

## WORLD ATOPIC ECZEMA DAY CAMPAIGN TOOLKIT

SEPTEMBER 14



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#### WORLD ATOPIC ECZEMA DAY INTRODUCTION

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

World Atopic Eczema Day was launched in 2018 to raise awareness about the disease globally and across Europe through an initiative coordinated by International Alliance of Dermatology Patient Organizations (GlobalSkin) and the European Federation of Allergy and Airways Diseases Patients' Associations (EFA).

#### The day marks the effort of the patient community to:



#### BUILD

Build a global movement for awareness and change, improving the lives of people living with atopic eczema.



#### **EMPOWER**

Empower patient groups to make their voices heard by providing targeted messages and materials.



#### SUPPORT

Support and honor atopic eczema patients, their families and caregivers.



#### INFORM

Inform the general public about atopic eczema and enhance understanding for the disease and the people living with it.

#### World Atopic Eczema has focused on specific themes through the years:

#### **▶** 2018: Raising Awareness for Atopic Eczema

Participants were encouraged to join the global movement through the launch of <u>AltogetherEczema.org</u> which united the patient community by identifying critical issues and sharing stories to deliver change. Messaging also included a focus on quality of life with atopic eczema.

#### ▶ 2019: Atopic Eczema – Beneath the surface

The launch of the World Atopic Eczema Day logo brought the community together to focus on how atopic eczema is much tougher on patients than people understand. It seriously impacts patients' lives beyond their skin.

#### 2020: How do YOU care for atopic eczema?

'In 2020, we brought attention to patients and their families, and how the disease seriously impacts daily life. We encourage healthcare professionals and decision makers to join the movement.

This Communications Toolkit was developed with Patient Organizations in mind. Check out the information, advice and assets provided and start inspiring others to get involved. Remember, together we are stronger!

If you need more information about World Atopic Eczema Day please contact:

- ▶ EFA info@efanet.org
- GlobalSkin info@globalskin.org





#### **KEY MESSAGES WITH PROOF POINTS**

The following data proof points can be used as supplementary information to enhance the key messages for your campaign. Proof points will vary by organisation and geography. Organisations may also want to substitute local data for some of the disease statistics listed below.

#### MESSAGES FOR PATIENTS, FAMILIES AND CAREGIVERS

#### **KEY MESSAGE**

## Atopic eczema rules daily life and over-all wellbeing. Having a child with atopic eczema is tough on parents as many feel helpless watching the suffering of their kids.

## Supportive care from parents and caregivers allows joyful moments to happen for children living with atopic eczema.

#### **PROOF POINTS**

#### **FATIGUE:**

There is increasing evidence of the elevated risk of developing psychosocial and mental comorbid diseases in childhood, such as childhood low self-esteem, abnormal psychological development or lack of socialization skills. Children with atopic eczema also show excessive dependency, clinginess and fearfulness. Emotional and physical fatigue owing to chronic sleep loss may negatively affect social relationships, leading to an increased risk of depression and anxiety. [8]

#### **SLEEP LOSS:**

In children with atopic dermatitis, sleep disturbance is not limited to the affected child alone but also extends to parents caring for the children with AD. Sleep disruption and greater tiredness are linked with severity of the child's skin disease. [16]

#### **ANXIETY AND DEPRESSION:**

High levels of anxiety and depression have also been found in parents of a chronically ill child, especially mothers. There is a positive correlation for depression with increasing disease severity. [9] Parents often experience exhastion, frustration, helplessness, feelings of guilt, sleep deprivation and instability of spousal and other relationships. Parents of children with atopic eczema also have more absences from work, poor social activities and stress about childcare. Many worries are related to disease triggers and medication. [8] [10]

Caring for atopic eczema is not only a physical and mental burden, but also a financial one.

#### **QUALITY OF LIFE:**

Caring for children affected by atopic eczema can be extremely time consuming and impair personal relationships, decrease psychosocial functioning and cause sleep loss among family members. Atopic eczema may also result in work absence or decreased work productivity for caregivers. Atopic eczema can greatly decrease the quality of life of families of affected children in many fronts, including sleep, finances and relationships. [11]



#### **KEY MESSAGES WITH PROOF POINTS**

#### MESSAGES FOR HEALTH CARE PROVIDERS/POLICY MAKERS

#### **KEY MESSAGE**

#### **PROOF POINTS**

When individuals living with atopic eczema receive timely and appropriate care, a better quality of life is possible.

#### **DEPRESSION:**

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].

#### **EXACERBATIONS:**

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 atopic dermatitis experience up to 113 days per year with exacerbations [4].

#### LONELINESS:

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].

#### **EMOTIONAL IMPACT:**

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 do not have an optimistic view of their life with eczema [7]

#### TREATMENT FAILURE:

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 [12] [13] [14] [15].

Atopic eczema is not just a skin disease; it often leads to anxiety and depression and the development of other chronic conditions.

