

National
Eczema
Association

Blueprint 2025

Charting a path to progress
with the eczema community



**2021–2025 Strategic Plan
of the National Eczema Association**

An Introduction to Blueprint 2025

We begin this new year with clarity and purpose – by casting a bold vision for action and impact that will reach every one of 31 million Americans living with eczema. It is an honor to introduce “Blueprint 2025: Charting a path to progress with the eczema community,” a strategic plan to guide our work through 2025.

In March 2020, just as the reality of the Coronavirus-19 pandemic was reshaping the world and our lives, we took a high-altitude look over the eczema landscape at scientific, social, political and economic trends and events likely to affect our community over the next five years. For a moment, we paused. Was it possible to carry out strategic planning amid so much uncertainty spurred by global health, social justice and economic crises? We quickly recognized that these fast-changing circumstances made it even more crucial to set a course and prepare to adapt as needed.

Next, we took time to listen and reflect. In-depth interviews with two dozen community members helped us visualize what a better future for people living with eczema might look like. We then determined the scope of capabilities and influence needed to achieve that future state. Additional input from our Board of Directors and other advisors shaped this final plan that is now our Blueprint. It will be used to help us set priorities and take action, to evaluate emerging needs and opportunities, to measure progress and make course adjustments.

At the heart of this plan is a connected, empowered community of stakeholders united to fulfill the promise of a better future. Collaboration is one of our values and is emphasized throughout the plan. We are committed to finding ways for every allied person to use their skills and experience to speed progress; we hope you’ll find something here that interests and excites you to commit more deeply than ever before. Some of the many ways to engage are listed on page 8 and this list of opportunities will grow as we partner to enact Blueprint 2025.

With you, we will energetically pursue the vision of “a world without eczema.” **With** you, we commit to create community, generate knowledge and take collective action to improve the lives of people affected by eczema. **With** you, we cannot fail.



Julie Block, President & CEO
National Eczema Association

January 20, 2021

Executive Leadership Team

Julie Block, President & Chief Executive Officer

Scott Sanford, Chief Operating Officer

Lisa Butler, MBA, Senior Vice President, Strategic Partnerships & Programs

Wendy Smith Begolka, MBS, Vice President, Scientific & Clinical Affairs

Amber Whiteside, Director, Marketing & Communications

Rachel Lee Holstein, Director, Development

Board of Directors

Cynthia Kim – Chairwoman; Los Angeles, CA

Sarah Young O’Donnell – Secretary; New York, NY

Christina Crowley – Chief Financial Officer; Berkeley, CA

Mike Bristol; Longmont, CO

Rachael Bronstein; Miami, FL

Elizabeth Hoff; Houston, TX

Nathan Jetter, MD; Chicago, IL

Peter Lio, MD; Chicago, IL

Dinesh Shenoy; San Diego, CA

About Eczema

Eczema is the name for a group of conditions that cause the skin to become itchy, inflamed and red in lighter skin tones or brown, purple, gray or ashen in darker skin tones. Eczema is very common; more than 31 million Americans have one or more of the seven forms of eczema. The most common form of eczema is atopic dermatitis (AD).

Eczema is not contagious. You can’t “catch it” from someone else. While the exact cause of eczema is unknown, researchers do know that people who develop eczema do so because of a combination of genes and environmental triggers.

When an irritant or an allergen from outside or inside the body “switches on” the immune system, it produces inflammation. It is this inflammation that causes the symptoms common to most types of eczema. Each form of eczema has its own set of triggers and treatment requirements, which is why it’s so important to consult with a healthcare professional who specializes in treating eczema.

About the National Eczema Association

The National Eczema Association (NEA) is a 501(c)(3) non-profit organization founded in 1988 by a group of patients, health care professionals and others concerned about the enormous social, medical and economic effects of eczema.

Acknowledgements:

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A Firm Foundation

Our year-long planning process included a review of our strengths, challenges and past performance. We identified many ways in which our organization and the eczema community have grown and matured over the years, especially since 2015 when the ["Roadmap to Advocacy"](#) strategic plan was adopted.

