

Patient Association Communications Toolkit



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Atopical Lives project

Developed through the collaborative work
of GlobalSkin and the European
Federation of Allergy and Airways
Diseases Patient Associations

World Atopic Eczema Day 2019: Communications 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!

This toolkit was developed through the collaborative work of GlobalSkin and the European Federation of Allergy and Airways Diseases Patient Associations (EFA). Please note that the included templates mention both organizations in the text. When you are adapting it for local use, please include only the organization(s) of which you are a member. It contains a series of materials that you may wish to use to drive awareness of: atopic eczema, our growing patient organization community, and the second World Atopic Eczema Day on September 14, 2019.

AltogetherEczema, launched in 2018, is a growing movement aiming to help start conversations within the eczema and atopic dermatitis community about what matters most to them. We need your support to ensure the movement successfully reaches the community worldwide.

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

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Campaign Overview

Atopic eczema is much tougher on patients than people understand. It seriously impacts patients' lives beneath the surface of the skin, and can severely affect an individual's health and overall wellbeing. Further, atopic eczema sits at the center of a number of other health issues – it almost always restricts life, impacts mental health, and leads to the development of other diseases.

Patients are at the core of change in atopic eczema awareness and care. Working together with patient groups across the globe, we will rise up together for action on atopic eczema. The 14th of September will mark the second World Atopic Eczema Day, and we'll continue to organize, advocate, and share our stories year after year. This year, we are looking beneath the surface of atopic eczema and its impacts on life.

This second annual World Atopic Eczema Day marks a growing movement aiming to:



Empower a cross-sector and multinational community to build a global movement for change to improve the lives of people living with atopic eczema.



Engage the general public on the topic of atopic eczema by enhancing understanding of the condition's impact on patients' quality of life.



Empower patient groups with a set of common messages and materials.



Support and honor atopic eczema patients and their caregivers.

Call-to-Action:

This World Atopic Eczema Day, we encourage our partners to:



Join the atopic eczema support network.



Support our community of atopic eczema patients, aiming to raise awareness, share experiences and call for change.



Join us in working together until health systems address the full range of atopic eczema's impact – help us improve the lives of millions around the world.



You are not alone. Connect and help others by sharing your story with our atopic eczema community.

World Atopic Eczema Day Key Messages

Theme

World Atopic Eczema day - Beneath the surface - Join the movement

Key Messages	Call to action
<p>Atopic eczema is much tougher on patients than people understand. It seriously impacts patients' lives beyond their skin.</p>	<p>Join the atopic eczema support network.</p>
<p>We don't just have atopic eczema. It almost always restricts life, impacts mental health and leads to the development of other diseases.</p>	<p>Join us in working together until health systems address the full range of atopic eczema's impact. Help us improve the lives of millions around the world.</p>
<p>Patients are at the core of change in atopic eczema awareness and care. Working together with patient groups across the globe, we will rise up together for action on atopic eczema.</p>	<p>Support our community of atopic eczema patients, aiming to raise awareness, share experiences and call for change.</p>
<p>Today is the second World Atopic Eczema Day, and we'll continue to organize, advocate, and share our stories year after year. This year, we are looking beneath the surface of atopic eczema and its impacts on life.</p>	<p>You are not alone. Connect and help others by sharing your story with our atopic eczema community.</p>

Proof Points

Proof points will vary by organisation and geography. Organisations may also want to substitute local data for some of the disease statistics listed below. Find some suggestions for globally-relevant proof points below:

- 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].
- 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%) [2].
- Intense and persistent itching is one of the most debilitating symptoms, causing long-lasting, extreme pain, with more than 60% of moderate-to-severe patients reporting itch at least 12 hours a day [2].
- While atopic dermatitis can also develop in adulthood, up to 85% of adults with atopic dermatitis have lived with this chronic disease since childhood [3].
- 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 [4].
- 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 [2] [4] [5]. Fifty per cent of atopic dermatitis patients report feelings of depression and/or anxiety [5], and 39% report feeling often or always embarrassed about their appearance [6]. People with severe atopic eczema report serious impact of the disease in their emotions; 43% experience small, 27% moderate, 21% large and 9% very large consequences. That means that 30% have large (very) emotional consequences and two thirds don't have an optimistic view of their life with eczema [7]
- Studies suggest that treatment failure rates within the current treatment landscape are high. Up to 78% of adults with moderate-to-severe disease do not experience significant improvements despite treatment [8] [9] [10] [11] [12].

Sources

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12. Iskedjian M., Piwko C., and Shear N., "Topic calcineurin inhibitors in the treatment of atopic dermatitis: a metaanalysis of current evidence", *Am J Clin Dermatol*, vol. 5, no. 4, pp. 267-279, 2004.

Introducing the World Atopic Eczema Day Logo: Utilization Guidance

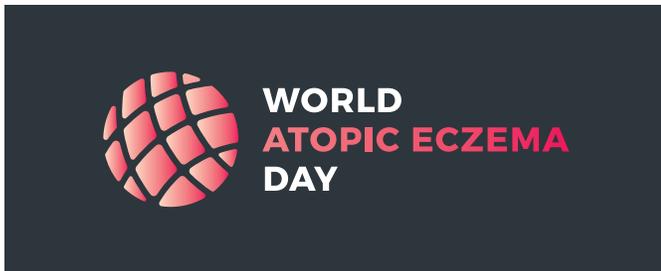
The visual identity of World Atopic Eczema Day has been designed to capture a sense of community, strength and collaboration using representative colors and imagery of the skin.

The World Atopic Eczema Day has been designed to convey a sense of unity within the eczema and atopic dermatitis community by portraying a collection of inflamed skin cells. Together, these skin cells form a shield that represents the critical role skin plays as a protective barrier and symbolizes strength – particularly that we are stronger together. Further, the globe-shape of the shield nods to the worldwide nature of the atopic eczema patient community movement.

