



European Federation of Allergy and Airways
Diseases Patients' Associations

EFA Atopic Dermatitis/ Eczema Consensus Europe Project

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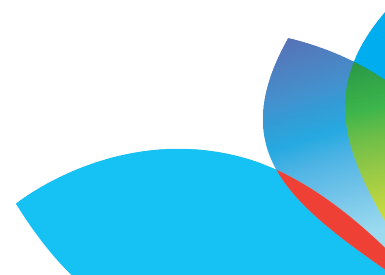
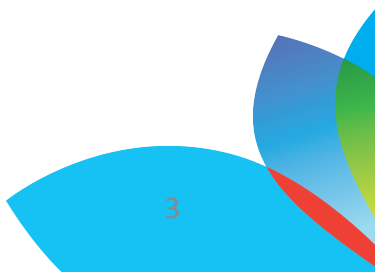


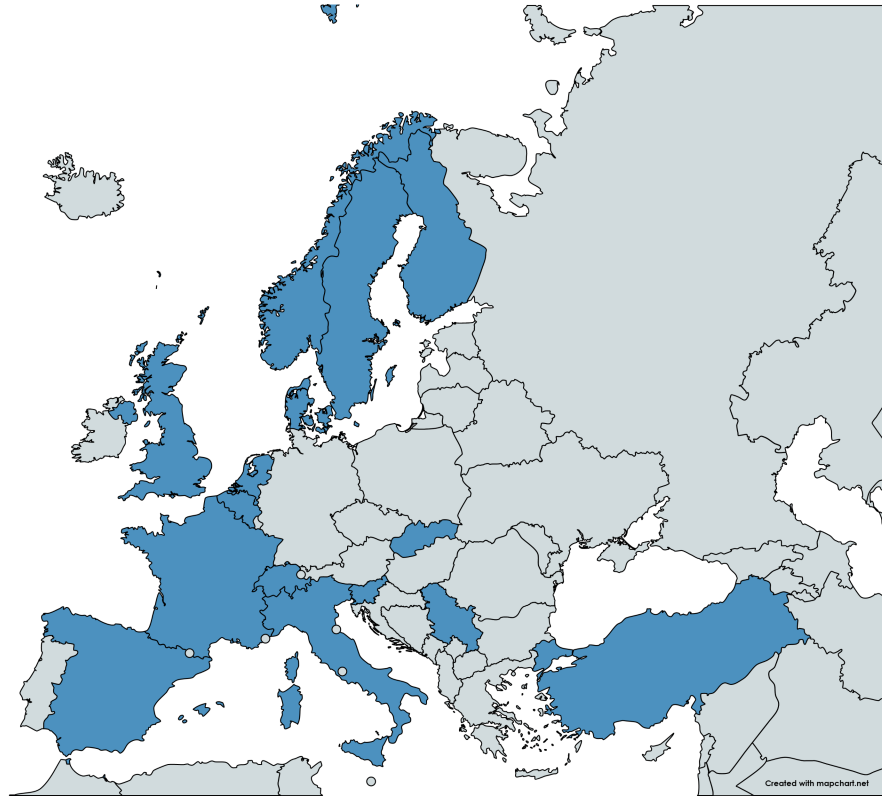
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Context and Background

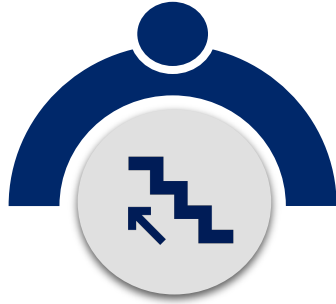


Who are we?



- A European federation of **45** allergy, asthma and chronic obstructive pulmonary disease (COPD) national patients' associations, present in **26 European countries**
- Currently **21 members are active in the atopic dermatitis community, in 17 countries** (map)
- We are the voice for over 200 million people living with allergy, asthma, COPD and atopic dermatitis in Europe
- We are dedicated to making Europe a place where patients can live **uncompromised lives**, have the **right and access to high quality care**, **participate** in their care, and to have a **safe environment**.

Project background



Despite growing awareness and advancement around skin conditions, **the burden** atopic eczema/dermatitis (AD/E) patients endure each day is **not sufficiently recognised**.



The lack of a strong consensus on the burden of AD/E in Europe from the healthcare community leads to a persisting approach to give **low priority to atopic eczema as a serious chronic disease**.



To fill the awareness and care gaps and develop a consensus position on the burden of AD/E on patients, **in early 2021 EFA created the AD/E Consensus Europe project**.

