

Awareness Toolkit

Whether you live with eczema or atopic dermatitis, care for someone with the condition, or are already actively involved with a patient association, your voice is important!

AltogetherEczema is a growing movement aiming to help start conversations within the eczema and atopic dermatitis community about what matters most to them. To ensure the movement successfully reaches the community worldwide, we need your support.

This toolkit contains a series of materials that you may wish to use to drive awareness of the AltogetherEczema movement and the first ever World Atopic Eczema Day on September 14, 2018. You may also find it helpful to read this document in conjunction with the Take Action Advocacy and Social Media toolkits, available <u>here</u>.

Check out the information, advice and assets provided and start inspiring others to get involved. Remember, together we are stronger!

The content of this document includes:

- √ Campaign overview
- ✓ Guidance for media outreach: World Atopic Eczema Day
- √ Top tips for media outreach
- ✓ Assets to support communications activities:
 - Key messages
 - Campaign visual identity
 - Template media pitch
 - Media statement for patient associations
 - o Reactive Q&A



Campaign overview

AltogetherEczema is a growing movement aiming to:

unite people with eczema & atopic dermatitis, as well as caregivers, around shared experiences and hopes for the future;

Provide a central hub
for people all over the
world – patients and
patient leaders
(advocates) – to
identify common
issues, share
information & insights,
and work together to
find solutions; and

Build/enhance
advocacy skills
amongst patient
leaders, and enhance
capacity to aid incountry, regional and
global mobilization

AltogetherEczema.org provides a central hub, allowing supporters to:

Directly share
experiences of life
with eczema or
atopic dermatitis,
as well as
aspirations for the
future

Interact with content and features to explore key issues for the community; and Utilize tools to campaign for changes that will improve the lives of those living with eczema & atopic dermatitis

On the first ever World Atopic Eczema Day (September 14) GlobalSkin is launching AltogetherEczema, urging the eczema and atopic dermatitis community to share their story and experiences of life with the condition, as well as their aspirations for the future.



To help drive awareness of the movement and the condition, AltogetherEczema is asking people to:

- Support the AltogetherEczema campaign and what it stands for;
- Join the movement and share their story; and
- Get involved with their local patient association

AltogetherEczema: call-to-action

Visit AltogetherEczema.org to share your experiences of living with atopic dermatitis or eczema, sign up to join the movement and help campaign for change.

World Atopic Eczema Day 2018: call-to-action

This World Atopic Eczema Day, visit AltogetherEczema.org to:

- Hear from Tonya Winders, President and CEO of Allergy & Asthma Network and President of Global Allergy & Asthma Patient Platform, on the impact of atopic dermatitis on family life, and how that experience compelled her to act and advocate on behalf of patients; and
- Take part in our short survey to share what it's really like to live with or care for someone with eczema or atopic dermatitis – helping to kickstart a new international conversation about urgent action that needs to be taken for those living with the condition(s).



Guidance for media outreach: World Atopic Eczema Day

To maximize visibility of World Atopic Eczema Day and the launch of AltogetherEczema, engage suitable local media outlets to share the news and raise awareness of the growing movement. Consider the following:

- ✓ When developing your local media list, consider optimal pitch timings, for example, some outlets publish weekly or monthly and therefore it may be suitable to share the news under embargo in advance of World Atopic Eczema Day to ensure inclusion in the next issue.
- ✓ Internal and external spokespeople (for example those living with eczema or atopic dermatitis) provide an important perspective and offer depth to the story. Consider identifying spokespeople in advance of media outreach, noting availability for interviews before offering up to the media.

If journalists would be interested in an interview with Christine Janus, CEO of GlobalSkin, get in touch at info@altogethereczema.org and we will facilitate an appropriate time.

On the following pages, check out our top tips and assets developed for you to adapt and use at a local level on and around World Atopic Eczema Day.



Top tips for media outreach

Email remains the most preferred contact method for journalists. Here are our **top tips**:

- Start by focusing on the media outlet's audience and tailor
 your pitch as appropriate.
 What will resonate with their readers?
 Do they typically cover similar subjects?
 - 2. Keep the pitch short and succinct.
 - Copy supporting content into the body of the email (attachments often don't get through the firewall!).
- 4. Include appropriate links and contact information, ensure you have spokesperson availability on hand.
 - 5. Be sure to create an email subject line that stands out.
 - Follow up with priority journalists via phone to discuss your email and offer an interview if it would be appropriate.



