



Take Action Advocacy Toolkit

For too long now, the needs of those living with eczema or atopic dermatitis have been neglected. Misunderstanding, lack of awareness, and a generally low priority in health systems, means that people living with these conditions continue to face huge challenges, every day.

AltogetherEczema has been created to break this paradigm. The new global patient community will champion what matters most to people living eczema or atopic dermatitis, with an emphasis on action. Today, any individual, community or group can use their voice to make a difference.

Making a difference is what this 'Take Action Advocacy Toolkit' is all about. AltogetherEczema advocacy aims to **bring together diverse groups, in order to amplify common messages and make unified calls for action.**

Effective AltogetherEczema Advocacy means **convincing decision-makers** – *those individuals or organizations that can make the changes that we want to become reality* – that they should:

1. **Support the AltogetherEczema campaign and what it stands for;**
and
2. **Recommend that eczema and atopic dermatitis services, care & treatment are given greater priority within health systems**

These decision-maker 'asks' will vary across the world, but they should form the foundation of the action we want to incite!

Within this toolkit, you will find guidance and tools to inform local advocacy activity, helping you to tell a compelling story, find partners and engage the people that make relevant decisions to act. Check out the information, advice & assets provided and get involved.



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The content of this toolkit includes:

- ✓ **Your role**
- ✓ **The principles of effective advocacy**
- ✓ **Materials checklist**
- ✓ **Planning worksheet**
- ✓ **Top tips for meetings**
- ✓ **Do's and do not's for meetings**
- ✓ **Briefing paper for decision makers**
- ✓ **Template letter for decision makers**



Your role

As an empowered member of the AltogetherEczema community, you have the most important role in advocacy. Your voice, will, passion and enthusiasm must be harnessed, if we are to change lives all over the world!

Advocacy starts when different people **unite behind a common goal**. There are already many active organizations for you to partner with – whether you live, or care for someone, with eczema or atopic dermatitis.

How can **YOU** get started?

- Connect with your local patient association by using the [AltogetherEczema directory](#) and learn about key advocacy issues in your country.
 - If there is no patient association in your country, contact GlobalSkin for help at info@altogethereczema.org.
- Once you are part of a patient association, use this toolkit to plan and execute advocacy activity!



Principles of effective advocacy

Although the advocacy landscape will be different in each country, there are a few key principles* to adhere to.

Below is a 'roadmap' for delivering effective advocacy:

1. **Define the situation** – What is the impact of eczema & atopic dermatitis? What are the current policies or barriers to success that need changing?
2. **Establish goal and objectives** – Develop a clear long-term goal and the objectives that will help deliver it.
3. **Identifying your target audiences** – Who are the individuals or groups that make the decisions you want to change? Who influences them?
4. **Developing key messages to influence your target audience(s)** – Harness key context and storytelling to develop messages that will engage your target audience.
5. **Developing and implementing an advocacy plan** – Utilize different communication & campaigning methods to reach target audiences and make a compelling case for change.
6. **Monitoring & evaluation** – Track all of your advocacy activity, measure its success and use feedback to refine your approach.

* principles adapted from 'Stop the global epidemic of chronic disease : a practical guide to successful advocacy' [WHO]. Available here: <http://www.who.int/chp/advocacy/en/>



Materials checklist



Are you aware of any...

- Relevant lobby days?
- Key election campaigns?
- Relevant marches/rallies?
- Key conferences or speeches?



Have you considered creating or leveraging any...

- Letters and emails?
- Social media content? (check out the AltogetherEczema social media toolkit housed under "Your Community – Make the Case" for more!)
- Articles that could be pitched to traditional media outlets such as your regional newspapers?
- Petitions?
- Opinion polls?
- Policy papers or "white papers"?





Advocacy planning worksheet

When developing an advocacy strategy, there are a number of key questions to ask yourself, both in terms of the issue at hand and the decision makers involved. Use this worksheet to ensure you have covered all of your bases!

Issues Clarification:

1. What is the ONE issue that needs some kind of change? (Describe in one sentence)

2. Who is the person in power (policy maker) who can influence or make a decision about the change you would like to see? (More than one? Complete a worksheet for each)

3. What is this person's title?

4. What can this person truly and realistically do to bring about the change you want? (e.g. introduce a law/bill, introduce you to the policymaker, change a law, list a drug, open a clinic.....)



5. Describe what you think this person most cares about in his/her role? What are his/her primary priorities or motivations?

6. How can you connect your issue to one or more of these priorities or motivations?

7. What objections is this person likely to have to your request?

8. How can you address these concerns? Validate and offer an alternative way of viewing the objection.

Additional notes:



Top tips for meetings

How to prepare

1. Source images, statistics or a short emotive patient video to help the decision maker truly understand what it feels like to live with eczema and atopic dermatitis.
2. Consider what persuasive evidence you can use to support your case, such as statistics or a petition with signatures.
3. Ask yourself, what does success look like? What is the impact of the change? Can you link success back to the decision maker's own priorities?
4. Identify all the elements of the ASK to present a succinct case; such as timeframe, information about who else to involve, how the change should be announced and by whom.
5. Consider the timing of the meeting request. Is this near an important milestone such as an election or World Atopic Eczema Day?

Once you are fully prepared, participate in the meeting

1. Be on time, well dressed and well organized. Turn your mobile phone off, totally off.
2. Agree to the length of time for the meeting before you get started.
3. Ask the decision maker what they may already have heard about your subject, or if they know someone who is living atopic eczema?



