Advocacy Alignment

Workshop 6th Oct 2021



The aims of the workshop



PURPOSE

To align on the needs of the Atopic Eczema community that can be supported by the GlobalSkin activities

OBJECTIVES

Identify the needs of the Atopic

Eczema community at member

organizations that can be supported

by global activities

OUTCOMES

A framework for a global policy document that can be adapted by members. Plus, a common understanding of how GlobalSkin resources can be leveraged by members



The main themes emerging

(after prioritization exercise)



Access to new and emerging therapies; protocols that restrict access; cost of self-care and financial impacts caused

The need for a holistic, multidisciplinary approach to AE care that is standardized through the use of better guidelines

Improve access to dermatologists and increase the number available; increase knowledge of primary care physicians to facilitate faster and accurate diagnoses

Other themes were also mentioned

(position 4 through 11 after the prioritization exercise)

4: Geographic disparities Overcoming disparities in both care and the available treatments

5: AE in the workplace Facilitating employers understanding of AE as a chronic condition

6: Public awareness Addressing myths, barriers and facilitating public support

7: Research funding Encouraging more research into AE, its impact and its treatment

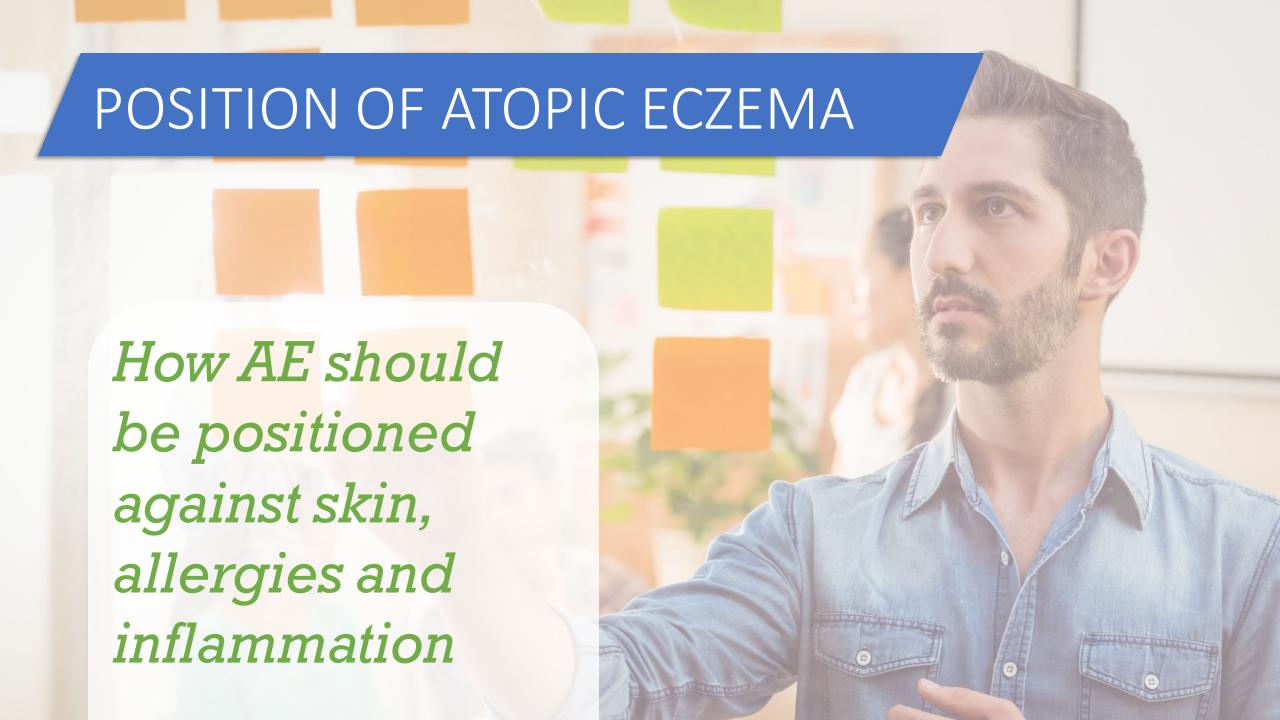
8. Family finances Addressing the overall financial burden caused by AE

9: Burden of AE Developing more evidence (e.g. GRIDD) to outline the burden of AE

10: Understanding in schools Ensuring schools have the knowledge and policies around AE

11: Guidelines on corticosteroids

New guidelines that ensure responsible use of corticosteroids





Atopic Eczema has unique challenges



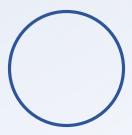
CLEAR FEEDBACK THAT ATOPIC ECZEMA IS UNIQUE

- Needs to be at the forefront and where possible on its own in the communication
- Attributes of AE are unique (e.g. itch) and need to be understood clearly by others



IMPACT IS HIGHER THAN MANY OTHER CONDITIONS

- E.g. HIV controlled with one pill a day AE requires much more intensive daily care
- Need to be careful of diluting this message by including AE with other conditions



WHERE NECESSARY BE FLEXIBLE IN HOW AE IS POSITIONED

- Look at what the audience cares about
- If they are focused on inflammation or allergies then position AE as a pressing disease there
- If focus is on dermatology, then position AE as the most pressing disease there



Areas of current work by attendees

FDA/Topical Steroids

Pressure for regulatory action to change practices General education on topical steroid use for HCPs

Racial disparities

Access to care barriers
Misdiagnoses due to skin color

The elderly and AE

Misdiagnosis in the elderly

Quality Register (Sweden)

Includes a look at systemic treatments
Will hopefully identify what approaches are best for which kinds of patient

Benchmarks

Global efforts to establish benchmarks of care and good practices

Slovenia registry

Designed by patients to capture the true experience