Over this same period, eczema has benefited from a surge of scientific interest and investment from life science companies developing new treatments for eczema. We heard from community members that this fast-changing environment is a source of great hope, but it can also be overwhelming and hard to make sense of.

As the pace of change further accelerates, NEA will be relied upon more than ever to translate the promise of a better tomorrow into meaningful differences – both in the near-term and for generations to come. Grounding this Blueprint are new descriptions of our long-range purpose and core beliefs that will guide NEA's decisions and interactions for the next decade and beyond.

Our Vision

A world without eczema.

Our Mission

NEA is the driving force for an [eczema community](#) fueled by knowledge, strengthened through collective action and propelled by the promise for a better future.

Our Values

- **Transformative:** We embrace the future, think big and are passionate leaders of innovative change.
- **Patient-centered:** We embody the true lived experience of all people affected by eczema, elevate their voices and address their needs.
- **Collaborative:** We will empower one another and work with all those who share our vision for a better future for all those affected by eczema.
- **Truth-seeking:** We rely on science, evidence and reason to inform our evolving understanding of eczema.
- **Accountable:** We are honest, trustworthy, credible and transparent.

Building Blocks: Key Definitions

Reflecting back and looking ahead led us to appreciate how central the concept of "community" has become to NEA's identity and its existence, as is now captured in our new mission statement (above). We also recognized that what we mean by the term "eczema community" has expanded over the years to reflect a multitude of personal and professional interests in making life better for those who live with eczema. Many people seek out NEA to connect with others who understand and share the experience of living with eczema. Each individual's unique perspective, based on their own experience, is a source of strength and vibrancy for the diversity of our community.

To enhance understanding in how we are using two terms that appear frequently throughout the Blueprint, we share these definitions:

"Eczema community" is used to include:

- People directly affected by eczema (patients, caregivers, care partners, parents, family members)
- Health care professionals who provide care to eczema patients
- Researchers studying eczema
- People who work for companies developing and/or marketing products designed to relieve eczema
- Other allies inspired by NEA's vision of a world without eczema

"Diverse backgrounds and experiences" reflects NEA's intention to engage an eczema community inclusive of:

- All forms of eczema, types of symptom expression and degrees of severity
- People of different age, racial, ethnic and cultural groups
- People of all socioeconomic and education levels

Stronger By Design

When we set out to develop this strategic plan, we recognized the need for it to be clear and compelling, with enough detail to guide and benchmark our efforts for the next five years. Yet, we were living in a moment of unparalleled uncertainty due to concurrent global health, economic and social justice crises. Coupled with the fast-changing conditions within the [eczema community](#) itself, this plan would need to have built-in flexibility and resilience. Two elements of the plan's framework helped meet these divergent needs: Principles and Pillars.




As ideas began to take shape for ways NEA could advance the mission through 2025, a set of recurrent themes rose above areas of programmatic focus – almost like a roofline for the structure we set out to construct. The following five overarching “Principles” describe key priorities for how we will pursue progress over the next five years:

Our Principles

- NEA endeavors to reach people affected by eczema with accurate, up-to-date information relevant to their needs and interests.
- NEA commits to fully partner with [community members](#) of [diverse backgrounds and experiences](#) to create meaningful change for all.
- NEA empowers people affected by eczema to contribute data from their lived experience that will spark novel insights, enhance understanding of eczema and improve lives.
- NEA shares its key learnings, focused on experience in the U.S., with the [global eczema community](#) to collectively advance the vision of “a world without eczema.”
- NEA's Board, staff and volunteers work together to attract greater commitment to and investment in the organization's mission.

Similarly, the process of envisioning ways NEA could address unmet needs and catalyze further action helped to distill three key areas of programmatic focus we termed “Pillars.” Like physical pillars, they are inter-dependent supports that work together to provide essential structure. Each Pillar is described by a set of broad goals to keep us focused.