When creating assets on behalf of the community, consider incorporating the World Atopic Eczema Day logo to promote collaborative action and change.

Our Logos

Find these available for [download here](#).



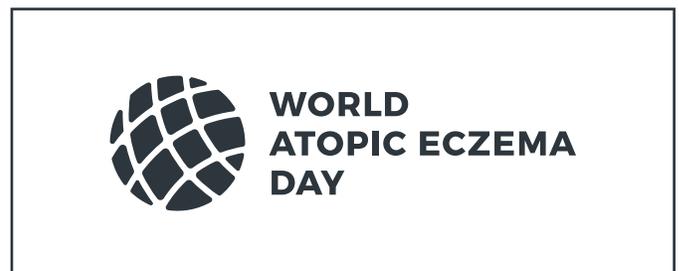
For coloured backgrounds



For coloured backgrounds

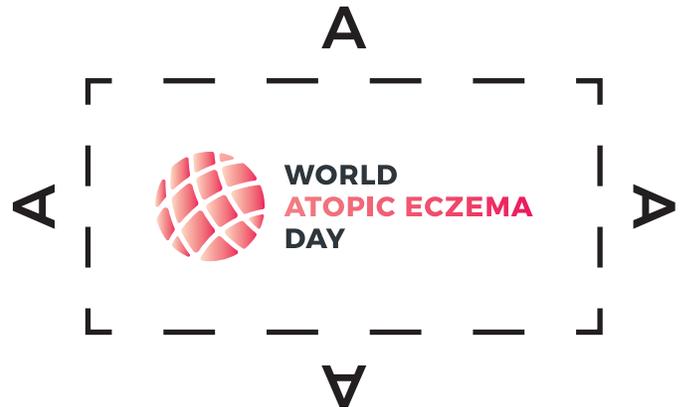


For white backgrounds



For white backgrounds

! When using the World Atopic Eczema Day logos, always maintain the “A” space around the logo when placing other graphic elements or copy nearby



When creating assets for your World Atopic Eczema Day campaign, consider incorporating the following font and colours that match the day’s logo:

Our Font

Montserrat

Available for [download here](#).

Aa Bb Cc Dd Ee Ff Gg Hh Ii Jj
Kk Ll Mm Nn Oo Pp Qq Rr Ss Tt
Uu Vv Ww Xx Yy Zz

Our Colours



#ee3e64
R 238;
G 62;
B 100;



#f9d3c0
R 249;
G 211;
B 192;



#282828
R 40;
G 40;
B 40;

Planning Your Atopic Eczema Day Campaign

This document outlines opportunities for patient groups to locally organize events, activities, and other campaign activations in the lead-up to or on World Atopic Eczema Day. It is meant to show the range of opportunities available and help groups to creatively brainstorm around what's most appropriate in their country. We've included throughout this document examples of how patient groups in other disease areas have organized similar events.

Advocacy Day Or Policy Event:

Advocacy days are policy-focused events during which volunteers visit local, regional, or national policymakers to raise awareness of atopic eczema and make an ask or recommendation to those decision makers. Publications and testimonials can be natural hooks to arrange the meetings and photos of the meetings with hashtag/sign can be posted on social media to increase your visibility. Advocacy days or policy events are typically hosted by supportive parliamentarians, parliamentary interest groups, or committees. These are formal events engaging leaders in the atopic eczema community, their partner organizations, and policymakers. [Click here](#) to view an example of an Alzheimer's disease patient group's advocacy day.

Awareness Rally:

Awareness rally: Awareness rallies are highly customizable and are typically coordinated with local patient groups and other community leaders. Rallies help to bring together the local community in an energetic event and provide resources for patients and caregivers. [Click here](#) to view an example of a cardiovascular patient group's recent rally.

Art Competition:

Art competitions engage people affected by atopic eczema to creatively reflect on their experiences. Caregivers, people living with the disease, and others could submit photos, essays, or another creative product to be broadly shared throughout their local community. Photos and essays could be shared with the public in a local exhibition, online, and you could potentially consider honoring several of the best examples with a prize or certificate. [Click here](#) to view an example of a cancer patient group's art competition.

Flashmob:

A flashmob is a pre-planned gathering of individuals who participate in a coordinated performance in an emblematic, public gathering place in their cities. The performance is intended to appear spontaneous. An atopic eczema flashmob could highlight the impact of atopic eczema on people living with the disease and their loved ones. It could also be an energetic performance that isn't directly related to atopic eczema, but provides an opportunity to share leaflets about the condition or your local association with spectators. It is recommended to film or livestream flashmobs or invite the media to cover them. [Click here](#) to view an example of a cancer patient group's flashmob.

Hack-a-thon:

A hack-a-thon engages teams of local technologists, researchers, and other innovators to develop a new tool that solves a problem faced by people affected by atopic eczema. The solution can then be “pitched” to a panel of local funders who could fund the development of the new tool. For example, hack-a-thon participants could create an app allowing parents to better track the sleep patterns of their child with atopic eczema. Hack-a-thons are casual, energetic events that engage the local philanthropic and innovator economy as well as those affected by eczema. [Click here](#) to view an example of a healthcare hack-a-thon.

Media Pitching:

Media pitching consists of contacting journalists who cover atopic eczema or related issues to make them aware of World Atopic Eczema Day and to encourage them to cover your organization’s activities for the day. This toolkit includes templates that you can use for pitching the media. Find top tips for pitching the media for World Atopic Eczema Day later in this toolkit.

Panel Discussion:

A panel discussion is an opportunity for local atopic eczema experts from academia, research, patient support, and medical fields to share their perspective on atopic eczema, raise awareness, and create a communal sense of action and direction. Panels are typically semi-formal events and primarily engage people who are already active in the atopic eczema community and also often official healthcare system representatives. A panel discussion can be in-person and streamed online. [Click here](#) to view an example of a panel discussion on heart disease.

