

THE
BURDEN
OF ATOPIC ECZEMA

Atopic dermatitis/eczema (AD/E) is considered the most common inflammatory skin disease, affecting up to 20% of children and adolescents worldwide. In Europe, its prevalence has steadily increased over the last four decades¹.

Often dismissed as 'just a skin condition', atopic eczema heavily impacts patients' physical and mental wellbeing, social life, and finances. Despite advances in how the disease is understood and managed, innovations and access to services and newer effective therapy remain crucial for patients.

The seriousness of AD/E and surrounding stigma is poorly understood by many, limiting progress in addressing quality-of-life issues and leaving patients and families to carry the burden by themselves.

Following one year of in-depth discussions around the reality of AD/E, patients and doctors from across Europe have reached their consensus on the struggle of AD/E patients in Europe. This call to action provides guidance and impetus to advance atopic eczema care.

“ The suffering of many AD/E patients today is alarming. This European Consensus should act as a wakeup call for health authorities to introduce structural changes in the healthcare systems to fully address AD/E and reduce the burden on patients.”

*Consensus Committee Co-Chair
and healthcare professional representative,
Andreas Wollenberg*

¹ Kowalska-Oleđzka E, Czarnaeka M, Baran A. Epidemiology of atopic dermatitis in Europe. J Drug Assess. 2019;8(1):126-8.

EUROPEAN CALL TO ACTION ON

The European Federation of Allergy and Airways Diseases Patients' Organisations (EFA) calls for policymakers to recognise that AD/E is a serious, complex chronic disease, and that patients require long-term treatment and multidisciplinary care to cope with it.

Policymakers must ensure that the patient journey for AD/E is respected at each stage, from diagnosis to treatment and care, with a supportive environment for them and their families. These recommendations for policymakers have been devised by EFA, based on insights from the multidisciplinary panel which informed the 2022 European Consensus Report on the burden of atopic dermatitis/Eczema in Europe².

Reduce the physical and emotional burden of AD/E on patients

Improve health literacy around allergy and AD/E to address misconceptions, reduce stigma, tackle false information on 'informal treatments' and encourage AD/E patients to seek intervention.

- EFA calls on policymakers to **support health information** that stresses that AD/E is not contagious but that it comes with a heavy burden for patients and caregivers.

Remote and flexible working schedules, financial supports, to enable AD/E patients and carers to manage and consult on their treatment alongside everyday life.

Improve the patient journey for AD/E patients

EFA calls that policymakers to introduce structural changes in their national health systems, eventually **improve diagnosis of the disease**, by:

- Enabling healthcare systems to adapt their focus away from merely diagnosing the disease, to **include continuity of care and support** for patients and families.
- Respecting the newest clinical guidelines, establishing an **agile system of referral for AD/E patients** that clearly defines responsibilities between GPs and dermatologists at the earliest opportunity, and improving interactions between healthcare professionals. This must also include **enhanced education for primary care professionals and pediatricians**, so no diagnosis is missed.



A statutory right to referral for each patient diagnosed with AD/E in Europe. As part of this, maintenance care for patients should be managed by a specialist as the severity of the disease can change over time, while primary care physicians should have basic training and be aware of their referral network.

- Incentivising healthcare systems to **seek the right patient pathway** based on response to treatments and quality of life.



A new clinical approach, where AD/E diagnosis is not static but adapts based on the developing condition of the patient and latest scientific evidence, to support a patient-centred care pathway.

EFA recommends that, to **improve access to personalised treatment and care**, policymakers must:

- **Support the introduction of personalised treatment plans** from day one of diagnosis, allowing AD/E patients to receive continuity of care from the get-go. This should also include further preparation outside regular consultation appointments, to improve efficiency.
- Reinforce existing national reference centers to cover and **enlarge the expertise on severe AD/E**.
- Set up Centres of Excellence on AD/E, with **multidisciplinary teams and ring-fenced budgets**.
- **Train doctors** in soft skills to allow for doctor-patient discussions on therapies concerns and allow doctors to provide the right information to patients.