Key Messages

Listed below are our key messages, created to ensure that all communication about AltogetherEczema is consistent. When speaking on behalf of our community, these messages may also provide useful talking points.



Eczema has a significant – and often hidden – physical and psychological burden, but remains a low priority for

healthcare systems all over

the world



AltogetherEczema is a growing movement of the global eczema & atopic dermatitis community, aiming to identify critical issues, share knowledge and deliver change





AltogetherEczema is motivated by what matters most to those living with eczema or atopic dermatitis September 14 marks the first-ever World Atopic Eczema Day, a global milestone to raise awareness of eczema & atopic dermatitis and call for urgent action to improve lives

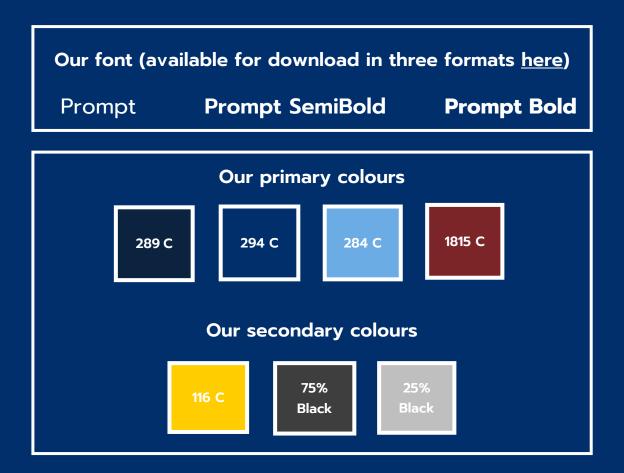


Campaign visual identity

The visual identity of AltogetherEczema has been designed to capture a sense of community, hope and collaboration using inviting colors and imagery.

Our tone should always convey a sense of unity within the eczema and atopic dermatitis community, as well as the idea that all of these parties are collaborating together as one to promote action and change. The AltogetherEczema platform is an inclusive place and safe haven for open conversation, and it should feel as such.

When creating assets on behalf of the community, consider incorporating the AltogetherEczema logo, in addition to the following font and colours:





Our logos

Find these available for download here.

For coloured backgrounds:





For white backgrounds:





When using the AltogetherEczema logos, always maintain the "A" space around the logo when placing other graphic elements or copy nearby.





Template media pitch email

SUBJECT: INTERNATIONAL MOVEMENT FOR ECZEMA SUFFERERS LAUNCHED ON FIRST EVER WORLD ATOPIC ECZEMA DAY

Dear [name of media contact]

Today, September 14, marks the first ever World Atopic Eczema Day to raise awareness of eczema and atopic dermatitis. It brings together those affected by eczema or atopic dermatitis to share experiences, future aspirations and drive action that improves lives all over the world.

To deliver that action, today GlobalSkin launches AltogetherEczema (AltogetherEczema.org), a new movement to elevate the urgent and unmet needs of the global eczema and atopic dermatitis community.

"The inaugural World Atopic Eczema Day is a long-awaited chance to honor and empower those affected by eczema or atopic dermatitis, and finally put their needs in the spotlight," said Christine Janus, CEO of GlobalSkin. "This community faces a huge range of challenges, whether physical or emotional, every single day. We hope by launching AltogetherEczema, we can kick-start a conversation within the community about what matters most. A clearer understanding of issues and priorities for those living with the condition will ensure that, together, we can work towards meaningful and relevant change."

[insert regional statistics from your local patient association]

If you would be interested in arranging an interview with Christine Janus, CEO of GlobalSkin, or [insert local spokesperson/patient] for



more information, please don't hesitate to contact us on [insert details].

Do let me know if you have any questions and I would be happy to discuss this further.

Thank you in advance for your support.

[Insert name and signature]

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GlobalSkin Launches International Movement for Eczema Sufferers on First Ever Awareness Day

Today, September 14, the global eczema community unites to observe the first-ever World Atopic Eczema Day to raise awareness and understanding of eczema and atopic dermatitis. World Atopic Eczema Day brings together those affected by eczema or atopic dermatitis to share experiences, future aspirations and drive action that improves lives all over the world.

To deliver that action, the International Alliance of Dermatology Patient Organizations (IADPO – also known as GlobalSkin) today launches AltogetherEczema, a new movement to elevate the urgent and unmet needs of the global eczema and atopic dermatitis community. AltogetherEczema.org will serve as the central hub for both people affected by eczema or atopic dermatitis, as well as patient leaders – providing resources, gathering insights and seeking to empower collective advocacy.

