National
Eczema
Association

High-level Summary of Interviews with External Stakeholders

Conducted on behalf of the National Eczema Association (NEA)
By the Kith Collective | June 12-July 16, 2020

Approach

- Conducted 20 interviews with a total of 23 individuals selected by NEA staff
- Individuals represented one or more stakeholder categories:
    - Persons affected by eczema (patients and caregivers), including Board members and donors (13)
    - Health care professionals specializing in the treatment of eczema patients (4)
    - Researchers studying eczema (4)
    - Staff of companies engaged in developing and/or marketing eczema treatments (6)
    - Senior staff of organizations with relevant policy expertise (4)
- Individuals with personal experience with eczema focused on moderate to severe atopic dermatitis, which reflects NEA's core constituency.
- Interviews were conducted with an expectation of confidentiality for viewpoints shared. A more detailed report of themes, viewpoints, insights, and ideas have been shared with NEA without attribution to individual statements.

General Learnings

- Across all stakeholder groups, NEA is viewed as the leading resource for patient-centered information and knowledge about eczema.
- NEA's annual "Expo" meeting was mentioned most often by name as its flagship program, although others placed high value on its content, community, and support in general.
- When asked about NEA's mission, stakeholders expressed the need for it to address two distinct elements – helping people affected by eczema live their best lives possible **today** and shaping a better **tomorrow** for people affected by eczema.
- Stakeholders stated that the greatest challenge people affected by eczema will face over the next 5 years is navigating the fast-changing treatment and care landscape. This reflects the expected entry of multiple novel eczema therapies to the market, changes in healthcare (generally) and dermatology (specifically), and deepening challenges accessing quality care and appropriate treatments.

Priority Needs and Challenges Identified

- **Reframing eczema:** There continues to be great need to increase understanding of the serious nature of eczema and its life-altering impact on the diagnosed individual and their immediate family (caregivers) as well as the many sources of burden it imposes on the individual, family, and society as a whole. This was viewed as essential both to improving the individual patient journey and a key factor in securing coverage of and reimbursement for novel therapies. There is also a need to bring to light the disproportionate prevalence of eczema among people of color, the different biology underpinning their disease, the shortage of information about treatment safety and efficacy for people with skin of color, and narrowed access to quality care they often face as a result of myriad economic, social, and educational disparities. Another question raised was the appropriateness of dermatology as the "medical home" for eczema care, considering evolving science and pressures on dermatology practice to prioritize more lucrative procedure-based conditions. Patients too reported feeling unwelcome in spa-like dermatology offices and worsening difficulty getting appointments with medical dermatologists. Several people expressed the need to engage more specialties (including allergy and immunology) and to better educate primary care providers (adult and pediatric) about eczema and its treatment.

- **Connecting patients/families to relevant resources sooner:** While NEA was viewed as the leading resource for eczema patients, stakeholders relayed that it can take months or years to find NEA, with frustrating – and frequently detrimental – delays in obtaining better quality medical attention and self-care practices. There was a strong desire for there to be tighter connection between settings of care and NEA, with suggestions coming from both patients/caregivers and physicians for how more partnership could enhance patient and provider experiences. In particular, these expert physicians related that by the time patients reach them, many have lost faith and trust in medical care and have adopted suboptimal self-care, often requiring a reset of the treatment regimen and restoring belief that better outcomes are possible. This shortage of expert eczema physicians also contributed to an inability to be seen by a doctor during a flare, which leaves the patient/caregiver on his/her own during a time of high need and also leaves a vital evidence gap in the medical record which can add to the challenge of gaining access to higher value therapies. Stakeholders also raised the need for information and resources to be available in a variety of formats with content and imagery that appeal to the diversity of the eczema community in terms of the type of eczema, symptom expression, age, race, ethnicity, and health literacy level. "Relatable" was a term used often to describe content, format, and messenger.

- **Services and tools to support informed decision-making:** Interest in relatable information was balanced with a need for unbiased, factually accurate information, especially as understanding of the biology of eczema deepens and the array of treatment options grows, recognizing that patients look to NEA for help to guide their decisions. The need for this information extended to primary care professionals and other specialists whom patients may encounter who are relatively unfamiliar with the changing landscape of eczema care. Models from cancer, MS, psoriasis, and rheumatoid arthritis, where there has been similarly rapid evolution of treatment options, were raised as informative to developing patient navigation services to assist patients to locate appropriate medical and mental health care providers, prepare for shared decision-making about therapy options, and support interactions with insurers.

- **Supporting equitable access:** Bringing a patient-centered focus to practice guidelines, coding issues, and coverage and reimbursement policy was regarded as essential to delivering on the promise of these new therapies. Developing and actively advancing a robust policy agenda to address these issues and others (such as NIH research priorities) was one of the most consistent unmet needs expressed by this group of stakeholders. It was viewed as vital to realizing the potential value of newer therapies to benefit individuals, as well as a social justice issue for the eczema community. Several people expressed concern that access to these therapies will be restricted, in part, based on inaccurate impressions about the severity of or burdens associated with eczema. This would put treatments out of reach for many patients, further widen care disparities, and could discourage further R&D investment. Directing research dollars to inform actionable care practices and fill evidence gaps in support of access was posited as an adjunct strategy.

- **Stay connected to stakeholders' needs and expectations:** NEA was praised for its courage to conduct strategic planning amid unprecedented uncertainty on so many fronts. It was suggested that the plan include regular review intervals to factor in changes external to eczema (including progress in recovery of the economy and healthcare system post-pandemic, outcome of 2020 elections, etc.) and to update assumptions related to the pace of progress in eczema. Many expressly welcomed the opportunity to share perspectives and hoped this would create ongoing opportunities for stakeholders to be in more regular dialogue with NEA staff about issues of mutual concern and shared priority.

Thank you to all who participated in these illuminating interviews