



EFA Community Report

#AtopicEczemaUnfiltered

World #AtopicEczemaDay 2024





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World #AtopicEczemaDay 2024

Atopic eczema/dermatitis (AE/D) is one of the most prevalent skin diseases in the world and one of the most under-recognised. Often dismissed as "just a skin condition," patients' needs are not addressed in a supportive and timely manner.

Aside from the physical burden, AE may have far-reaching effects on the patients' self-image, emotional and social interactions, and how others in society respond to them. The ability to work and performance at work and school are often also affected. Understanding the burden of Atopic Eczema is critical for better care, disease management and information to improve patients' lives.

Atopic Eczema Unfiltered

The <u>2024 #AtopicEczemaUnfiltered campaign</u> focused on the real experiences of people living with Atopic Eczema and shed light on the untold stories of Atopic Eczema patients. The international theme and toolkit have been co-created with the EFA atopic eczema community and our international partners from the <u>International Alliance of Dermatology Patients Organizations (GlobalSkin)</u>.

In a world where social media often present a polished version of reality, the true challenges of living with chronic conditions like Atopic Eczema remain largely unseen and misunderstood. **#AtopicEczemaUnfiltered** is a concept that was strategically drafted to resonate with a global audience, leveraging the universal understanding of the term "unfiltered" (without Photoshop or retouching) in the everyday use of social media which often presents a polished version of reality.

The overarching theme was flexible and adaptable, designed to reflect the diverse realities of patients and the unique national contexts in which patient organizations operate. It empowered participants to share their personal messages while fostering synergies between stories online, regardless of age or location.

Call to action

The hashtag **#AtopicEczemaUnfiltered** supported patients' commitment to authenticity, encouraging the community to share the reality of the disease as it is, therefore fostering genuine connections, raising awareness of the atopic eczema burdens, promoting empathy and empowering patients to speak about their lived experiences. EFA's efforts in the annual campaign was to get better recognition of atopic eczema at the policy level and ultimately improve access to timely care and treatment for patients with chronic skin diseases.





Objectives

Our global, European and national mission with the #AtopicEczemaUnfiltered campaign tagline is multifaceted.

- To bring patient groups to the forefront to foster a supportive community through the power of shared stories.
- To show the burdens of people living with atopic eczema and call for improved access to care and treatment options.
- To connect the Atopic Eczema community and the broader public, healthcare providers, and policymakers to ensure the voices of those affected are heard and acted upon.

Target audience

Primary Audience: Individuals living with Atopic Eczema across all age groups. Families and caregivers of those with Atopic Eczema and patient groups

Secondary Audience: healthcare professionals (dermatologists, primary care physicians, pediatrician, mental health specialists) and healthcare professional associations

Tertiary Audience: Policymakers, institutions, researchers and academia, health insurance companies, and organizations involved in healthcare policy and funding.

Toolkit

The 2024 #AtopicEczemaUnfiltered toolkit included background and practical information on the campaign – theme, hashtags, messaging, customizable social media cards, template press release and a support letter for medical societies and individual healthcare professionals. This year we have also included online patient advocacy tips for participating in the #AtopicEczemaUnfiltered campaign.

While the campaign was open to all messages, it encouraged national patient organizations to tailor it to their local context. For the European region, the following narrative was identified:

- General Awareness: Atopic eczema is a chronic condition that requires long-term management and support, highlighting its complex nature and the burden it places on patients and caregivers.
- Access to Care and Affordable Treatment: Timely access to dermatologic care and effective treatments remains a challenge, often leading to prolonged suffering and worsened symptoms.
- Daily Struggles of Patients and Caregivers: Parents and caregivers spend significant time managing the condition, including frequent doctor visits and providing ongoing support.
- **Psycho-Social Impact:** Atopic eczema contributes to higher rates of anxiety, depression, stigma, and isolation, affecting both patients and their families.
- **Financial Impact:** Patients and caregivers face financial strain from medical costs, medications, and lost wages due to the impact of the condition.







Cards

The customisable social media cards featured real patients and their quotes from <u>EFA's Atopical Lives</u> online exhibition.



EFA Campaign in numbers

The #AtopicEczemaUnfiltered campaign raised awareness about the challenges of living with atopic eczema, engaging a diverse range of audiences including healthcare professionals, civil society organizations, and EFA's community. Overall the campaign achieved **over 5,000 impressions and a reach of 2,580**, demonstrating its broad engagement across platforms.

On social media (<u>Linkedin</u>, <u>X</u>, <u>Instagram</u> and <u>Facebook</u>), the campaign generated **51 posts with +340 engagements and +100 clicks**, while email campaign reached **1,051 recipients**, **with an average open rate of 36.5% and a click-through rate of 19.4%**. Website traffic also reflected audience interest, with **1,227 users and 2,455 page views** across key campaign pages. Below is a detailed analysis of the campaign's numbers.





