Associate

**Christine Anderson** Office Manager



2013 Board of Directors (l to r) Carolyn Reese, Jamie Huber, Lisa Choy, Susan Lipworth, Elizabeth Hoff, and Jon Hanifin, MD. Not pictured: Uma Arumugam, MD, Eric Kageyama, Cynthia Kim, Dinesh Shenoy, Carl Siminow, and Donald S. Young, JD.

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# JANUARY 1, 2013 - DECEMBER 31, 2013

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# JANUARY 1, 2013 – DECEMBER 31, 2013

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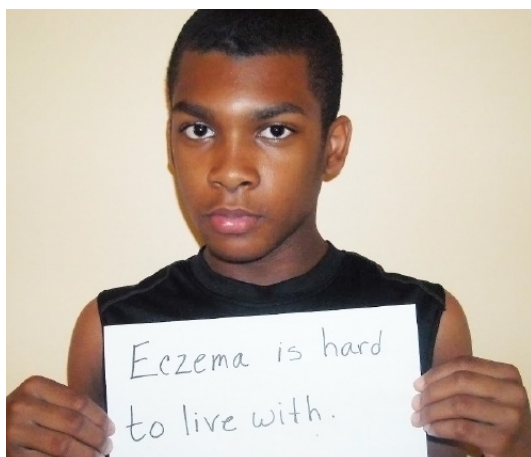
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