Our Pillars

-  **Community:** Reach individuals earlier in their care journey, connect them to professionals and peers and inspire them to participate in the mission.
-  **Knowledge:** Generate and promote information, research and resources that affirm the chronic, serious and heterogeneous nature of eczema and the burdens it imposes and improve treatment and management of eczema across the lifespan.
-  **Collective Action:** Mobilize [community](#) expertise and evidence to raise awareness, spur development of new treatments, enhance affordability and access to care and treatment, optimize care outcomes and improve quality of life.



Pillars are:
Tightly inter-dependent
Mutually reinforcing
Synergistic

You may notice the Pillars are embedded in our mission statement: “NEA is the driving force for an [eczema community](#) fueled by **knowledge**, strengthened through **collective action** and propelled by the promise for a better future.” Community, knowledge and collective action are the cornerstones of NEA and our Blueprint 2025.

Over the next three pages, we explore each of these Pillars in more detail through a set of “Pathways” that illustrate potential ways for this Blueprint to be carried out between 2021 and 2025.



Community Pathways

Over the years we have heard a two-part message from people affected by eczema when they discover NEA and the resources we have curated: **relief** to find an organization that recognizes and understands their needs and **frustration** that it has taken so long for them to become aware of NEA.

We want to reach more people and shrink this delay that occurs so often. We also seek to help people connect to eczema-informed health care professionals and other resources, including other people who have traveled similar paths so they can support one another and benefit from real, lived experience. Finally, once people have found their way to NEA, we want to help them discover ways to apply their talents and interests to advance our shared mission.

Ideas for expanding and connecting our community also apply to researchers, health care professionals and other **community members**, but here we focus on ways we will help those most directly affected by eczema find and benefit from NEA and others engaged with our organization:

Community Pathway 1

Increase the reach to those affected by eczema, as it occurs alone or in combination with related conditions

The easiest way to access NEA's resources and network is through our website. In 2020, our newly redesigned website, NationalEczema.org, welcomed 5.5 million users – but that is just a fraction of the people who could benefit. We will explore new partnerships and ways to expand outreach efforts so that more people affected by eczema learn about NEA and make use of our materials and connections, as early in their eczema journey as possible. We'll place special emphasis on identifying ways of reaching people with other immune-related conditions that frequently occur in combination with eczema.

Community Pathway 2

Provide space for eczema community members of all ages and backgrounds to connect, share lived experiences and support one another

NEA's renowned annual event – [Expo](#) – is valued by participants for the opportunity to form and strengthen bonds as much as it is for cutting-edge information shared from the podium and in breakout discussions. We aim to replicate this vibrant, welcoming, inclusive setting through other in-person and virtual venues, to create a more continuous opportunity for gathering, exchange and co-learning. This type of community hub can provide an especially important shelter from the stigma, isolation, depression and despair that are frequently part of the daily experience of people with eczema and caregivers alike.

Community Pathway 3

Collaborate with eczema-informed health care professionals (HCPs) to foster referrals from and to NEA

"Why didn't my doctor tell me about NEA?" is a question we hear a lot! We will work on promoting referrals in both directions – building on the existing network of physicians experienced in the treatment of eczema available through our [Eczema Provider Finder](#) and developing easy ways for them to point patients to NEA's resources. We will deepen our understanding of the eczema care landscape by conducting a nationwide analysis of the settings where medical care for eczema is provided, looking at academic and community-based practices, different medical specialties and geographic distribution. This will help identify gaps and enhance relationships with treating professionals to improve the care network.

Community Pathway 4

Cultivate community leaders and expand opportunities for them to engage and build their skills

We know that momentum in our mission will grow from more fully tapping into talents within our community given its large size, breadth and diversity. [NEA Ambassadors](#), a program launched in 2020, is one way for people to participate directly in shaping and delivering support, awareness, research and advocacy programs. As this and other programs grow, we see opportunities for a system of community-powered hubs to foster connection at a more "local" level – both in the geographic sense and in terms of specific interests and/or experiences. An inclusive, empowered, energized **eczema community** where individuals rise to their full potential will be an unstoppable force in achieving a world without eczema!



