



WORLD
ATOPIC ECZEMA
DAY

PATIENT ORGANIZATION TOOLKIT

World Atopic Eczema Day 2022

#InsideAtopicEczema



International Alliance of
Dermatology Patient
Organizations

GLOBALSKIN.ORG



EFA

European Federation of Allergy and Airways
Diseases Patients' Associations



Theme 2022: Inside Atopic Eczema

Atopic eczema is one of the most prevalent skin diseases in the world and one of the most under-recognized. Atopic eczema is often dismissed as “just a skin condition,” and patients’ needs are not addressed in a supportive and timely manner.

The Atopic Eczema Community comes together on September 14th to raise awareness for the disease, to speak up about the burden it has on patients and caregivers and to recognize the need for care and treatment that is reflective of the multidimensional nature of the disease.

On World Atopic Eczema Day 2022, we take a look Inside Atopic Eczema and explore five major burdens of the disease: the burden of extreme physical pain and itch, burden on families and caregivers, burden on finances, burden on mental health, and burden of daily management.

We call on healthcare professionals, health policy decision makers and all stakeholders help us build awareness of the burdens of atopic eczema.

Campaign Toolkit

The 2022 World Atopic Eczema Day Toolkit has been developed in partnership by [International Alliance of Dermatology Patient Organizations \(GlobalSkin\)](#) and [European Federation of Allergy and Airways \(EFA\)](#).

Inside this toolkit you will find the messaging for World Atopic Eczema Day 2022 and other tools that will help with your own World Atopic Eczema Day campaign.

#InsideAtopicEczema #AtopicEczemaDay



WORLD ATOPIC ECZEMA DAY

General Awareness

Atopic eczema is more than itchy skin, it is a systemic, multidimensional disease that affects the minds and bodies of people around the world.

Atopic eczema is a complex disease. We raise awareness of the immense burden it has on patients and caregivers and the need for care and treatment that is reflective of the multidimensional nature of the disease.

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INSIDE ATOPIC ECZEMA

"People don't have to be scared, I'm not contagious."

- Severe atopic eczema patient

September 14, 2022

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INSIDE ATOPIC ECZEMA

"We need faster, better treatment, starting from the diagnosis."

- Atopic eczema patient

September 14, 2022

Mental Health
Itch Physical Burden
Financial Burden Redness
Pain Psychological Burden
#InsideAtopicEczema
Burden of Daily Management
Children Multidimensional Disease
Dermatologists Caregivers
Doctors Burning
Families

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Join Us
#InsideAtopicEczema
SEPTEMBER 14, 2022



Burden of Extreme Itch and Physical Pain

Itch is a misunderstood and underestimated burden of atopic eczema. Many patients describe itch as all-consuming and worse than pain. This itch is often accompanied by pain caused by scabbing and the open wounds from the uncontrollable scratching.



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INSIDE ATOPIC ECZEMA

**"In the summer,
everything hurts,
itches and you scratch
until you bleed".**

- Severe atopic eczema patient



September 14, 2022



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INSIDE ATOPIC ECZEMA

**"The whole day your skin
feels itchy and painful.
You have to do your
very best to function
normally."**

- Atopic eczema patient



September 14, 2022

Burden on Family and Caregivers

Parents of atopic eczema patients need to spend hours every day caring for their child's skin; this takes focus away from other children. Time is lost to repeated doctor's visits and spouses of patients are required to provide continuous support.



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INSIDE ATOPIC ECZEMA

**"It breaks my
heart to see how
she suffers from
the itching."**

- Parent of a child with atopic eczema



September 14, 2022



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INSIDE ATOPIC ECZEMA

**"Sometimes I'm so tired
from all those sleepless
nights that I hardly
know my name."**

- Parent of a child with
atopic eczema



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Burden on Finances

Atopic eczema patients and caregivers see their family's savings reduced to cover for cost of doctors, specialists, expensive prescribed or over-the-counter medications, and topical treatments. Patients can also experience a loss of wages due to their inability to work as a result of their condition.



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INSIDE ATOPIC ECZEMA

"It puts a lot of mental and physical strain on you, and also on finances."
- Severe atopic eczema



September 14, 2022



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INSIDE ATOPIC ECZEMA

"A disease like atopic eczema is very costly. We need financial support from health insurance."
- Atopic eczema patient



September 14, 2022

Burden on Mental Health

There is a high level of depression and frustration for patients with atopic eczema compared to other skin diseases. Patients are expected to perform at a regular level (at work, school and life) because they are experiencing 'just eczema'.



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INSIDE ATOPIC ECZEMA

"Doctors don't always take you seriously. It's not life-threatening, but we suffer a lot mentally."
- Atopic eczema patient



September 14, 2022



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INSIDE ATOPIC ECZEMA

"People with the disease don't live anymore, we avoid going out or meeting people."
- Atopic eczema patient



September 14, 2022



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Burden of Daily Management

Topical treatments to help manage atopic eczema are burdensome and messy, as they need to be applied every day which takes a lot of time. Patients are careful of food choices to avoid flare ups, and lots of consideration on soaps, fabrics, sanitizers and sun exposure.