"The inaugural World Atopic Eczema Day is a long-awaited chance to honor and empower those affected by eczema or atopic



dermatitis, and finally puts their needs in the spotlight," said Christine Janus, CEO of GlobalSkin. "This community faces a huge range of challenges, whether physical or emotional, every single day. We hope by launching AltogetherEczema, we can kickstart a conversation within the community about what matters most. A clearer understanding of issues and priorities for those living with the condition will ensure that, together, we can work towards meaningful and relevant change."

Globally, eczema affects up to 20% of children and 10% of adults. Atopic dermatitis is the most common and chronic form of eczema, which typically causes patches of dry, itchy skin that may worsen and can erupt into a rash when scratched. But, people also often endure a significant negative impact on their emotional wellbeing, from an inability to sleep, as well as associated feelings of social exclusion and depression or anxiety. It is this hidden, multidimensional burden that needs urgent attention.

AltogetherEczema urges the eczema and atopic dermatitis community to share their story and experiences of life with the condition, as well as their aspirations for the future. By doing so we can investigate the key issues faced globally, utilizing shared knowledge and insight to build advocacy skills and campaign for change.

This World Atopic Eczema Day, GlobalSkin invites people living with or caring for someone with eczema or atopic dermatitis to participate in a short survey, outlining what it is like to live or care for someone with this condition. Your answers will help to kick-start a new international conversation that can help us to bring about positive change.



Visit AltogetherEczema.org to join this growing global community and join the conversation on Twitter and Facebook by using the hashtags: #AltogetherEczema and #AtopicEczemaDay

About AltogetherEczema

AltogetherEczema is a growing movement for the global eczema and atopic dermatitis community, aiming to identify critical issues, share knowledge and work towards change. AltogetherEczema.org provides a central hub for people all over the world – patients and patient leaders – to identify common issues, share information and insights, and work together to find solutions.

GlobalSkin, a not-for-profit organization, created AltogetherEczema. GlobalSkin is a unique global alliance, committed to improving the lives of skin patients worldwide. They nurture relationships with members, partners and all involved in healthcare – building dialogue with decision-makers around the globe to promote patient-centric healthcare. Learn more about GlobalSkin at GlobalSkin.org.



Media statement for patient associations

INTERNATIONAL MOVEMENT FOR ECZEMA SUFFERERS LAUNCHED ON FIRST EVER WORLD ATOPIC ECZEMA DAY

Today, September 14, marks the first ever World Atopic Eczema Day to raise awareness and understanding of eczema and atopic dermatitis. Atopic Eczema Day brings together those affected by eczema or atopic dermatitis to share experiences, future aspirations and drive action that improves lives all over the world.

To deliver that action, GlobalSkin today launches
AltogetherEczema, a new movement to elevate the urgent and
unmet needs of the global eczema and atopic dermatitis
community. [Insert name of organization] is proud support the
AltogetherEczema movement.

AltogetherEczema.org will serve as the central hub for both people affected by eczema or atopic dermatitis, as well as patient leaders – providing resources, gathering insights and seeking to empower collective advocacy.

Visit <u>AltogetherEczema.org</u> to join this growing community and share your story.



Reactive Q&A

The campaign Q&A is a central reference to help answer any questions that you or your chosen spokespeople may receive from the media while supporting AltogetherEczema. If you have any additional questions, get in touch with the team at info@altogethereczema.org.

1. What is eczema?

- Eczema is an umbrella term for a group of autoimmune diseases that
 affect the skin. The most common and chronic form of eczema –
 also known as atopic dermatitis typically causes patches of dry,
 itchy skin that may worsen and can erupt into a rash when scratched.
- But, significantly, patients also often endure a significant negative impact on their emotional wellbeing, from an inability to sleep, as well as associated feelings of social exclusion and depression or anxiety.

2. What is AltogetherEczema?

- AltogetherEczema is a growing movement for the global eczema & atopic dermatitis community, aiming to identify critical issues, share knowledge and works towards change.
- AltogetherEczema.org serves as the central hub, providing key resources and gathering insights to inform collective advocacy.