Photo Exhibition:

A photo exhibition is a creative opportunity to highlight the experience and lives of people with eczema and their loved ones. Photographs for an exhibition could be sourced from local artists or crowdsourced from the patients themselves. A photo exhibition is typically semi-formal and subdued and engages a wide range of people who are active or inactive in the atopic eczema community. If the photos are requested from patients, this could be in the form of a photo contest related to telling their atopic eczema story. [Click here](#) to view an example of a photo exhibition and contest from the psoriasis community.

Pledge-based Event:

Pledge-based events follow the model of a walk – volunteers sign up to raise funds for atopic eczema from their local network or increase their membership base, then participate in an awareness-raising event. Pledge-based events are highly customizable and can take advantage of local resources. Examples of pledge-based events include bowl-a-thons, dance-a-thon, and more. [Click here](#) to view an example of a bike-a-thon from the cancer community.

Proclamation:

Proclamations outline an organization’s mission, vision, and goals for a campaign. The proclamation can be shared with representatives from local, regional, and/or national government to be read in an official setting and endorsed. A template World Atopic Eczema Day proclamation is included later in this toolkit.

Reception Or Gala:

Receptions and galas bring together the atopic eczema community for a formal event that typically celebrates a milestone in atopic eczema – an award can be announced, an achievement marked, or a call-to-action released. Receptions and galas can also be used to raise funds if the event is ticketed. These events are typically formal and engage people who are active in the atopic eczema community. [Click here](#) to view an example of a gala organized by the Parkinson's disease community.

Social Media:

Social media demonstrates your organization's commitment to World Atopic Eczema Day and people who are affected by the disease. It is a low-cost, high-impact way to participate in global activities and amplify your work along with the work of other participating groups. This toolkit includes examples of social media that you can use for World Atopic Eczema Day and tips for how to create an effective social media effort. See our top tips for social media for World Atopic Eczema Day later in this toolkit.

Tabling:

Tabling consists of a day-long event at a highly-visible local institution such as a university, government center, or business where organizers share basic information about atopic eczema and resources. Tabling is a grassroots, low-cost effort that can be effective in raising awareness of eczema among people who might not recognize the disease's burden. [Click here](#) to view an example of the resources shared by the heart disease community when tabling.

Twitter Chat:

A Twitter chat is an online event where your organization starts an online conversation with people affected by atopic eczema about their experiences. Typically, the organizer of a Twitter chat starts the conversations by tweeting a series of questions, which for World Atopic Eczema Day, could target people living with atopic eczema, caregivers, and other stakeholders. It is an opportunity to build community, shed light on the challenges of atopic eczema, and help to inform the general public. [Click here](#) to learn about best practices in Twitter chats learned by the breast cancer community.

Walks:

Walks are a time-tested means of raising awareness of a disease and funds to help combat it. Through a walk, local volunteers sign up to walk a pre-determined route and engage their network to raise funds or increase their membership network. [Click here](#) to view an example of a walk organized by the cancer community.

Web Conference:

Web conferences are online meetings where people can connect and discuss shared issues via Skype, Zoom, or another online platform. For World Atopic Eczema Day, a web conference could focus on sharing information about resources for people living with eczema, sharing stories and experiences, or organizing around a specific priority. Web conferences could also be used to live-stream many of the in-person events listed above. [Click here](#) to view an example of recent web conferences organized by Alzheimer's Disease International.

Event Guidance: “How To” Roadmap

This roadmap can be used to help you plan your World Atopic Eczema Day event. It includes the questions you should answer in the lead-up to your event, checklists for logistics and content creation as you plan your event, and the steps you can take to ensure your event is a success and managed effectively.

Phase 1: Developing Your Event Plan

Questions to ask yourself:

- What is your goal for the event? Can you measure it effectively?
- How many people do you anticipate will attend your event?
- Will your event be public or by invitation only?
- Will media attend your event?
- What will the event format be? Panel? Roundtable conversation? Something else?
- Will you have external speakers? Whom? Are they available on your target date? Do they request an honorarium or can they contribute voluntarily?
- Will speakers organise travel arrangements themselves and how will they be reimbursed?
- What is your budget for the event, and is sponsorship, ticketing or outside funding an option?
- Will you solicit outside help? From an event planning firm? Photographer? Videographer? Etc.?
- What do you need from your venue? WiFi? Projector? Meals? Any specific set-up requirements?
- What kind of materials do you anticipate creating for the event and sharing with participants?
- What kind of location do you need? Inside or outside? Using an internal space or a rental?
- Do you anticipate to run the event in partnership with other organisations?
- Who is going to work on the event, what is needed?

Logistics checklist:

- Develop a budget and spreadsheet to track your expenditures.
- Identify target dates.
- Identify target speakers.
- Identify potential locations and ask for quotes.
- Identify potential outside vendors.

Content checklist:

- Define the objectives of your event.
- Draft invitation for external speakers.

Tips on having media attend your event

The media can raise awareness of your event, share news that comes out of your event, and help to shine a spotlight on atopic eczema and your organization. Find some tips below on inviting media to your event and managing their involvement:



Use online tools like Google News to find out who is writing about atopic eczema, healthcare, or related issues in your area.



Draft outreach to these journalists based on their level of knowledge of atopic eczema and the types of issues they typically cover.



Hooking a journalist's interest can be difficult—some potential ways to secure their interest is by sharing an embargoed press release, offering an interview with your organization's CEO, with Christine Janus, CEO of GlobalSkin, or with Mikaela Odemyr, President of the European Federation of Allergy and Airways Diseases Patients' Associations. You could also offer exclusive coverage of an event.



Be careful with what private or sensitive information you share with journalists. Their job is to report, and they may not feel obligated to support your perspective.



