



# THE DECADE OF ECZEMA

A Roadmap to Advocacy for the National Eczema Association

## EXECUTIVE SUMMARY

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**This report was created to help the staff and volunteer leaders of the National Eczema Association prepare to capitalize on a coming sea change in the treatment of the disease. In the pages of this Roadmap, readers will find a bold plan intended to guide NEA through this transformative moment in the history of treatment and care of eczema, and emerge prepared to expand the organization's impact in multiple directions.**

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The Roadmap is a call to action to unify and stand up for patients, to pull back the curtain on eczema, a long silent and under-served disease, by revealing that the disease not only damages the skin, but also breaks apart lives and still further, poses serious public health risks.

NEA as an organization is strong, enjoying loyalty and credibility among stakeholders. Those same stakeholders also have high hopes that NEA can make the most of the opportunities ahead. The release of promising new therapies that are part of an emerging healthy pipeline of new eczema drugs can bring attention to the burden and reality of living with eczema, and, with the support of a strategically engaged NEA, can bring real promise to patients who have spent decades with no real advancement in care.

Through a process of consultative conversations and surveys with a comprehensive sampling of stakeholders representing a range of backgrounds (staff, patients, patient families, volunteers, physicians, researchers and industry representatives), and informed by the Roadmap companion document *Assessment of Stakeholder Interviews*, a blueprint plan of action has been created that turns on **Five Transformation Keys**.



# FIVE TRANSFORMATION KEYS

## KEY 1: BREAKING THROUGH STEREOTYPES – A NEW PUBLIC UNDERSTANDING OF ECZEMA

Lack of public awareness is a major barrier for patients as it fuels ignorance, which in turn fuels stereotypes about eczema. The Roadmap proposes that one of NEA’s priorities is to create a new fundamental understanding of eczema among the public, including patients, their families and friends, and health care professionals, through a comprehensive and national communications campaign. Raising general public awareness of eczema will feed into the success of other Roadmap strategies in the medical, patient and policymaker communities. Further, a high-profile campaign will position NEA as the driving force of these changes and a leader among its alliances. And finally, through public messaging and broader outreach, the campaign will also provide a mechanism through which NEA can broaden its base.



The success of this campaign will depend on a well-executed plan, and upon clear data that articulate and demonstrate the burden of disease at the individual and population levels. Essentially, eczema matters because of its cost to the patient and to society.

“One of my students has eczema and the parents are overwhelmed. A social worker was going to turn in the parents because she thought they were not taking care of their daughter’s skin! I said, ‘Don’t second-guess this poor mom because of your lack of awareness about eczema!’”

- Parent of eczema patient

Communications specialists will mount a campaign for maximum visibility that will rise above other media “noise,” and change the back-story that most people have in mind when they think of eczema today.

## KEY 2: EQUIPPING ECZEMA MEDICAL PRACTICES FOR THE NEW ERA OF CARE

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Various medical specialties treat eczema patients yet care is largely fractured and uncoordinated. Emerging drugs are turning the medical system's attention to eczema and there is an ideal opportunity to carve out a new model. Key 2 calls for NEA is to create and activate 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.

“Eczema is a huge challenge. People still come in to find a quick fix. Actually, eczema is chronic, long term and has ups and downs. There are so many components to this disease— inflammation, itch, skin barriers, colonization bacteria hanging out in skin, food & dietary elements ... and more. We have to deal with all that in a 10-min visit, as well as fight myths around steroid addiction/safety.”

- Dermatologist and medical acupuncturist

This will be achieved through a NEA-convened coalition that we call **the Coalition United for Better Eczema Care (CUBE-C)**. NEA would build CUBE-C through collaborating with professional societies representing dermatology, allergy, and other disciplines of physicians and health care professionals that treat patients with eczema. The coalition would be charged with, in part, creating medical professional educational curricula and events, and authoring, compiling and/or disseminating and publishing treatment protocols based on newer models of care and available as well as emerging therapies.

## KEY 3: PROMOTING NEW MODELS OF CARE TO BETTER LEVERAGE RESOURCES.

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Home maintenance and treatment compliance are so important to successful eczema care yet there are extensive inconsistencies in medical offices approaches and, a network of ancillary professionals, both in-office and community based, are not being leveraged to “reach and teach” the patient effectively. NEA is in a unique position to promote new models of eczema care that are outside traditional spheres of practice and that leverage a broader range of resources. Because eczema is so often present with comorbid conditions, improved coordination of care is an integral part of better care for patients, and

holistic/comprehensive approaches are important to successful treatment. As the natural convener of experts, NEA can help to develop and promote a model that calls on in-office physician extender personnel (nurses, physician assistants) and community based personnel (e.g., mental health and social workers,) to define a model of care that extends from the office into the homes, schools and communities of eczema patients.