Knowledge Pathways

We want to understand eczema inside and out – its biology, its effects on how you feel (physically and emotionally) and its impacts on the individual, their family, the healthcare system and our economy. As we continue building on all that we have learned through the years, we must make this information available to the community in terms and formats that meet your needs. And we must help connect the dots between studies and fill remaining gaps and new ones that appear, all to help you find more complete and longer lasting relief.

These Pathways describe our approach:

Knowledge Pathway 1

Equip people and families affected by eczema with relatable information and resources to help them navigate the complex, fast-changing care landscape

Eczema affects people at all stages of life, from newborns to seniors, and we recognize that information needs and preferences can differ across the lifespan and by generation. Some information needs are urgent, such as during a bad flare or when considering a new treatment, while others may be more periodic, like seeking tips for simplifying self-care routines or boosting coping skills. We also recognize that some people prefer to read a detailed article in print, while others opt for a short video that highlights key-takeaways on Instagram. To better match this wide array of needs and expectations, we will experiment with a greater variety of ways to share information and to direct information that is more personalized to your interests.

Knowledge Pathway 2

Accelerate innovative research

Supporters of NEA have made us the largest private nonprofit funder of eczema in the world, a mark that fuels ambitions to expand our [grant-making program](#) and develop more [research resources](#) centered on the lived experience and expertise of eczema patients and caregivers. For instance, with the 2020 launch of [EczemaWise](#), a mobile application for tracking symptoms and triggers, we are collecting an increasingly large pool of anonymized data to build a more complete picture of the dynamic, daily experience of eczema from which new insights and advances will emerge. Connecting researchers to this sought-after “real world data” and attracting new research disciplines to focus on eczema are other ways we will work to speed research momentum.

Knowledge Pathway 3

Advance a new understanding of the racial diversity of those with eczema and the associated impacts

Much of what is known about eczema is based on studies of people with white skin, leading to a large gap in awareness of and facts about the biology, presentation and burden of eczema on skin of color. This gap contributes to delays in diagnosis and inadequate care for people of color with eczema that we seek to address by expanding research and enhancing medical education focused on these topics. Crucial to advancing understanding is making sure that more people of color with eczema are directly involved in these efforts, to ensure that their perspectives and experiences inform and shape the studies, the learnings that come from them and action steps that follow.

Knowledge Pathway 4

Support a greater number of health care professionals (HCPs) to become more capable and confident in managing eczema patients

We are fortunate to have extremely dedicated and caring HCPs who are recognized experts in treating eczema. But they’re not accessible to everyone, especially as often as might be desired. We also know that detection and care of eczema often begin in primary care and urgent care settings, by providers who may not be familiar with the full range of treatment options and/or aren’t prepared to educate patients about the importance of self-care between visits. Through medical education, training and support programs, we will help spread eczema expertise to a wider array of primary care and specialty HCPs so you receive better care, closer to home.



Collective Action Pathways

When individuals come together to enhance their situation and achieve a common objective, they are taking collective action. It is the force often cited for “making the impossible possible.” Collective Action is the Pillar of our strategic plan that leverages the size, the breadth, the [diversity](#) and the passion of our eczema community to create positive change with lasting impact. It is also the set of actions that depends most on rallying individuals to take part in group activities that seek to resolve shared pain points.

The following are some of the ways we will mobilize community expertise:

Collective Action Pathway 1

Amplify the lived experience of individuals affected by eczema

NEA is fully committed to empowering those who know eczema best – individuals diagnosed with eczema, their family members and care partners – to put that expertise to use. There are limitless opportunities, from expanding public awareness to informing development of innovative medical treatments, skin care products and approaches to care. We will prepare individuals to participate in these patient-focused activities and act as a “matchmaker” between those seeking lived expertise and those ready and willing to share it.