ATOPIC DERMATITIS / ECZEMA

To properly support the process of **developing new treatments for AD/E**, EFA calls on policymakers to:

- **Introduce regulatory changes at EU level that ensure patients are involved** in the design and implementation of clinical trials.
- Support the introduction of quality-of-life endpoints in all relevant clinical trials.
- **Call on regulators to recognise** the limitations in current methodologies used to grade the overwhelming impact of AD/E and measure itch (e.g., EQ-5D), alongside developing new methodologies and tools for this purpose.
- **Earmark EU funding for research** to help experts better understand the causes and mechanisms of AD/E and develop improved treatments.



Building on the example of U-BIOPRED and 3TR EU-IMI projects on asthma as a best practice, **EFA calls for the introduction of an ambitious research project under the Innovative Health Initiative (IHI) on AD/E** which in turn could lead to improved treatment, quality of life and, ultimately, prevention.

- **Put the right policy frameworks in place to capitalise** on the opportunities offered by Real World Data to better understand AD/E and aid the development of new treatments.



EFA calls for the establishment of national registries for AD/E which will allow the collection of high-quality data, with the ultimate objective of improving care and outcomes for patients.

Introduce health policy changes to **guarantee that AD/E patients, especially those with comorbidities, receive the best treatment and multidisciplinary care.**

- EFA calls for a **reinforced role for specialised nurses**, as their function is essential to instruct patients on treatment and disease management.
- EFA calls for an **increased role for psychologists in AD/E care**, including training in dermatology as part of their curricula, to address the psychological element of the disease and encourage discussion on mind/body interactions.
- EFA calls for an **enhanced role for pharmacists**, to support patients when necessary, according to the primary care situation. This should include training modules for pharmacists on the detection and management of topical corticosteroids concerns, which may improve practices and adherence to treatment.
- **EFA calls for an enhanced role for nutritionists**, to create a more holistic approach to AD/E care and in recognition of the fact that intervention here can add to a multidisciplinary care approach and improve patients' quality of life.

To install a supportive environment for patients addressing treatment and care, policymakers must:

- **Support the financing, set up and integration of 'atopic schools' in national healthcare systems** as part of each AD/E reference center.
- **Ensure that health systems are equipped to make the most of developments in digital healthcare** to ensure that the care options offered to AD/E patients are comprehensive. This should include the creation of a framework that allows AD/E patients to fully utilise telemedicine, providing options for the self-management and support of their condition.

Improve treatment adherence and the patient pathway by looking at quality standard pathways and Patient Reported Outcomes (PROs) and introduce a 'no blame' approach to non-adherence.

- EFA calls for more **emphasis on AD/E flare-up prevention and disease management** to dramatically reduce the recourse to hospitalisation due to AD/E.

Reduce the financial and economic burden on AD/E patients

Introduce a new classification for the reimbursement of AD/E treatments that guarantee patients sufficient access to basic necessary care such as emollients, bedding, clothing or nutritional support.

Recognise the societal and human costs of access delays, particularly economic considerations such as lost productivity through work absence.

² The Burden of Atopic Eczema / Dermatitis - European Consensus Report 2022, European Federation of Allergy and Airways Diseases Patients' Associations (EFA), September 2022: www.efanet.org/images/2022/EFA_Burden_of_Atopic_Eczema.pdf

EUROPEAN CONSENSUS REPORT 2022

The Atopic Eczema Consensus Call to Action emanates from a project ran by EFA in 2021-2022 aiming at informing healthcare policymakers and stakeholders on current unmet needs in the care of AD/E in Europe.

The report results from the discussions and agreements of a panel of 15 leading European AD/E healthcare professionals and expert patients representing several sectors and European countries. The report is the result of the discussions of the Consensus Committee, a panel of 15 leading European AD/E healthcare professionals and expert patients representing several sectors and European countries. Their discussions were facilitated by EFA.

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The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) is a network of 46 allergy, asthma and COPD patients' organisations in 26 European countries and it works for European patients with allergy, asthma and chronic obstructive pulmonary disease (COPD) to live uncompromised lives, have the right and access to the best quality care and a safe environment.



35 Rue du Congrès, 1000 Brussels, Belgium
Tel.: +32 (0)2 227 2712
E-mail: info@efanet.org
www.efanet.org



@EFA_Patients



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