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4. Bring something to show and to leave behind such as the briefing document in this toolkit.
5. Make sure it is a conversation, rather than a 'show'. Ideally, you are building a collaborative working relationship.
6. Be clear on what would be a positive outcome.
7. Thank everyone!
8. Do not give up... Remember, it may take several meetings to achieve your goal.



Do's and do not's for meetings



Do	Do not
Research your meeting contacts and any areas of specialization	Overload the visit with too many issues
Make the case by presenting data and clear examples	Confront, beg or be argumentative
Use examples related to the stakeholders' interests	Overstate your case or be too wordy
Be open to and aware of counter arguments and be prepared to respond to these	Be too specific when dealing with generalist politicians
Admit when you don't know something and offer to find out the answer and follow up with additional information	Make promises that you can't deliver
Treat everyone, regardless of seniority, with respect and thank staff if they facilitated a meeting	Be afraid to take a stand on issues



Briefing document for decision makers

Disease prevalence and description

Atopic dermatitis (AD) is the most common form of eczema. It is currently an incurable, chronic immune-mediated systemic disease with a debilitating effect on 2-10% of adults worldwide.¹ Estimates suggest that up to 27% of the US population have some form of skin condition,² and that 6.6% of the European Union population have skin problems, with significant differences between countries.³

Atopic dermatitis is more than 'just a skin condition'. People living with atopic dermatitis feel its effects – both on their skin (often with a relentless itch, redness, swelling and lesions) and on their well-being (often linked to sleep deprivation, social isolation, symptoms of anxiety and depression, and an overall reduced quality of life). Patients with inadequately controlled atopic dermatitis face the devastating and unpredictable physical and psychological impact of the disease, every day.

While AD can also develop in adulthood, up to 85% of adults with atopic dermatitis have lived with this chronic disease since childhood.⁴

Up to 72% of patients with moderate to severe atopic dermatitis experience atopic comorbidities, including: asthma (approximately 40%), allergic rhinitis (38.5%-51%), allergic conjunctivitis (20%-24%), food allergy (34%), chronic rhinosinusitis (26%) and nasal polyps (13%).⁵

Exacerbations and unmet needs

Patients with severe atopic dermatitis report disease exacerbations up to 192 days per year, meaning that they spend over six months per year in a compromised state of health. Patients with moderate AD experience up to 113 days per year with AD exacerbations.⁶



As atopic dermatitis' visible symptoms and lesions often appear on the hands and face, many adults with atopic dermatitis feel embarrassed, self-conscious, distressed, anxious and often avoid work and social activities.^{5, 6, 7} Fifty per cent of atopic dermatitis patients report feelings of depression and/or anxiety [12], and 39% report feeling often or always embarrassed about their appearance.⁸

Up to 78% of adults with moderate-to-severe disease do not experience significant improvements despite treatment.^{9, 10, 11, 12}

Patients report that 10% of their working time is affected during an exacerbation.⁶ This is further affected by an increased number of sick days.

Treatment

The management of atopic dermatitis, especially when inadequately controlled, is an economic burden for patients. More, it increases when the severity of the disease increases.

Current atopic dermatitis management strategies include restoring the skin barrier, targeting symptoms, minimizing the number of disease exacerbations and reducing their degree and duration while minimizing treatment-related adverse effects.

Topical corticosteroids (TCS) are recognized as the mainstay of atopic dermatitis treatment, but, like any medication, they come with the risk of side effects. For a subset of moderate-to-severe atopic dermatitis patients, TCS have been found to not provide adequate control of the disease or are not advisable.^{13, 14} According to American Academy of Dermatology guidelines, oral immunosuppressive drugs (or systemic treatments) are recommended in AD care for the subset of patients for whom certain treatments (topical regimens and/or phototherapy) do not adequately control the disease. Nevertheless, these treatments are also linked with several short- and long-term adverse effects, safety risks, interactions and contraindications.¹⁵



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Policy landscape

There are no atopic dermatitis-specific healthcare policies in place at global, regional and local levels.

International clinical guidelines for the diagnosis and management of atopic dermatitis do not exist and national standards of care are currently outdated.

Source: [GlobalSkin Position Paper](#)



Template letter for decision makers

[Your Address]

[Decision maker's name & address]

[Date]

Dear **[Name]**,

As an active member of the AltogetherEczema community, I am writing to you to request a meeting to discuss the 2-10% of adults worldwide living with the impact of this life-limiting chronic disease whose awareness and resourcing for treatment is not considered a priority among other conditions.

There are **[insert number]** of people affected by eczema and atopic dermatitis across **[insert name of region]** and the impact is extensive. For instance:

- **[insert statistics from your local organization – e.g. number of working days lost]**

Atopic dermatitis is a complex, chronic immune-mediated disease affecting far more than just the skin. People experience the impact of eczema both on their skin – including a relentless itch, redness, swelling and painful lesions – and on their psychological wellbeing. The disease is often also linked to sleep deprivation, symptoms of anxiety and depression, and an overall reduced quality of life. This can affect people's ability to work and participate in everyday activities, in effect creating social isolation.

Solutions exist that have the potential to improve the health and outcomes of people with the condition, but we need your support.



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I would greatly appreciate the opportunity to discuss the unmet need, the eczema community's aspirations for the future and ultimately what can be done in **[country/region/etc.]** to improve care and treatment. I am available at **[contact email or telephone number] to set up** a time that is convenient for you.. In the meantime, for more information, please refer to the document attached.

Many thanks in advance for your support.

Yours sincerely,

[Name]



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Thank you!

**Your voice can help make a real difference to the
eczema and atopic dermatitis community.**

**If you have any questions, please do not hesitate to get
in touch with the team at info@altogethereczema.org**



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