Social Media				
Total posts	51			
Impressions	5,259			
Engagement	342			
Reach (Instagram, Facebook)	2,580			
Link Clicks (LinkedIn, Facebook)	111			

Mailings				
Total mailings	11			
Recipients (healthcare professionals, NGOs, EFA Newsletter)	1,051			
Av. Opening rate	36.5%			
Av. Click through rate	19.4%			

efanet.org				
June - September 2024	Users	Page views		
EFA Campaign page - WAED	600	1173		
EFA Campaign page - Join	456	979		
EFA Campaign page - Stories	85	143		
EFA Campaign page - Advocacy	69	121		
News - WAED toolkit is out	16	38		
TOTAL	1227	2455		





Atopical Lives

The <u>#AtopicalLives exhibition</u> is an EFA project featuring real people affected by atopic eczema of different age groups, portraying the similarities and differences among patients in Europe for the first time.

On <u>World Atopic Eczema Day 2023</u>, EFA released a new video series to complete the exhibition. The videos feature the daily lives of child and adult patients living with atopic eczema in Europe and were produced in collaboration with EFA Member associations from Serbia, Slovenia, Spain and Turkey.



'Under the skin you see' (adult patient documentary): An endless race to find a balance between the constraints of your illness and the will to live to the fullest. Watch the atopic eczema patients on top of their lives in English, Slovenian, Serbian and Turkish.



'Skin in the game' (child patient documentary): Daily treatments and family - children with atopic eczema learn early the importance of discipline to be healthy and play, skin in the game. Watch it in English, Spanish and Turkish.

#AtopicalLives documentaries 2023-2024				
Video title	Views	Impressions		
Under the skin you see (EN)	80	2416		
Under the skin you see (trailer)	187	491		
Pod kožo, ki jo vidite (SLO)	13	427		
Tüm tuhaflıklara rağmen (TRK)	22	531		
Pogledaj ispod kože (SR)	71	654		
Skin in the game (EN)	43	230		
Oyun söz konusu olunca cilt (TK)	29	255		
La piel en el juego (SP)	49	382		
TOTAL	494	5386		





Reach out to MEPs

We reached out to 12 Members of the European Parliament (MEPs) to raise awareness about the needs of atopic eczema patients. MEP András Kulja (EPP) not only supported World Atopic Eczema Day on social media but also agreed to meet with EFA on 30 September to discuss the campaign and the pressing issues faced by atopic eczema patients

EFA COMMUNITY

Building awareness and support in Europe

World Atopic Eczema Day 2024 brought together EFA members and partners to raise awareness, improve access to care, and foster connections within the atopic eczema community. Six member organizations implemented impactful projects with EFA financial

Thank you, MEP Andras Kulja MD, for standing with patients on World

#AtopicEczemaDay! Your support is invaluable for raising awareness and
advocating for better care, all to improve the lives of #patients with atopic eczema
across Europe.

Andras Kulja MD • 2nd

Member of the European Parliament | Vice-Chair of the ENVI Committee | Surge...
4d • ⑤

Today, we stand with the thousands in Hungary and millions across Europe who
face the relentless challenges of atopic eczema—a condition that goes beyond
skin. For those affected, it's a daily struggle with pain, chronic ...more

European Federation of Allergy and Airways Diseases Patients' A...

FFA



support, including <u>Udruženje pacijenata s alergijama</u>, astmom i atopijskim dermatitisom, <u>Zavod Atopika</u>, <u>Društvo Atopijski dermatitis</u>, <u>Allergia Iho Astma</u>, <u>Asociación Española de Personas con Alergia a</u> <u>Alimentos y Látex (AEPNAA)</u>, <u>Vereniging voor Mensen met Constitutioneel Eczeem (VMCE)</u>. Through personal consultations, social media campaigns and local events, these initiatives provided patients with practical resources, peer support, and access to consultations with the healthcare professionals.

The #EFACommunity efforts were remarkable: over 100 patients received personalised consultations and social media campaigns reached more than 77,000 people. These activities also drove new memberships to organisations, increased social media followings and increased awareness of atopic eczema's challenges and care needs.

By empowering patients and building a more connected community, these projects have laid a solid foundation for future efforts to improve the lives of people with atopic eczema at national and European levels.

Participating organisations and activities

EFA Community addressed key challenges:

Access to Better Atopic Eczema Care: EFA members emphasised the urgent need for faster access to dermatologists and specialists. Long waiting times leave patients feeling unsupported and often drive them to seek unreliable information.

Resource Management: Despite facing time and staffing constraints, many organizations efficiently achieved their goals by leveraging EFA's World Atopic Eczema Day (WAED) toolkits, highlighting the value of shared resources.





Peer Support: Peer interactions emerged as a vital aspect of the campaigns. Patients found emotional relief and practical insights through connections with others who share similar experiences, reinforcing the power of community.