EFA has been vocal in advocating change for all people living with AD/E in Europe.



In 2018, EFA published the biggest Quality of Life survey report on AD/E, *Itching for Life*, which surveyed almost 2,000 patients across 9 European countries. This breakthrough piece shone a light on the disease burden felt by AD/E patients.

Objectives and scope of the project



Develop a consensus report containing policy recommendations on the burden of Atopic Eczema in Europe.

Raise awareness on the emotional and economic burden of Atopic Eczema/Dermatitis

Bring the discussion on Atopic Eczema/Dermatitis at higher, international level

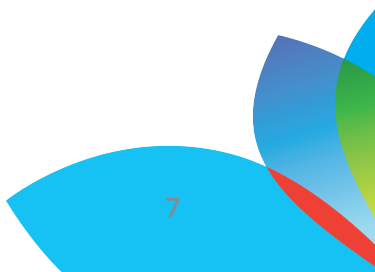


Creation of a pan-European Consensus Committee, comprised of **15 key opinion leaders** amongst **patients and healthcare professionals** to contribute to the creation of the Consensus Report by providing an understanding of the current situation from a medical and patient perspective.



First meeting held in April 2021 with the second being held in October 2021. Final report and recommendations published in September 2022

Developing Atopic Eczema Burden Consensus



Consensus Committee Members 1/2

Co-Chairs



Andreas Wollenberg

Prof. Dept. of Dermatology, Ludwig-Maximilian University, Munich. Head of Conservative and Pediatric Dermatology Unit, Dept. of Dermatology, LMU Munich



Joana Camillo

Founding President, Portuguese Association of Atopic Dermatitis (ADERMAP) and Executive Director of Creating Health



Gitte Rasmussen

Clinical Nurse Specialist, Department of Dermatology – Aarhus University Hospital



Carle Paul

Full Professor and former Chair, Department of Dermatology, Larrey Hospital – CHU Toulouse and Paul Sabatier University



Sibylle Plank-Habibi

Head of Dietitian Team, Department of Dermatology and Allergology – Vital Klinik Alzenau



Ozlem Ceylan

Founding President, Living with Allergy Association



Swen Malte John

Chair, Department of Dermatology, University of Osnabrück



Mette Sondergaard Deleuran

Chair, Department of Dermatology, University of Aarhus

Consensus Committee Members 2/2



Jan Gutermuth

Chair, Department of Dermatology
& Head of Skin Immunology,
Immune Tolerance Research Group,
University Hospital Brussels



Tina Mesaric

Project leader – Institute
Atopika



Elizabeth Angier

Clinical Director, Primary Care –
West Hampshire Clinical
Commissioning Group – University
of Southampton



Esther Serra Baldrich

Deputy Head of the Immunoallergic
Cutaneous Immune Diseases Unit of the
Dermatology Department of the
Hospital de Sant Pau.



Zsuzsanna Szalai

Leader of the department of
Paediatric Dermatology of Heim
Pal National Children's Institute
Budapest, Hungary



Rob Horne

UCL Professor of Behavioural
Medicine, UCL School of Pharmacy
University College London



Johannes Ring

Professor and Chairman of the
Department of Dermatology and
Allergy, Biederstein of the
Technische Universität München