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INSIDE ATOPIC ECZEMA

"Sometimes I am not able to hold anything with my hands. I need help."

- Severe atopic eczema patient

September 14, 2022

WORLD ATOPIC ECZEMA DAY

INSIDE ATOPIC ECZEMA

"I like to be with friends and go out for dinner. But it is not easy to live spontaneously."

- Severe atopic eczema patient

September 14, 2022

Blanks

Use these blank cards to fill in your own text and add your own logo.

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September 14, 2022 #InsideAtopicEczema

WORLD ATOPIC ECZEMA DAY



Call to Action

Inside-Out Activity

As part of our campaign to show the **#InsideOfAtopicEczema** we are calling on patients, carers, and healthcare professionals to join us in turning our clothes inside out to make atopic eczema visible. When people living with atopic eczema face itching and discomfort every day, even wearing clothes can become unbearable on their sensitive skin. We want to bring the community together and give attention to the everyday burden in our Inside Out action.

Join us in the **#InsideAtopicEczema** Challenge! The goal is to create a virtual “flash mob” to raise awareness of the burdens of Atopic Eczema. Share and re-share user videos and pictures to keep the messages coming!

Who can participate?

Social media users

For “boomerangs”: Instagram users

For video submission: Anyone with Facebook, Twitter or Instagram

How to participate?

Take pictures or videos of yourself showing off your inside-out piece of clothing.

How to participate?

Create a video (or boomerang) showing off your inside-out piece of clothing.

How to submit your pictures or videos

There are 2 ways: post it on your own social media, and then tag us (you can find our handles on the last page of this toolkit), OR you can send us your videos or photos here: <https://share.vidday.com/o-p24eji>. Any submissions are subject to creative reproduction.

Please make sure to use the hashtags **#InsideAtopicEczema** **#AtopicEczemaDay** when posting videos.

Here’s an example of a social media post that you can do:





Call to Action

Outreach to Atopic Eczema Influencers

Let's reach a bigger audience! There are many atopic eczema advocates that feel the pain and burden of the disease and have dedicated their time and energy to advocating for it.

Why not reach out to these individuals to ask if they want to amplify the #InsideAtopicEczema campaign? Use the below script and fill in your own blanks.

Finding influencers

Instagram and Twitter have made it easy to search for any topic using hashtags. To start, try using the following hashtags to search out accounts with large followings: #AtopicEczema #Eczema #EczemaWarrior #EczemaAwareness

Once you have found and followed creators that you would like to reach out to, you can use the following script:

"Hi (name), I'm (name)! I'm with (organization) and I would like to invite you to participate in the upcoming "World Atopic Eczema Day" campaign called #InsideAtopicEczema. We are hoping to gain some traction and general awareness by posting boomerangs of eczema sufferers wearing a piece of clothing inside out. This represents the many burdens we feel from ____ (fill in the blanks based on your needs____).

You can visit <https://bit.ly/World-Atopic-Eczema-Day-2022> for more information on the campaign. We would love to have you participate. Please let me know if you would be interested.

- (Sign off)"

Here are some great accounts to follow on Instagram if you need a head start:

@nicolajohnston	@eczemafriend
@eczemaconquerors	@the_eczema_diaries
@wokewithinskin	@eczema.life
@skinsoul.health	@eczema_warrior



Template Press Release

World Atopic Eczema Day 2022

Unite to recognize the many burdens of Atopic Eczema

September 14th

On September 14th, World Atopic Eczema Day, the patient communities across the globe join forces to raise awareness for the disease, speak up about the physical, financial and mental health burdens on patients and caregivers and insist on their right to access appropriate care and treatment.

Atopic eczema (also known as atopic dermatitis (AD) is one of the most prevalent skin diseases in the world. It is more than itchy skin, it is a systemic, multidimensional disease that affects the minds and bodies of over 230 million people worldwide. However, despite its prevalence, it is often dismissed as “just a skin condition,” leaving patients without the multidisciplinary care they need.

[Organisation name] joins the International Alliance of Dermatology Patient Organisations (GlobalSkin), the European Federation of Allergy and Airways Diseases Patients’ Associations (EFA) and calls on healthcare professionals, health policy decision makers and all stakeholders to recognize and take action to alleviate the burdens of atopic eczema. #InsideAtopicEczema #AtopicEczemaDay

[INSERT GLOBAL, EUROPEAN OR LOCAL QUOTE HERE]

[INSERT LOCAL STATISTICS]

Today, we draw attention to atopic eczema, a complex disease that has an immense burden on patients and caregivers. Globally, atopic eczema affects up to 20% of children and 10% of adults.

Patients with this disease spend most of their lives requiring comprehensive daily care and management. Caring for a child with atopic eczema can affect personal relationships, decrease psychosocial functioning, bring sleep loss for family members and a feeling of helplessness in dealing with the child’s daily suffering. Atopic eczema may also result in work absence or decreased work productivity for adult patients and for parents.

