EoE Knowledge Exchange Summary Report

2021

Background and Objectives

Eosinophilic esophagitis (EoE) is a chronic and progressive type 2 inflammatory disease that damages the esophagus and prevents it from working properly.[1] Over time, excessive type 2 inflammation causes scarring and narrowing of the esophagus, making it difficult to swallow.[2] Approximately 1 in 1,000-2,000 people live with EoE around the world[3]; however, this is expected to increase.[2,3] Currently, EoE is frequently confused for other, more common digestive conditions with similar symptoms, such as acid reflux or gastroesophageal reflux disease (GERD). As a result, people living with EoE often face delayed or incorrect diagnoses, suggesting the prevalence of the disease is higher than currently understood.[4]

There are several patient advocacy groups (PAGs) and medical societies driving efforts in EoE, with many doing so as part of a broader allergy agenda. However, as EoE is a relatively new disease, the patient community remains small and disparate compared to those of other more well-known chronic conditions. EoE has also been absent from policy debates, and while EoE is occasionally covered under the broader allergy and airways policy agenda, the specific needs of EoE patients are overlooked as more prevalent conditions, like food allergies, take precedence. As a result, awareness around EoE is limited and there remains a high unmet need amongst patients.

To build on existing efforts and help drive momentum in EoE, the Global Allergy & Airways Patient Platform (GAAPP), Regeneron, and Sanofi Genzyme co-hosted the first virtual EoE Knowledge Exchange on September 16, 2021. The EoE Knowledge Exchange involved global, regional and national PAGs and medical societies, and aimed to:

01

Bring together key stakeholders within the EoE community and increase collaboration

02

Generate new insights to help increase global recognition of EoE

03

Establish global priority areas and identify activities needed to raise disease awareness

This report summarizes the key takeaways and discussions from the EoE Knowledge Exchange, focusing on three topics: the burden of the disease; the key challenges the patient community faces; and potential activities to improve EoE care. All insights are based on the participants' contributions during the meeting.

Participants

The EoE Knowledge Exchange brought together 13 representatives from PAGs and medical societies from across eight countries, providing representation from North America, Europe and Australia.

Moderators

Tonya A. Winders, *President, Global Allergy & Airways Patient Platform (GAAPP)*

Maryam Hassimi, *Global Public Affairs Lead, Immunology, Sanofi Genzyme*

Ilana Tabak, *Director, Patient Advocacy, Immunology, Regeneron*

Participants

Rebeca Andrádas, *Head of International Projects, Spanish Association for EoE (AEDESEO)*

Dr. Arjan Bredenoord, *President, European Society of Eosinophilic Oesophagitis (EUREOS)*

Amanda Cordell, *Trustee & Chair, EOS Network*

Eleanor Garrow-Holding, *President & CEO, Food Allergy and Anaphylaxis Connection Team (FAACT)*

Dr. Thomas Eiwegger, *Chair, Biologicals Working Group, European Academy of Allergy and Clinical Immunology (EAACI)*

Jennifer Gerdts, *Executive Director, Food Allergy Canada*

Dr. Roberta Giodice, *President, Italian Association of Families Against Eosinophilic Esophagitis (ESEO)*

Sarah Gray, *Founder & President, AusEE, Inc.*

Ellyn Kodroff, *Founder, Campaign Urging Research for Eosinophilic Disease (CURED)*

Dr. Salvatore Oliva, *Italian Association of Families Against Eosinophilic Esophagitis (ESEO)*

Susanna Palkonen, *Director, European Federation of Allergy and Airways Diseases Patients Associations (EFA)*

Dr. Imke Reese, *Scientific Advisory Board Member, German Allergy and Asthma Association (DAAB)*

Mary Jo Strobel, *Executive Director, American Partnership for Eosinophilic Disorders (APFED)*

Key Takeaways

The Burden

> "The journey can look so different between patients"
> – Patient Advocacy Group Participant

Throughout the Exchange, participants shared their experiences and knowledge on the burden of the disease, highlighting how EoE is an invisible, progressive, and life-long condition, which has a significant impact on patients and their families. When patients first experience symptoms, they often describe challenges, such as difficulty swallowing; but as the disease progresses, the challenges become increasingly complex with some patients experiencing increased food impactions. Moreover, the nature of the disease means everyone experiences it in a unique way and even on an individual level. As patients transition through life stages, for example, from childhood to adolescence to adulthood, EoE symptoms can change and evolve. It's this unpredictability of the disease – with some participants likening it to type 1 diabetes – that makes the search for a unifying solution extremely challenging. In addition to the physical impact, participants also stressed the significant psychological and financial burden attached to EoE due to its life-long nature, its debilitating impact on people's social life, the complexity of management and the costly diagnostics and dietary treatments.