[Click here](#) and scroll to Advocacy & The Media for more helpful tips on how to engage with the media from the International Alliance of Patients' Organizations.

Phase 2: Logistics And Outreach

Questions to ask yourself:

- Who would you like to attend your event? If it's invite-only, do you have all of the contact information you need? If it's a public event, how will you reach your intended audience?
- Will you need to track your attendees through a ticketing service, registration website, etc.?
- Who will manage responses, questions, and other follow-ups from attendees?
- Do you need to share anything with attendees ahead of event? Pre-reads? Confidential Disclosure Agreement or other legal forms? Reminder emails? When does each piece need to be shared and who will share it?

Logistics checklist:

- Develop an invitee outreach tracker to keep track of who has been invited, when they've been invited, and whether they've accepted your invitation, are tentative, need more information, or have declined.
- Create list and timeline of the materials you will share, i.e., a plan for what you will send to event attendees and invitees when.
- Finalize venue.
- Finalize on-site details, e.g., WiFi, participant packs, notepads, signage, any other meeting services or materials.
- Secure outside vendors (for meals; audio-visual equipment like projectors, microphones, and recording devices; logistics; printing; etc.).
- Conduct outreach by sending invitations to potential attendees and speakers. If your event will be open to the general public (i.e., not invitation-only), you can also promote the event on your website, social and traditional media, and via your partners.

Content checklist:

- Create and execute public relations plan and collateral, if a public event. Your public relations plan should prepare you to communicate your event to the public and raise their interest in attending via traditional and social media, local influencers, and advertising.
- Create and execute marketing plan and takeaway documents for attendees, if a public event.
- Develop and send save-the-date and/or invitation for attendees.
- Develop internal and external agendas for your event.
- Create and share pre-event content, e.g., content for event attendees to read or review before the event, Confidential Disclosure Agreement or other legal forms, reminder emails.
- Identify materials that will be distributed at the event.

Phase 3: Content Development And Attendee Management

Questions to ask yourself:

- Who is creating content for your event? Is it only your internal team, or will external speakers/attendees need to contribute?
- What content will you share at your event? Slides? Handouts? Group exercises? Electronic materials package?
- Do you need signage during the day of the event to help attendees find the event?
- Do you need logistics information to be sent in advance to the attendees?
- Do you need to run briefing or rehearsal for speakers prior to the event?
- Will attendees need to register or sign-in when they arrive at the venue?

Logistics checklist:

- Continue to manage invitee responses through your outreach tracker to manage your overall headcount and track who needs follow-up invitations or additional information.
- Ensure that venue and/or vendor has all audio-visual equipment like projectors, microphones, and recording devices that you'll need.

Content checklist:

- Event content, e.g., slides, agenda, handouts, signage, sign-in sheets, materials for group exercise, posters etc.
- Develop internal run of show that documents for your internal team who will be responsible for doing what and when on the day of the event.
- Speeches/presentations/briefing bullet points you may need to prepare your internal/external speakers.

Phase 4: Execution

Questions to ask yourself:

- Who from your team will be on-site the day of the event to support your operations?
- Who else will be onsite the day of the event? Photographers? Volunteers? Partners? Media?
- Who will take care of live social media onsite or is it pre-programmed?

Logistics checklist:

- Pick up or coordinate delivery of all relevant event content.
- Coordinate with external providers.
- Develop day-of plan for who will be responsible for what at the event.
- Register attendees.

Content checklist:

- Send thank you note to attendees and any follow-up materials.
- Publish and share relevant materials online.
- Think about dissemination of the event outcomes and how they feed into your broader goals.
- Create a checklist to evaluate your event, its results, and plan for future events. Evaluating your event should be based on what your initial goals were and will differ based on the goal and scope of your event. Find below some guidelines for evaluating your event:
 - Measure outcomes, not logistics. For example, try not to focus on the sheer number of people who were in the room, but what came as a result of who attended, e.g., new revenue, volunteers, or signatories on a petition.
 - Consider a brief, simple survey of attendees. You could circulate the survey via email following the event or, if possible, ask attendees to complete a survey before they leave.
 - Your evaluation should focus on the event you've completed, but also set the stage for future events. For example, if in your evaluation you find that many people attended your event, but only a few attendees signed up to volunteer with your organization, consider for your next event how to increase volunteer sign-ups.

Template World Atopic Eczema Day Proclamation

An official proclamation can be used to attract the media by stating that observance of World Atopic Eczema Day has received endorsement by the Governor, Mayor, Ministry of Health official, or another government representative in your community. A copy of the proclamation can be framed and placed in your local organisation's office, or printed in a future newsletter.

The letter to your local official requesting their endorsement should be sent to their office several weeks prior to World Atopic Eczema Day. This allows enough time to coordinate an official signing ceremony. The ceremony is a good opportunity to take photographs that can be sent to local media outlets or used as part of your World Atopic Eczema Day social media campaign.

Sample Letter to Official Requesting a Proclamation:

Date: [INSERT DATE HERE]
[INSERT NAME OF OFFICIAL]
[INSERT OFFICIAL'S TITLE]
[INSERT ADDRESS]

Dear [INSERT OFFICIAL NAME],

As a representative of the atopic eczema patient community and a partner of [INSERT GLOBALSKIN AND/OR THE EUROPEAN FEDERATION OF ALLERGY AND AIRWAYS DISEASES PATIENTS ASSOCIATIONS], I am writing to request your recognition of the second World Atopic Eczema Day and the impact that atopic eczema has on the quality of life of many members of our community.

This year's observance of World Atopic Eczema Day, endorsed by GlobalSkin and the European Federation of Allergy and Airways Diseases Patients Associations (EFA), is September 14th.

Atopic eczema is much tougher on patients than most people understand. 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. [INSERT PREVALENCE IN YOUR COUNTRY] Atopic eczema's systemic nature means that it seriously impacts patients' lives beyond their skin. It almost always restricts life, impacts mental health and leads to the development of other diseases.