Calling on relevant professional societies, NEA would convene a network of leaders to form an alliance called **Partners in Eczema Care (PIE-C)**. Examples of products of this group's work are "extender" treatment practices, as well as community kits on eczema care usable in the home, school and office.

#### KEY 4: FOCUS NEA'S RESEARCH AGENDA WHERE THERE IS HIGH VALUE/YIELD FOR THE INVESTMENT

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 a patient perspective. The Roadmap calls on a reinvigorated Scientific Advisory Committee to **develop and guide a strategic focus for NEA's investment in medical research**. Inherent here is the notion that NEA's allocation to research should grow commensurate with increased funding of the organization, which will come to pass as the Roadmap unfolds and NEA expands.



Research support should be directed where NEA can play a unique role, where the value of the research has most impact, or should be directed to early-concept work that shows promise. Targeting support in this way yields exponential benefits, as promising research supported early potentially becomes a "leg up" for more substantial funding from sources such as the National Institutes of Health.

“Everyone presents this disease differently, responds differently, cycles through it differently. Can we better understand genetics, how the disease works, and then define and translate into ways of coping and medically treating? I don't think there is just one eczema.”

- Member, NEA Board of Directors and eczema patient

There is also vast need for data and evidence – for a more serious body of work – that establishes the burden of disease. An additional critical area of focus for NEA is fostering and disseminating research that proves that eczema is serious and matters. **NEA must become the steward of burden of disease research.** No one else will.

Also, NEA should **invest in the future of eczema science** through supported Fellowships for early career investigators at institutions, as well as through career grants for work that will greatly influence the field in this way, helping to expand the research pipeline for future innovation.

## KEY 5: ADVOCATING FOR ACCESSIBLE AND AFFORDABLE NEW TREATMENTS

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With new eczema treatments on the horizon, there is the sterling opportunity to get out ahead of the drug rollout, anticipate the barriers to come for patients, and intervene early to ensure access to these new treatments. The Roadmap directs this advocacy to the private insurance and regulatory sectors.

First, NEA should advocate for the development of data and evidence that will prove the burden of eczema and its comorbidities, and measure the impact eczema has on the health system and on society as a whole. NEA will be funding this type of research (see Key 4) and this strategy is a good complement to that focus. NEA’s Scientific Advisory Committee will be a key resource for developing this body of work, as will other interested investigators and epidemiologists focused on this topic.

Also important is building consensus among eczema experts regarding disease severity and appropriate use of available therapies. This will help insurers understand why different patients need different treatment plans, and ensure that patients who do need new answers have access to different or more sophisticated treatments. Data and metrics will incentivize insurers and medical professionals to treat according to the standard of care. In affecting change and creating new policies that improve life for patients, **advocacy and science walk hand in hand.**

"If people around you know more, it reduces the stigma, and if payers make treatments affordable or more affordable, and if the treatment works, then you begin to have a world that isn't perfect, but is becoming better."

-Pharmaceutical industry representative

NEA’s role is also to educate private insurers about the serious nature of eczema and its consequences when not treated adequately or appropriately. Drawing on medical advisors, and pursued in a professional and collegial manner, this

advocacy helps insurers understand how policies may be onerous and exclude too many patients, and how those policies may result in greater longer-term cost for other areas of healthcare that they also insure.

Affordability of treatments is increasingly an insurmountable barrier both because of high pricing of medicines as well as the prevalence of high-deductible insurance plans that increasingly shift the burden of cost to patients. Tackling affordability of treatments is not a battle that NEA can or should fight on its own. The Roadmap recommends working with well-connected coalitions, focused at the state level, to unite in advocacy for better affordability.

The Roadmap also recommends NEA educate in regulatory environments – where there are often unrealistic requirements for drug development - about the serious nature of eczema and needs of patients. Untainted by commercial interests, NEA can effectively educate about the types and extent of therapies that are needed in order to achieve a good quality of life for eczema patients. Agencies are placing increasing importance on patient centered processes, and the Roadmap suggests that there are many vehicles for delivering that message and mounting a case for the eczema community’s needs.

## MARSHALLING RESOURCES

Implicit in these Five Keys and enabling this transformation is the redirecting of NEA’s community beyond thinking of the Association as a source of patient support. This is a critical perceptual shift, one that puts NEA’s purpose as enabling the community to take *action*, to become a change-agent. Empowered volunteers will create value for each other through local and regional activities, and will, through guidance and strategy from NEA, develop the leadership and advocacy skills to present a persuasive voice at the table for federal regulatory action, and relevant state-level policy decisions.