Participants agreed it is precisely this kaleidoscopic of characteristics and the multi-faceted impact that defines EoE as a disease.

Key Challenges

a) Awareness and education

Despite the significant physical, psychological and financial burden of EoE, there is limited awareness and education about the disease. As a consequence, patients often aren't equipped to recognize their symptoms or distinguish them from other, more common conditions such as GERD. In addition, as initial symptoms can be mild, many patients' natural instinct is to learn coping strategies to tolerate the symptoms and delay seeking care, as they are unaware of the cost of inaction. The group noted, for example, instances of patients living in silence for ten years before their symptoms hit a breaking point and the severity of the disease forced them to seek support.

Similarly, there is limited education about EoE within the medical community. As it is a relatively "new" disease, many healthcare providers (HCPs) do not learn about EoE in medical school. In addition, EoE is often deprioritized among over-stretched general practitioners due to the low likelihood of them encountering patients with EoE in their career. As a result, patients with swallowing issues are often dismissed by doctors until their disease progresses and they experience food obstruction.

Recent research shows that the average time for a correct diagnosis is four years in adults, two years in adolescents, and one year in children.[5] Participants also shared anecdotally that it could sometimes take up to nine years for adults to get a proper diagnosis. Moreover, when they are diagnosed, many patients are not equipped with sufficient information.

> *"We get a fair amount [of patients] who come after 10 years of living with it [EoE] and living with it in silence or not really doing anything about it because they didn't think they needed to because their doctor said it was no big deal. Then, they reach the point where symptoms have exploded so much that the damage has really increased and that's when they come seek support."*
> – Patient Advocacy Group Participant

To reduce time to diagnosis and improve outcomes, patients need education on the disease, and the value of early intervention, while HCPs need a standardized approach to diagnostics and referrals.

b) Treatment and care

In addition to – and partially as a result of – the limited awareness and education about EoE, the treatment options and standard of care are often inadequate and complex. For instance, the dietary regimens that are prescribed to patients are often extremely detailed and demanding to follow, especially for those transitioning into adulthood and will no longer have supervision from their parents. These diets can also place a significant financial burden on families and can be unrealistic to maintain, particularly for lower-income families and in countries where medical insurance coverage is lacking. Despite the group agreeing that many patients prefer dietary treatments, they can be logistically difficult to execute. For example, the group discussed the limited availability of local and sophisticated specialists, such as dieticians, who help monitor the disease and support adherence, causing doctors to rely on medical therapeutic options instead.

EoE care is also complex to manage due to the multi-faceted nature of the disease. Firstly, EoE care necessitates a multi-disciplinary approach, often including an array of specialists, from gastroenterologists to dieticians to psychologists. However, participants stressed that there is often a dearth of specialists available, and even when there are the right HCPs in place, breakdowns in communication and coordination among them is common. This results in patients and their families receiving mixed messages about how to manage the condition, what treatment to use and when to follow-up. The complexity of such care also means it is extremely fragile, and, thus, if one specialist moves or leaves their position, the coordination between the care providers can collapse to the detriment of the patient's health.

Lastly, participants emphasized how these challenges in EoE care span the entire patient journey as sufficient follow-up is often deprioritized by patients and their HCPs. For example, many patients struggle to accept EoE as a life-long condition and therefore stop care after completing a 12-week course of dietary treatment under the illusion that they have dealt with the disease. This is compounded by a lack of guidelines specifically on the follow-up stage for medical practitioners resulting in patients falling out of care, experiencing symptoms, and facing the daunting prospect of starting the journey all over again.

It's precisely this complex and innately fragmented nature of EoE care that requires HCPs to think holistically about the patient journey.