I have taken the liberty of drafting a sample proclamation for your review. We would appreciate receiving this proclamation by [INSERT DEADLINE]. Please contact me if you require any additional information. Thank you for your consideration of this request.

Sincerely,
[INSERT YOUR NAME]
[INSERT YOUR TITLE]

Sample World Atopic Eczema Day Proclamation

Greetings:

It brings me great pleasure to mark today, September 14th, the second annual World Atopic Eczema Day. World Atopic Eczema Day gives us the opportunity to raise awareness and understanding of atopic eczema, and to honor those living with the disease and their families.

Globally, atopic eczema affects up to 20% of children and 10% of adults. And, the disease is much tougher on patients than people understand. 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. Atopic eczema's systemic nature means that it seriously impacts patients' lives beyond their skin. People living with atopic eczema often suffer from negative mental health impacts such as depression and anxiety, and are more likely to develop chronic conditions such as cardiovascular disease.

In recognition of the significant impact that atopic eczema has on patients' quality of life, I, **[INSERT OFFICIAL'S NAME]**, **[INSERT OFFICIAL'S TITLE]**, do hereby call upon our community, our healthcare providers, and our government officials to continue to make progress on this important issue in the years ahead.

Dated this **[INSERT DAY]** of **[INSERT MONTH]**, **[INSERT YEAR]**.

SIGNATURE OF OFFICIAL

Why Use Social Media?

Social media provides instant access to a worldwide audience, spanning across multiple different platforms. The statistics below, for the most popular social networks, show the number of users on each platform – and these are growing rapidly!



Instagram
800 million



Facebook
2.19 billion



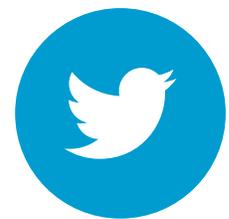
YouTube
1.3 billion



Snapchat
191 million



Pinterest
175 million



Twitter
336 million

BE PRIVACY SMART:

Remember that social media is a public place – think before you post and take time to review your individual privacy settings!

KNOW YOUR AUDIENCE:

Remember to choose a platform that's appropriate for the audience you are trying to reach. For instance, a common insight is that Twitter is more factual and informative, whereas Facebook is more emotional and engaging.

Tips for Developing Content



Simple:

Use clear, brief & compelling language that is accessible to all!



Succinct:

Keep it short! Did you know that on Facebook posts that are 80 characters or less earn 86% more engagement? For Instagram, we recommend 138-150 characters and 71-100 for Twitter.



Visual:

Include visual content where possible. For some examples, check out the graphics we have developed as part of this communications toolkit.



Keep It Timely:

Distribute your posts evenly throughout the day to encourage more engagement. Consider using tools such as Hootsuite to schedule posts in advance.



Share Tips & Advice:

Help those living with eczema or atopic dermatitis better manage their condition by sharing valuable and informative content.



Tell An Honest And Open Story:

Connect the community. Use the information presented as a conversation starter, and as an opportunity to ask your audience questions about their experiences.



Keep The Conversation Going:

- Create Twitter polls to understand how people perceive eczema and atopic dermatitis.
- Start Facebook and Instagram live sessions to discuss the impact of the disease and challenges.
- Use Instagram and Facebook stories: this is the perfect way to share moments during your day, especially when the disease is challenging. You can add location to your stories, customize them with filters and stickers, and also mention other accounts.

Twitter & Facebook Best Practices



Twitter best practices



Mention accounts

Mention relevant Twitter accounts if they are related to your post and your voice will sound real. Put an @ and then type their name. This notifies them that you're talking about them and their community of followers.



Tell your story with and without sound.

Since videos on Twitter automatically play with sound off, it's important to make sure your video entices viewers, even when muted. When sound is off, beautiful imagery and on-screen text can help promote your content. When enabled, your video's sound should offer additional value to viewers.



"Pin" relevant tweets

Pin tweets to the top of your account from the upper right menu. This will stick your tweet to the beginning of your timeline, so it will be the first thing people see when landing on your page.



Hashtags

Join the conversation by using [#AtopicEczemaDay](#)

Twitter & Facebook Best Practices



Facebook best practices



Videos

Tell your story in video format without sound, the same way that you would on Twitter. When creating videos, share your story in a way that is easy to digest.



Facebook Live

Organize Facebook live sessions to talk about eczema or atopic dermatitis and interact in real time with your followers. At the end of your broadcast, you can post the video to Facebook, download it to your phone, change the privacy settings, or delete it entirely.



Mention other accounts or pages

Mention public Facebook pages or users if they are related to your post. Link to their Facebook page, which also notifies the page owner that you're talking about them.



Hashtags

In the same way as you would on Twitter, join the conversation by using #AtopicEczemaDay

Social Media Posts

Here are a few examples of posts that you can use to help spread the word about our growing community. You should consider altering the text and length of the post depending on the platform.

A common insight for social media is that Twitter is more factual and informative, whereas Facebook is more emotional and engaging. Facebook is the home of videos where users spend longer consuming content, whereas photos and GIFs perform best on Twitter as these are quick and direct.

Join the conversation by using #AtopicEczemaDay. This will help to signpost when content relates your community to your followers and enable other users to track your content and engage with your conversation.

Finally, these posts are simply our suggestions. Please feel empowered to update them based on your local contexts, strategies, and priorities.

Suggested Posts For People Living With Atopic Eczema:

Today is the 2nd #AtopicEczemaDay. Join me by sharing your story with our community to raise awareness and call for change.

This #AtopicEczemaDay, I'm looking beneath the surface to expose the condition's full impact.

You are not alone! Join me this #AtopicEczemaDay to help people understand what it's really like to live with atopic eczema.

Suggested Posts For Patient Associations:

Today is the 2nd #AtopicEczemaDay and we're thrilled to be part of atopic eczema support network.