Collective Action Pathway 2

Transform disease management and decision-making in clinical care settings

Care guidelines that shape the medical care you receive are generally written by committees of clinical experts based on the way eczema presents in their settings of care. We aim to expand these expert panels to include patients and caregivers so that the day-to-day physical and psychosocial impacts of eczema are recognized and reflected in care guidelines. We will also work with a wide range of experts to develop tools that enhance shared decision-making between patients, caregivers and their HCPs so that treatment is tailored to individual needs and preferences.

Collective Action Pathway 3

Establish and advance federal and state policy agendas to address patients' unmet needs

For several years, NEA has actively pursued improved public policy that affects people with eczema, working primarily through coalitions for chronic conditions and skin diseases. To complement this broad-based approach, NEA will define, articulate and pursue an agenda that addresses needs specific to the [eczema community](#). We will establish relationships and engage with legislators, policymakers and regulators. We will also channel our community's voices to influence the federal research agenda, approval and coverage of novel therapies and federal and state support for improved awareness, education and care.

Collective Action Pathway 4

Expedite and improve patients' access to quality care and treatment

The surge of scientific investment in eczema may yield new treatments, yet without a concerted effort to inform various gatekeeping bodies about the totality of burdens eczema poses on the individual, the family and society, these treatments may reach just a small fraction of those who could benefit from them. We will equip [community members](#) with evidence to expand their access to services and products that can help achieve better health outcomes. We will also actively encourage participation in clinical trials so that the innovation cycle thrives and continues to yield new care options that meet more patient needs.

Collective Action Pathway 5

Build a diversified and sustainable revenue pipeline

To ignite and fuel all the efforts described in this Blueprint 2025, it is essential that we attract new supporters through a greater variety of [charitable giving programs](#) and sponsorship opportunities. We will add more ways for individuals to target their gifts, engage their personal networks and make use of tax-advantaged means for supporting our work. Through our Corporate Council, [Seal of Acceptance](#) and other strategic partnerships, we will engage with companies with aligned, mission-related interests to advance shared priorities. In all approaches to generating revenue, we will uphold our stated Values, [Board-approved gift acceptance policy](#) and applicable federal and local statutes.



Co-constructing the Future

Blueprint 2025 provides a sketch of a future NEA – one that will be built in collaboration with you. Some of the Pathways described on pages 5-7 build on existing programs, while others are new proposals that will take shape over time. We purposefully chose the word “pathways” to reflect the many possibilities for acting on the high-level goals stated within each of the Pillars.

As with most charitable organizations, our activities depend on the ability to attract human and financial resources and we will phase in new activities as quickly as resources allow. We will also maintain flexibility so we can respond to emerging needs and opportunities that are consistent with our stated Mission, Principles and Pillars.

In all we do, we strive to be accountable to our community. We will form a Blueprint 2025 Advisory Council to help the Board and staff prioritize new activities and evaluate progress. We will also create and regularly update a Blueprint 2025 metrics dashboard. These additional actions will help us balance discipline and flexibility, core strengths that will augment NEA’s ability to advance our vision of a world without eczema.

Chart Your Pathway

You are essential to fulfilling the promise of a better future for all affected by eczema. There are many ways to get involved – or become more involved – in our community, a few of which are listed below. New opportunities will be created as we work with the community to bring Blueprint 2025 to life. We encourage you to accelerate our shared progress by taking one or more of these actions today:

- Sign up for NEA [E-news](#) to get the latest NEA and eczema news and be alerted to opportunities to contribute your lived experience to the mission
- Take an active role in awareness, research and advocacy by joining [NEA Ambassadors](#)
- Download [EczemaWise](#) to turn your whys into wise while helping to build a unique patient-generated data repository
- Make your investment in a future free of eczema through a [donation to NEA](#)
- Connect to knowledgeable HCPs using the [Eczema Provider Finder](#)
- Find eczema-friendly products in the [Seal of Acceptance directory](#)



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