> *"EoE patients would profit from a very clear message from us clinicians. This is something that should be demanded – that gastroenterologists, immunologists, pediatricians are all providing the same message on how to diagnose, how to treat, when to biopsy and how to follow-up."*
> – Medical Society Participant

c) Shared decision making

Finally, all participants cited the lack of strong and coordinated shared decision making as a key challenge. First and foremost, the group stressed that patients are not given the support or education necessary to feel empowered to ask the right questions of their HCPs or fully understand the guidance they are provided. Although EoE treatment guidelines exist, they are not tailored for patients and therefore are too complex for them to leverage. Secondly, the group reiterated that shared decision making is particularly challenging in EoE because it's not just confined to a patient and their one doctor, but it must occur between all the stakeholders involved. For example, while shared decision making may occur between a patient and their gastroenterologist, it may be lacking between their dietician and psychologist.

This lack of coordination often results in mixed messaging or contradictory counsel being given to patients and their families, provoking them to self-manage their disease in ways that can be counterproductive.

Improving shared decision making by empowering patients and coordinating specialist care is essential for improving the patient's experience and, consequently, ensuring adherence.

> *"If they [patients] don't have a choice in their treatment, they are very unlikely to follow the physician's advice. Personally, I think that we can improve treatment if we improve the involvement of the patient in their treatment by providing more and better information to that patient. That will improve treatment adherence and, eventually, also treatment result of course."*
> – Medical Society Participant

Activities to Improve EoE Care

In the context of these challenges, preliminary activities were identified to improve EoE care and outcomes, aimed at patients, healthcare providers, and policymakers.

Target Audience	Focus Area	Current Challenges and Considerations	Potential Activities
Patients, families and caregivers	Education	• Resources and information for those experiencing symptoms is lacking • Broader community awareness of EoE is needed to ensure a supportive environment that is sensitive to the needs of patients and caregivers.	• Publicly available disease education content about EoE • Partnerships with search engines to display targeted EoE resources • EoE school education programs
	Shared decision making	• Patients need to feel empowered and well-equipped to play an active role in their care	• Lay friendly guidelines • Short videos with tips on how to communicate with HCPs and ask the right questions
Healthcare providers	Education and training	• The referral process and when to refer patients for further diagnostic tests needs to be improved • There needs to be greater awareness of clinical guidelines	• Diagnostic and treatment algorithms • Clinical guideline promotion during medical training programs • Trainings for HCPs, especially dietitians and psychologists who work in EoE • Extracurricular EoE-related activities in medical degree programs • Patient-friendly flow charts representing treatment options that HCPs can use in consultations
	Shared decision making	• Shared decision making must be strengthened to improve EoE care and help ensure better adherence	• Simple questionnaire to use in consultations, which considers the behaviors many patients adopt (e.g., avoiding hard foods)
Policy makers	Awareness raising	• Lack of evidence and awareness of the global burden and kaleidoscopic nature of the disease, including its physical, mental and socioeconomic impact • To spark action among policymakers, a combination of emotion, evidence and economics is needed	• A global survey on the burden of EoE • Data that contrasts the cost of living with EoE versus the cost of living without it • Citizen research projects that make patients and caregivers part of the data generation process • Patient videos to convey full impact of the disease

Conclusions and Looking Forward

The virtual EoE Knowledge Exchange brought together key stakeholders to uncover new insights and build momentum for the community moving forward. The discussions stressed the multifaceted, evolving and life-long nature of EoE and the significant physical, psychological and financial burden it places on people and their families. It also shone a light on the limited awareness and education among all stakeholders; the intricate and coordinated care and treatment that is required; and the need for improved and harmonized shared decision making. Finally, the Exchange provided an initial opportunity to collectively explore activities to help address these unmet needs.

The Exchange was a first step to increasing collaboration and action in a disease area that has been overlooked and deprioritized around the world. By bringing together key stakeholders from across different regions and sectors, it provided an invaluable opportunity to holistically look at the existing challenges and prioritize areas of unmet need, offering a springboard for future collaboration and collective action. Subsequent Exchanges will hope to harness this momentum and further explore the specific topics agreed on by participants, such as the role of type 2 inflammation in EoE; methods for rallying policymakers; and increasing collaboration with other key EoE stakeholders, such as specialists. Together, we hope to elevate the understanding of the disease and improve patient care in pursuit of a better future for people living with EoE around the world.

References

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