Snezana Sundic Vardic

President Association Allergy
and me. Marketing
Consultant

Consensus Meetings

**First meeting
April 2021**

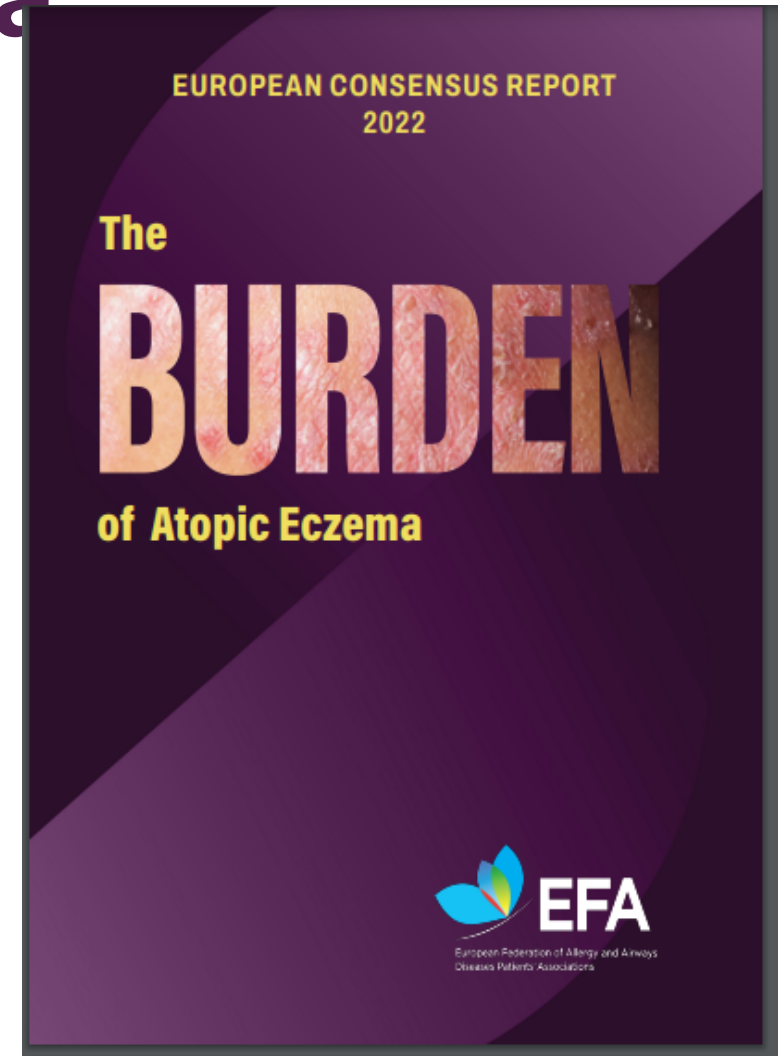
- Literature review ahead of the meeting
- Discussion on the main burdens of the disease; Participants provided their input, adding in their sectoral and personal experience
- Identification of challenges in the patient pathway

**Second
meeting
October 2021**

- Participants worked to develop solutions and actionable policy proposals that reflect the consensus position of both healthcare professionals and patient representatives
- After the meeting EFA developed a list of policy recommendations, reflecting the need for additional action on AD/E across Europe.

European Consensus Report on the Burden of Atopic Eczema

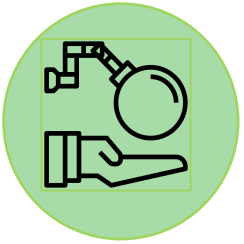
- The AD/E Consensus report has been published on 7 September 2022
- The Report is available in 10 languages
- A social media campaign will take place to launch the report, ahead of the WAED



Policy recommendations and calls to action

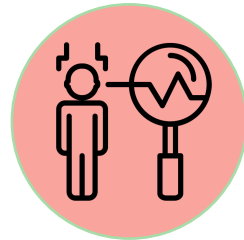
Main topics and challenges from the Consensus Committee

Consensus Committee members identified the following categories of challenges for AD/E patients, before moving to develop specific recommendations and calls for action:



Physical and emotional
burden of AD/E

The burden of AD/E can impact a person in various ways throughout their life.



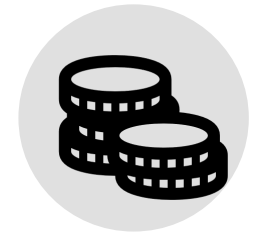
Diagnosis and care burden
of AD/E

People with AD/E can face a challenging patient journey due to a lack of awareness on the disease and barriers in the healthcare system, affecting both patients and specialists.



Developing new
treatments for AD/E

New treatments for AD/E need to be developed and accessible to patients.
The access to existing and novel treatments should be guaranteed to all patients



Financial and economic
burden of AD/E

The lack of reimbursement of medically necessary products and productivity loss impose a financial burden on patients and caregivers.

Other deliverables

Journal Article and Advocacy Toolkit for Patients' Organisations

Consensus Paper

- *Expert consensus on the burden of atopic dermatitis/eczema in Europe*, to be submitted to the JEADV for publication

Advocacy Toolkit

- To accompany the final report of the AD/E Consensus Committee and the policy recommendations, an advocacy toolkit has been developed for use at European and national level.



Overview of key stakeholders profiles



Template outreach letter for national ministries of health



Social media content



Project slide deck

What's next?

What's next?

Finalisation of the Article and submission to the JEADV

Advocacy toolkit to be shared with Patients' Organisations

Advocacy training for EFA members

Translation of the advocacy toolkit in 10 languages

Video recording of consensus committee members for national outreach

EU and WHO level advocacy

THANK YOU

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