3. Why has GlobalSkin launched AltogetherEczema?

- AltogetherEczema is a growing movement for the global eczema & atopic dermatitis community, aiming to identify critical issues, share knowledge and deliver action to improve lives. The movement aims to:
 - Unite people with eczema & atopic dermatitis, as well as caregivers, around shared experiences and hopes for the future:
 - Provide a central home for people all over the world –
 patients and patient leaders (advocates) to identify



- common issues, share information & insights, and work together to find solutions; and
- Build/enhance advocacy skills amongst patient leaders, and enhance capacity to aid in-country, regional and global mobilization
- GlobalSkin has launched AltogetherEczema,org to provide a central hub, allowing supporters to:
 - Directly share experiences of life with eczema or atopic dermatitis, as well as aspirations for the future
 - Interact with content and features to explore key issues for the community; and
 - Utilise tools to campaign for changes that will improve the lives of those living with eczema & atopic dermatitis

4. What is the purpose of the survey on AltogetherEczema.org?

- We want to know what issues matter to people with eczema or atopic dermatitis, how this condition impacts life and what barriers are encountered. We are asking the community to share answers to a few questions to help start a new global conversation that can help us to bring about positive change for people living with the condition(s).
- The survey will take approximately five minutes to complete on the AltogetherEczema website – AltogetherEczema.org and, once submitted, you can view your answers in real-time and compare these with the rest of the global community!

World Atopic Eczema Day:

5. What is World Atopic Eczema Day?

- GlobalSkin has launched the first ever World Atopic Eczema Day to raise awareness of eczema & atopic dermatitis, as well as provide a platform to call for urgent action to improve lives.
- The European Federation of Allergy and Airways (EFA) is also marking Atopic Eczema Day in Europe on this date.



6. What is happening on World Atopic Eczema Day?

- Atopic Eczema Day activities taking place all over the world aim to:
 - Unite people with eczema & atopic dermatitis around shared experiences and amplify what the community want to change.
 - Share information, stories and goals of the global eczema & atopic dermatitis community with wider audiences, asking them to help support action for those living with the condition(s).

7. What is the difference between Atopic Eczema Day and Atopic Dermatitis Day?

 There is no difference. Atopic dermatitis and atopic eczema are terms that are often used interchangeably for the same chronic form of eczema.

8. What activities are GlobalSkin hosting to coincide with World Atopic Eczema Day?

- On the first ever World Atopic Eczema Day, GlobalSkin is launching AltogetherEczema, a new global patient community dedicated to what matters most to people living with or caring for someone with eczema or atopic dermatitis.
- Eczema affects up to 20% of children and 10% of adults worldwide. By raising awareness and providing a central global hub, AltogetherEczema, we want to harness community voices to act for change that will improve the lives of those living with eczema & atopic dermatitis.
- This Atopic Eczema Day, visit AltogetherEczema.org to:
 - Hear from Tonya Winders, President and CEO of Allergy & Asthma Network and President of Global Allergy & Asthma Patient Platform, on the impact of atopic dermatitis on family life, and how that experience compelled her to act and advocate on behalf of patients; and



Take part in our short survey to share what it's really like to live with or care for someone with eczema or atopic dermatitis – helping to kick-start a new international conversation about urgent action that needs to be taken for those living with the condition(s).

9. What is GlobalSkin asking the community to do on World Atopic Eczema Day?

- This Atopic Eczema Day there are a number of ways the community can help raise awareness of eczema & atopic dermatitis, such as:
 - Visit AltogetherEczema.org to share your story and join our global community.
 - Share a picture of yourself and answer to the following question on your own social media channels: Name one issue you would like to campaign for change?
 - Join the conversation on Twitter and Facebook by using #AtopicEczemaDay

10. What important role do local patient associations play?

- Patient associations are important as they provide a localized platform where patients can connect with others, share their stories, and understand that there are people out there living with the same condition. In addition, these associations inspire to educate and empower patients to seek the appropriate level of treatment, and to not settle for living a less than ideal quality of life.
- Connect with your local patient association by using the AltogetherEczema directory and learn about key advocacy issues in your country.



11. Where can people go to learn more about World Atopic Eczema Day?

- Visit AltogetherEczema.org or GlobalSkin.org to learn more about World Atopic Eczema Day, find information on eczema & atopic dermatitis, and support the global community to make the case for change that improves the lives of those with the condition(s).
- You can also visit efanet.org to be connected with the European Federation of Allergy and Airways (EFA) and find out more information on this program and their role in Atopic Eczema Day.



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