The office based in San Rafael will become a Headquarters for training and support of regional leaders, who will in turn provide additional training to a cadre of other volunteers. Together, they will implement actions that take NEA further along this Roadmap. These volunteers will include a mix of patients, community members and medical providers. Creation of these regional hubs will take place in a stepwise fashion over a period

of several years, perhaps eventually moving to a formal regional structure with some paid staff.

Staffing at the national office will need to evolve in structure and competencies, through expansion and possible redeployment of existing staff into new areas of focus. Critically, this roadmap presumes growth over a period of time with several new, pivotal staff positions populating the National Office within three to five years. These would focus on research, advocacy and community/volunteer development Roadmap priorities. This will take careful change management to ensure that the existing staff is engaged in the transformation process, and feels honored for the good work that has brought NEA to this point.

Bolstering this model is the recommendation that NEA launch an innovative medical professional program that is also based on action-oriented goals and strategies. The **Medical Professional Action Program – or MPAP** – would be largely focused on issues that clinicians and NEA commonly care about such as access to care and treatments. NEA would mount an advisory group of community-based practitioners to define issues of urgency, always driven by the question: ‘Is this in the best interests of patients?’ that in turn would inform NEA’s advocacy actions.

MPAP is the place from which NEA will cultivate ambassadors for and champions of foundational Roadmap strategies. Professionals join this program for a fee because it helps them change policies, improves access to their practices and the treatments they prescribe, and creates a better world for their patients.

“NEA needs to be positioned to educate, to team up with industry in a way that has no partiality, to ensure that when these meds come out, they are affordable and available, and worth the price.”

- Pediatric dermatologist and NEA Scientific Advisory Committee member

As the momentum of Roadmap work takes hold, so should an emphasis on donor/community fundraising as a way to balance or ideally out-weigh industry funding. Staffing this with an “expansion” expert will also be a key task in the early days of the plan. Further, NEA will have to recalibrate its budget allocation so that dollars spent reflect new priorities. NEA will be equipped to share a strategic vision with industry and explore where there are areas of overlap that represent common interests, leading to different (and greater) opportunities for industry funding.

# MANAGING CHANGE

This plan outlines profound change that must be managed carefully with the patient community, with a clear message that articulates the process, and compellingly describes the vision of the future that this Roadmap creates. While NEA's culture must shift from providing individualized support, there is no need for patients to feel abandoned through the transformation. The responsive, and responsible, way to lead the community through these changes is to teach the community how to better meet its own needs under the leadership and umbrella of NEA and the strategies and templates that HQs will put forward and promote. Further, the Transformation Keys now become the filter through which NEA programming and allocation of resources should be evaluated. It will be incumbent on NEA staff leadership to make decisions about every major NEA program based on the potential impact it has or doesn't have on the Five Keys.

“What's before us now is to leverage NEA's fundamental strengths, and understand how to be flexible and adaptable because we don't know exactly how the market/industry will change. ... It's important to understand the organization's core strengths so that we can leverage whatever change may come about. We need that foresight.

- Member, NEA Board of Directors and parent of child with eczema

Creating a time-limited Roadmap Oversight Committee will provide the community with an invitation into the process so that they can remain engaged with the transformation work and can hold NEA accountable for its commitment to constituents.

## JOURNEY'S END

NEA's leaders have recognized the unique intersection of opportunity and need that is coming up as new drugs and treatments materialize through the development pipeline.



This advocacy blueprint will prove NEA's essential contribution to resolving the core issues and meeting priorities of its community of stakeholders. Executed carefully, the work involved in the Roadmap's Five Transformation Keys will elevate NEA as a great force in the emerging era of care – a new eczema reality that is played out between and among dermatology physicians and researchers, patients, policy makers, insurers, and pharmaceutical companies.

Through accessing its potential for powerful advocacy, NEA can establish a greater connection and sense of common purpose among these stakeholders, which is an important step to broadening the organization's own base of support. This is the time, this is the moment – the Decade of Eczema – to act and to lay a stake for NEA's leadership in the groundswell of change. It is the ideal time for this advocacy to occur. NEA's foresight, and its commissioning of the Roadmap to Advocacy, ensure that the community can be prepared for the changes ahead and leverage them so that eczema patients and their families will not only improve their lives, but thrive in society.

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**With the Roadmap, there is a new culture coming, one that emphasizes the empowering, mobilizing, and engaging of a community to help affect change that in turn will improve lives for patients and their families.**

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*The National Eczema Association commissioned Healthy Change Consulting, <http://healthychange.biz>, to produce the **DECADE OF ECZEMA** – A Roadmap to Advocacy. December 2014*