Join [Organization Name], GlobalSkin, EFA and the growing global community to encourage health systems to address the full range of atopic eczema’s impact. Be part of the conversation on channels like Twitter, Facebook, Instagram and LinkedIn by using the hashtags: #UniteForAtopicEczema and #AtopicEczemaDay



Template Press Release (Continued)

“As a global community, we mark September 14, as World Atopic Eczema Day. We unite to raise awareness for the disease and the impact it has on millions of patients and their caregivers worldwide. We recognize and validate the emotional toll and financial burden atopic eczema can have and how this multi-dimensional disease impacts mental health, restricts life, and often leads to increased risk for the development of other health conditions. We call upon healthcare professionals and policy makers to join us on this awareness day by demonstrating how they support and care for atopic eczema patients all over the globe. Together we can make change happen.”

- Jennifer Austin, Chief Executive Officer, GlobalSkin

“The inside of atopic eczema and what patients cope with every day is too often overlooked by most people. Even in 2022, patients are struggling to receive the care they need to be able to live their lives to the fullest. What patients need, and patient organisations are pushing for, is a multidisciplinary approach to caring for atopic eczema/dermatitis. That is why at EFA we urge healthcare providers to work with other patients, their caregivers and other healthcare providers to understand their unique needs and deliver the best care for them.” - Carla Jones, EFA President

About The Organisations:

International Alliance of Dermatology Patient Organizations (GlobalSkin)

GlobalSkin is a unique global alliance, committed to improving the lives of skin patients worldwide. With 190 Members organizations globally, they nurture relationships with their membership, partners and all involved in healthcare—building dialogue with decision-makers around the globe to promote patient-centric healthcare. Since 2018, GlobalSkin has been working with the global Atopic Eczema Community and launched AltogetherEczema.org, a central hub for people all over the world to identify common issues related to atopic eczema, share information and insights, and work together to find solutions. Learn more at [GlobalSkin.org](https://www.GLOBALSKIN.org)

European Federation of Allergy and Airways Diseases Patients Associations (EFA)

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) is the voice of the 200 million people living with allergy, asthma and chronic obstructive pulmonary disease (COPD) in Europe. We bring together 45 national associations from 26 countries and channel their knowledge and demands to the European institutions. We connect European stakeholders to ignite change and bridge the policy gaps on allergy and airways diseases so that patients live uncompromised lives, have the right and access to the best quality care and a safe environment.

Learn more at [efanet.org](https://www.efanet.org)



Template Support Letter

World Atopic Eczema Day 2022

Atopic eczema patient groups can seek support in many organisations and individuals. Do not put boundaries and make the action viral at local and national level. Send the template letter below to the following:

- Your institutions (Ministry of Health, medicines agency)
- Your healthcare professionals (ask the local medical societies to join the activity and inform doctors at national level about it)
- The civil society organisations in your country (other patient organisations, public health advocates)
- Your patients support network (reach out to education services and networks)
- Take the opportunity to win some ambassadors (contact TV presenters, national celebrities, artists and sportspeople, and philanthropists)

SUBJECT: Support patients in showing the many burdens of Atopic Eczema on World Atopic Eczema Day

Dear [name of organization or individual],

We are writing you because September 14 marks World Atopic Eczema Day; a day where those affected by eczema join to raise awareness about the disease. We hope [name of partner organization] will unite with [Organisation name], the International Alliance of Dermatology Patient Organisations (GlobalSkin), the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) and help communicating the many burdens eczema has.

The theme: #InsideAtopicEczema

On World Atopic Eczema Day 2022, we take a look Inside Atopic Eczema and explore five major burdens of the disease: the burden of extreme physical pain and itch, burden on families and caregivers, burden on finances, burden on mental health, burden of daily management.

The action: turn your clothes inside out in support of patients

For this years' campaign, we have developed a call-to-action activity that will add a more personal and visual touch. Join us in the #InsideAtopicEczema challenge! The goal is to create a virtual "flash mob" to raise awareness of the burdens of Atopic Eczema. Share and re-share user videos to keep the messages coming!



Template Support Letter (Continued)

Your role: picture you and share it

Put your clothing inside out and take a picture of yourself or create a video showing off how it looks.

Share your video on social media using the hashtags #InsideAtopicEczema or sending it us to: <https://share.vidday.com/o-p24ejj>.

Any submissions are subject to creative reproduction.

About atopic eczema

Atopic Eczema is one of the most prevalent skin diseases in the world. It is more than itchy skin, it is a systemic, multidimensional disease that affects the minds and bodies of over 230 million people worldwide. However, despite its prevalence, it is often dismissed as “just a skin condition,” leaving patients without the multidisciplinary care they need.

Thank you in advance for your support.

[Insert name]



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European Federation of Allergy and Airways
Diseases Patients' Associations

THANK YOU!

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

If you have any questions, please do not hesitate to contact the team at:

info@globalskin.org | info@efanet.org



[@GlobalSkin_IADPO](https://www.instagram.com/GlobalSkin_IADPO)



[EFA YouTube Channel](https://www.youtube.com/EFAYouTubChannel)



[@IADPOforGlobalSkin](https://www.facebook.com/IADPOforGlobalSkin)



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[GlobalSkin YouTube Channel](https://www.youtube.com/GlobalSkinYouTubeChannel)