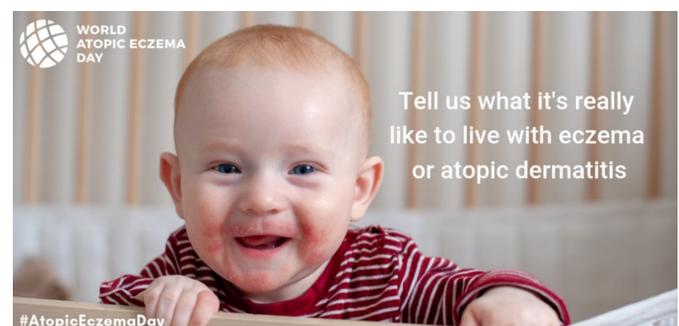
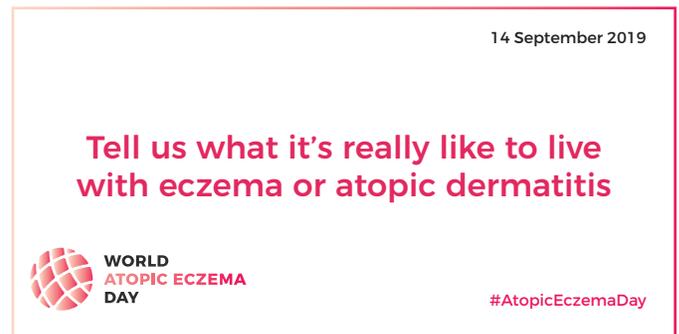
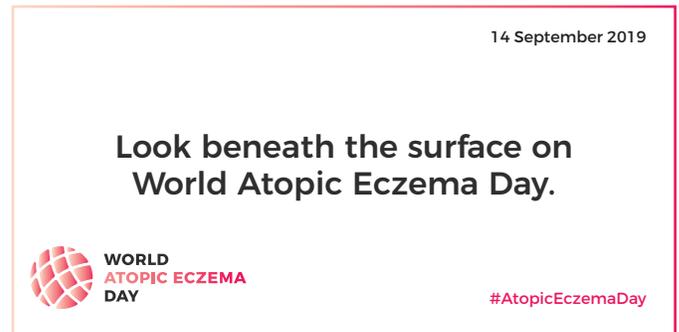
Today is the 2nd #AtopicEczemaDay and we'll continue to organize, advocate, and urge action year after year. Because atopic eczema goes beneath the surface.

Our voices are stronger together. Join us on this #AtopicEczemaDay in working together until health systems address the condition's full range of impact.

Social Media Visuals

As you know, visuals are vital. They are attention-grabbing and allow users to understand your post and engage with ease. To accompany your social posts, we've developed a number of visuals that are available for patients, carers and patient associations!

Find these slides available for [download here](#)



Atopic Eczema Media Briefing Guide

The following set of facts can be used for reference as you prepare to cover the second annual World Atopic Eczema Day. These facts provide background on atopic eczema's pathology and how it affects patients.

Atopic Eczema Key Facts:

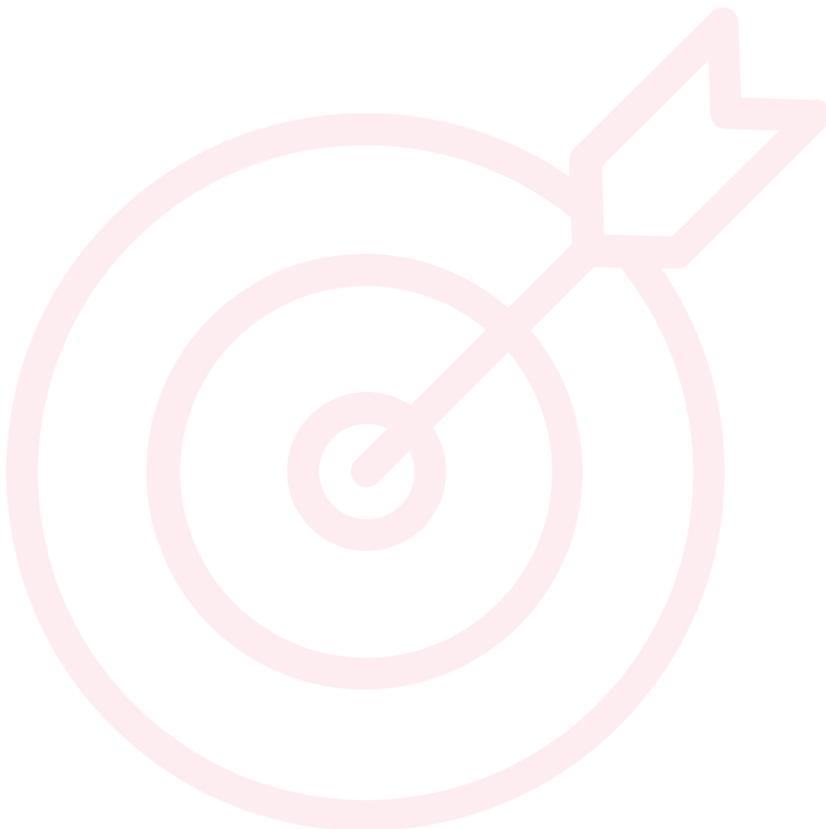
Background Information on Atopic Eczema

- Eczema is an umbrella term for a group of autoimmune diseases that affect the skin.ⁱ
- Atopic eczema is the most common form of eczema.ⁱⁱ It causes patches of dry, itchy skin that may worsen and can erupt into a rash when scratched.ⁱⁱⁱ Breaks or cracks in the skin barrier can also result in infection and bleeding.^{iv}
- Atopic dermatitis and atopic eczema are terms that are often used interchangeably for the same chronic form of eczema.^v
 - “Atopic” means there is a genetic predisposition toward developing allergic hypersensitivity and disease.^{vi}
 - The progression of allergic diseases, beginning with atopic dermatitis in infancy and subsequent development of allergic rhinitis and asthma in childhood, is known as Atopic March (or Allergic March).^{vii}
- Typically, atopic eczema is common in early childhood and as the child ages; however, children are increasingly failing to “outgrow” the condition, with more and more people experiencing severe eczema into adulthood.^{viii} Eczema affects up to 20% of children^{ix} and 10% of adults worldwide,^{x,xi} with one in ten atopic eczema patients suffering from a severe form of eczema.^{xii} For adult patients, eczema is more common among women in their thirties and men over 65.^{xiii}
- There is no known cure for eczema; for most patients, eczema is a lifelong condition.^{xiv}