Community Engagement: Social media and digital platforms were instrumental in reaching large audiences, with significant engagement and new memberships reported across all participating organisations. Television programs and local events also played a key role in raising awareness.

Udruženje pacijenata s alergijama, astmom i atopijskim dermatitisom (AAA Association), Bosnia & Herzegovina - "Navigating Eczema: A Path to Support"

The AAA Association's campaign highlighted the vital need for education and health literacy for patients with severe atopic dermatitis. Building on these efforts, the organisation plans to expand its Atopy School project to further address these critical gaps.

Through their campaign, the AAA Association provided 43 free patient check-ups and organised educational workshops attended by 40 participants. Their activities resonated widely, drawing attention from policymakers, healthcare providers, and media outlets.

In numbers:

- Reach: 60 attendees at events, 200 people engaged through email campaigns
- Engagement: 16 volunteers, 23 new followers and 13 media articles covering the campaign
- Social Media Impact: total reach of 23,000 with 112 likes across platforms

Zavod Atopika (Institute Atopika), Slovenia – Workshops and consultations

The project placed a strong emphasis on fostering community connections and delivering tailored support to patients. By collaborating with 10 external organisations, the initiative successfully enhanced available resources and expanded its network.

The project provided direct consultations to 15 families and engaged over 150 participants in workshops and public events aimed at raising awareness about atopic eczema.

In numbers:

- Social Media Reach: 40 posts and 35,000 total reach.
- Workshops: over **20 children participated in creative activities** fostering social interaction.

Društvo Atopijski dermatitis, Slovenia - "Get Your Answers" Marathon

As part of the project, one-on-one doctor consultations were organised for 53 patients and caregivers. These sessions provided a safe and supportive space for participants to share their experiences and concerns. The consultations highlighted a critical need for faster access to healthcare specialists, drawing attention to the challenges posed by long waiting times for medical care. The campaign was covered on Slovenian TV and increased awareness of AD across Slovenia.

In numbers:

- Social Media Engagement: 109 likes, 6 shares, and 4,905 impressions.
- Membership growth: 16 new social media followers and 7 new membership applications.





Allergia Iho Astma (Finnish Allergy, Skin, and Asthma Federation), Finland – Atopic Eczema Day Campaign & Activity Trail

The project emphasized the importance of fostering a supportive environment for patients and caregivers to share their experiences and concerns. There is an urgent need for faster access to healthcare specialists, drawing attention to the challenges posed by long waiting times for medical care.

To amplify awareness, Finnish Federation combined local and digital outreach efforts. Key activities included designing posters for local events, developing social media content in Finnish and organising three community events. Materials were also distributed to 40 associations across Finland, fostering collaboration and enlarging the campaign's reach.

In numbers:

- Reached 37,000 people through social media
- Gained 18 new members for the association
- Inspired 13 out of 43 national associations to contribute with activities to the WAED campaign
- Peer support and educational materials helped raise awareness.

Asociación Española de Personas con Alergia a Alimentos y Látex (AEPNAA), Spain

AEPNAA's #AtopicEczemaUnfiltered or 'La Dermatitis Atópica Sin Filtros' campaign raised awareness about the significant physical, emotional, social, and economic burdens of atopic eczema (AE) while empowering patients to share their experiences. The campaign provided a comprehensive view of living with AE through patient testimonials and professional insights and emphasised the importance of understanding and addressing this often-overlooked condition.

The campaign featured a mix of digital outreach, including social media posts, videos, an allergologist's article, email newsletters and blog content. These efforts helped engage patients and the broader public, fostering greater visibility of AE and promoting self-advocacy within the community.

In numbers:

- Social Media Reach: 18,736 views across Instagram, Facebook, and X.
- Engagement: 440 interactions on social media.
- Direct Outreach: ~1,200 members reached via newsletters and blog articles.

Vereniging voor Mensen met Constitutioneel Eczeem (VMCE), the Netherlands (report pending)





Acknowledgments

World Atopic Eczema Day

World Atopic Eczema Day is coordinated by the International Alliance of Dermatology Patient Organizations (GlobalSkin) and the European Federation of Allergy and Airways (EFA). We extend our sincere thanks to our sustainable corporate partners Sanofi and Regeneron for their support through unrestricted grants.

Atopical Lives online exhibition

EFA thanks the 19 patients and their carers, who chose to contribute to the atopic eczema community in 2018 and 2022 by welcoming us to their lives in eight different countries (Czech Republic, France, Italy, the Netherlands, Serbia, Slovenia, Spain, Turkey).

EFA thanks its sustainable funding partners whose unrestricted educational grants have made possible the Atopical Lives project as follows:

- Pfizer and Sanofi/Regeneron for the 2018 pictures, video and exhibition
- AbbVie and Sanofi/Regeneron for the 2022 pictures and 2023 videos