Atopic Eczema Key Facts:

Atopic Eczema's Impact on Patients

- Atopic eczema has a significant impact on patients' quality of life, with night-time itching leading to insomnia and the condition's inflammatory nature leading to increased instances of anxiety and poor cardiovascular health. Further, eczema flares can lead to absenteeism from work and school, in addition to lost productivity when working (presenteeism).^{xv,xvi,xvii}
- Patients often endure a significant negative impact on their emotional wellbeing: from an inability to sleep, as well as associated feelings of social exclusion resulting from stigma, and depression or anxiety.^{xviii,xix}
- Recent evidence suggests that patients with atopic dermatitis are at a significantly increased risk of suicidal ideation and suicidal attempt.^{xx}
 - Patients with AD had 44% higher odds of suicidal ideation and 36% higher odds of suicide attempts compared with patients without AD.^{xxi}
- Treatments for atopic eczema are available, but under-diagnosis and less-than-optimum care for patients remains common.^{xxii} The advocacy and patient community landscape for atopic eczema is young and evolving.



Atopic Eczema – Common Myths:

Myth: Atopic eczema is an infectious disease caused by bacteria, viruses, fungi or parasites.

Fact: Atopic eczema is a chronic inflammatory condition believed to be caused by the body's autoimmune response; uncontrolled scratching can lead to the development of infection.^{xxiii}

Myth: Atopic eczema is contagious and can spread to others through physical contact.

Fact: Atopic eczema is not contagious. The condition is at times hereditary as it tends to run in families.^{xxiv}

Myth: If both parents have atopic eczema, their child will inherit the condition.

Fact: While a family history of atopic eczema, asthma or hay fever is the strongest predictor of developing atopic eczema, the cause of atopic eczema is not solely hereditary.^{xxv}

Myth: Atopic eczema isn't a serious condition; it doesn't require treatment because it is easily "outgrown."

Fact: There are varying severities of atopic eczema. Sometimes children grow out of the condition, but sometimes it carries into adulthood.^{xxvi}

Myth: Atopic eczema is just a skin condition – it doesn't impact quality of life.

Fact: Atopic eczema is a chronic disease. Its itching can harm patients' mental health, lead to depression and social isolation.^{xxvii}

Myth: Having atopic eczema is cheap, it just requires an over-the-counter cream treatment.

Fact: Atopic eczema is an expensive disease and out of pocket cost is high, and for some unaffordable. Treatments may not be covered by health insurance and certainly not for other aspects affecting them, such as hygiene products, bed linen, clothes or foods.^{xxviii}

Myth: Atopic eczema flares are triggered by the same factors for all patients, whether environmental allergens or irritants like latex.

Fact: Atopic eczema triggers vary for everyone.^{xxix}

Myth: Atopic eczema only appears on the face, inside of the elbows, or behind the knees.

Fact: Atopic eczema can appear anywhere on the body.^{xxx}

Myth: Food allergies cause atopic eczema.

Fact: Food allergies may trigger flareups and make symptoms worse, but foods are not the primary cause of the atopic eczema.^{xxxi}

Myth: Regular baths and showers can make atopic eczema symptoms worse.

Fact: Bath and shower frequency isn't as important as using warm water, minimizing use of fragranced soaps, and moisturizing afterward. Hot water can trigger atopic eczema flares.^{xxxii}

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Top Tips for Media Outreach

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

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

Template Media Pitch Email

SUBJECT: GLOBAL ATOPIC ECZEMA PATIENT COMMUNITY COMES TOGETHER TO MARK THE SECOND ANNUAL WORLD ATOPIC ECZEMA DAY

Dear [name of media contact],

September 14, 2019, marks the second annual World Atopic Eczema Day to raise awareness and understanding of atopic eczema, while honoring those living with the disease and their families. World Atopic Eczema Day brings together those affected by the disease and encourages them to share their experiences, engage their local communities, and call for change.

On this second World Atopic Eczema Day, the patient community marks its continued commitment to organize, advocate, and share its stories year after year. This year, [Organization Name], GlobalSkin, and the European Federation of Allergy and Airways Diseases Patients Associations (EFA) invite the public to look beneath the surface of atopic eczema to further raise awareness and understanding of the impact it has on patients' lives.

Atopic eczema is much tougher on patients than people understand and seriously impacts patients' lives beyond their skin. Atopic eczema is a complex, chronic immune-mediated disease that causes a relentless itch, redness, swelling, and painful lesions. Further, atopic eczema seriously impacts patients' 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.

[Insert regional statistics and/or information about your local patient association activities]

If you would be interested in arranging an interview with Christine Janus, CEO of GlobalSkin, Mikaela Odemyr, EFA President, or [Insert local spokesperson/patient] for more information, please don't hesitate to contact us at [Insert local patient association 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]

Media Talking Points for Patient Associations

- The global atopic eczema patient community is coming together to mark the second annual World Atopic Eczema Day.
- Today, September 14th, marks the second annual World Atopic Eczema Day to raise awareness and understanding of atopic eczema. Today we acknowledge the impact that atopic eczema has on patients' lives, and we honor those living with the disease and their families. We want to send a strong message: "You are not alone!"
- On this second World Atopic Eczema Day, the patient community marks its commitment to continue to organize, advocate, and share its stories year after year. This year, GlobalSkin, the European Federation of Allergy and Airways Diseases Patients Associations (EFA), and [Insert name of organization], a member of [Insert affiliation] have come together to look beneath the surface of atopic eczema to further raise awareness and understanding of its impact on patients' lives.
- [Insert/mention data on atopic eczema prevalence at national level]
- Atopic eczema 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.
- [Insert your local organization's call for action on atopic eczema, if applicable]
- [Insert name of organization] is a proud supporter of World Atopic Eczema Day. Utilize the day's hashtag, #AtopicEczemaDay, to join this growing community and share your story.

Template Press Release

EMBARGOED UNTIL SEPTEMBER 14

GLOBAL ATOPIC ECZEMA PATIENT COMMUNITY COMES TOGETHER TO MARK THE SECOND ANNUAL WORLD ATOPIC ECZEMA DAY

Today, September 14, marks the second annual World Atopic Eczema Day to raise awareness and understanding of atopic eczema, a complex, chronic immune-mediated disease that causes itch, redness, swelling, and painful lesions and seriously impacts patients' lives beyond their skin. World Atopic Eczema Day brings together those affected by atopic eczema to share experiences, engage their local communities, and call for change.

On this second World Atopic Eczema Day, the patient community marks its commitment to continue to organize, advocate, and share its stories year after year. This year, [\[Organization name\]](#), GlobalSkin, and the European Federation of Allergy and Airways Diseases Patients Associations (EFA), have come together to look beneath the surface of atopic eczema to further raise awareness and understanding of its impact on patients' lives.

[\[INSERT LOCAL COMMUNITY SPOKESPERSON QUOTE\]](#)

[\[INSERT LOCAL PREVALENCE STATISTICS\]](#)

Globally, atopic eczema affects up to 20% of children and 10% of adults. And, the disease is much tougher on patients than people understand. Also known as atopic dermatitis, it 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. Atopic eczema's systemic nature means that it seriously impacts patients' lives beyond their skin. It almost always restricts life, impacts mental health, and leads to the development of other diseases.

This World Atopic Eczema Day, GlobalSkin, EFA, and [\[Organization name\]](#) want to remind people affected by atopic eczema that they are not alone. Patients and families are encouraged to mark the day by connecting and helping others by sharing their stories with the global atopic eczema community. In this way, the atopic eczema community

can work together in encouraging health systems to address the full range of atopic eczema's impact – ultimately, the movement aims to improve the lives of millions around the world.

Join this growing global community and join the conversation on Twitter and Facebook by using the hashtag: #AtopicEczemaDay

About GlobalSkin

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. In 2018, GlobalSkin launched the AltogetherEczema platform. Its website, AltogetherEczema.org, provides a central hub for people all over the world to identify common issues, share information and insights, and work together to find solutions. Learn more about GlobalSkin at GlobalSkin.org

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

The European Federation of Allergy and Airways Diseases Patients Associations (EFA) is a network of 42 allergy, asthma and chronic obstructive pulmonary disease (COPD) patients' organizations across 25 European countries. It works to ensure that all Europeans with allergy, asthma, and COPD have the ability to live uncompromised lives, have the right and access to the best quality care, and have a safe environment. Learn more about EFA at efanet.org.

About [Organization name]

[Organization details]

###

Partner Outreach Guide

This resource provides a template for conducting outreach to key stakeholders to solicit their support ahead of World Atopic Eczema Day. The template can be used to engage with policymakers, healthcare providers, or other non-governmental organizations.

SUBJECT: INTERNATIONAL MOVEMENT FOR ECZEMA SUFFERERS CONTINUES TO BUILD WITH SECOND ANNUAL WORLD ATOPIC ECZEMA DAY

Dear [name of partner organization],

We are writing you because September 14, 2019 marks the second annual 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 to drive action that improves lives all over the world. And we need your support.

We hope [name of partner organization] will help support action for those living with atopic eczema and their families by helping us share information on atopic eczema and its impact on people around the globe with your audiences. [Insert specific request for funds or other types of support.]

Building on last year's success, the second annual Atopic Eczema Day will feature activities taking place all over the world that aim to unite people with eczema and atopic dermatitis around shared experiences to foster a sense of community and honor those affected by the disease.

[Insert regional events/materials taking place on September 14]

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.

[Insert regional statistics from your local patient association]

We are pleased to invite you to join us in developing and supporting an active network of advocates this World Atopic Eczema Day. Together, we will continue to drive global momentum, increase connectivity, and amplify the voices of millions affected by this disease.

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]

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 or other stakeholders while supporting World Atopic Eczema Day.

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.

3. 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 wants 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).

2. What is World Atopic Eczema Day?

GlobalSkin, the European Federation of Allergy and Airways Diseases Patients Associations, and their member organizations are marking World Atopic Eczema Day on September 14th in order to:

- To empower a cross-sector and multinational community with the aim of building a global movement for change in advancing efforts to improve the lives of people living with atopic eczema.
- To engage the general public on the topic of atopic eczema by enhancing understanding of the condition's impact on patients' quality of life.
- To empower patient groups with a set of common messages and materials.
- To support and honor atopic eczema patients and their caregivers.

4. What is the difference between World 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.



5. How can the community get involved on World Atopic Eczema Day?

This World Atopic Eczema Day there are a number of ways the community can help raise awareness of eczema & atopic dermatitis, such as:

- Share one of the social media slides or messages suggested in this toolkit
- Join the conversation on Twitter and Facebook by using #AtopicEczemaDay

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

Visit AltogetherEczema.org, efanet.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).



WORLD
ATOPIC ECZEMA
DAY



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 get in touch with the team at

info@globalskin.org