#### **ANXIETY:**

High levels of anxiety and depression have also been found in parents of a chronically ill child, especially mothers. There is a positive correlation for depression with increasing disease severity. [9]

#### LIFETIME IMPACT:

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]

#### TREATMENT FAILURE:

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]



#### PROOF POINTS: SOURCES

- 1. http://www.worldallergy.org/UserFiles/file/WhiteBook2-2013-v8.pdf
- 2. E. Simpson, T. Bieber and L. Eckert, "Patient burden of moderate to severe atopic dermatitis: Insights from a phase 2b clinical trial of Dupilumab in adults", Am Acad Dermatol, vol. 74, no. 3, pp. 491-498, 2016. Available: <a href="https://www.sciencedirect.com/science/article/pii/S0190962215024718">https://www.sciencedirect.com/science/article/pii/S0190962215024718</a>
- 3. Guttman-Yassky E., Nograles K. and Krueger J., "Contrasting pathogenesis of atopic dermatitis and psoriasis-part I: clinical and pathologic concepts", J Allergy Clin Immunol, vol. 127, no. 5, pp. 1110-1118, 2011. Available: <a href="https://www.jacionline.org/article/S0091-6749(11)00183-7/abstract">https://www.jacionline.org/article/S0091-6749(11)00183-7/abstract</a>
- 4. T. Zuberbier, S. Orlow and A. Paller, "Patient perspectives on the management of atopic dermatitis", J Allergy Clin Immunol, vol. 118, no. 1, pp. 226-232, 2006. Available: <a href="https://pubmed.ncbi.nlm.nih.gov/16815160/">https://pubmed.ncbi.nlm.nih.gov/16815160/</a>
- 5. Torrelo A., Ortiz J., Alomar A., 2012. "Atopic dermatitis: impact on quality of life and patients' attitude towards its management", Eur J Dermatol, 22(1), pp. 97-105, 2012. Available: <a href="https://www.jle.com/fr/revues/ejd/e-docs/atopic\_dermatitis\_impact\_on\_quality\_of\_life\_and\_patients\_attitudes\_toward\_its\_management\_291853/article.phtml?cle\_doc=0004740D">https://www.jle.com/fr/revues/ejd/e-docs/atopic\_dermatitis\_impact\_on\_quality\_of\_life\_and\_patients\_attitudes\_toward\_its\_management\_291853/article.phtml?cle\_doc=0004740D</a>
- 6. Carroll C.L., et al., "The burden of atopic dermatitis: Impact on the Patient, family, and Society", Pediatric Dermatology, pp. 22(3)192-9, 2005. Available: https://pubmed.ncbi.nlm.nih.gov/15916563/
- 7. De Carlo G., et al., "EFA Report Itching for Life Quality of Life and Cost for People with Severe Atopic Eczema in Europe", 2018. Available: <a href="https://www.efanet.org/news/3373-european-report-itching-for-life-quality-of-life-and-costs-for-people-with-severe-atopic-eczema-in-europe">https://www.efanet.org/news/3373-european-report-itching-for-life-quality-of-life-and-costs-for-people-with-severe-atopic-eczema-in-europe</a>
- 8. Na, C.H., Chung, J. and Simpson, E.L., "Quality of Life and Disease Impact of Atopic Dermatitis and Psoriasis on Children and Their Families". Children, 6(12), p.133, 2019. Available: <a href="https://europepmc.org/article/med/31810362">https://europepmc.org/article/med/31810362</a>
- 9. Schonmann, Y., Mansfield, K.E., Hayes, J.F., Abuabara, K., Roberts, A., Smeeth, L. and Langan, S.M., "Atopic eczema in adulthood and risk of depression and anxiety: a population-based cohort study". The Journal of Allergy and Clinical Immunology: In Practice, 8(1), pp.248-257, 2020. Available: <a href="https://europepmc.org/article/med/31479767">https://europepmc.org/article/med/31479767</a>
- 10. Hale, G., Davies, E., Grindlay, D.J.C., Rogers, N.K. and Harman, K.E., "What's new in atopic eczema? An analysis of systematic reviews published in 2017. Part 2: epidemiology, aetiology and risk factors." Clinical and experimental dermatology, 44(8), pp.868-873, 2019. Available: <a href="https://pubmed.ncbi.nlm.nih.gov/31502320/">https://pubmed.ncbi.nlm.nih.gov/31502320/</a>
- 11. Yang, E.J., Beck, K.M., Sekhon, S., Bhutani, T. and Koo, J., "The impact of pediatric atopic dermatitis on families: A review". Pediatric dermatology, 36(1), pp.66-71, 2019. Available: <a href="https://pubmed.ncbi.nlm.nih.gov/30556595/">https://pubmed.ncbi.nlm.nih.gov/30556595/</a>
- 12. Ashcroft D., Dimmock P., and Garside R., "Efficacy and tolerability of topical pimecroliumus and tracolimus in the treatment of atopic dermatitis: meta-analysis of randomized controlled trials", BMJ, vol. 330, no. 7490, pp. 516- 522, 2005. Available: https://www.bmj.com/content/330/7490/516
- 13. Meggitt S., Gray J. and Reynolds N., "Azathioprine dosed by thiopurine methyltransferase activity for moderate to severe atopic eczema: a double-bind, randomized controlled trial", Lancet, vol. 367, no. 9513, pp. 839-846, 2006. Available: <a href="https://www.researchgate.net/publication/7247068\_Azathioprine\_dosed\_by\_thiopurine\_methyltransferase\_activity\_for\_moderate-to-severe\_atopic\_eczema\_A\_doubleblind\_randomised\_controlled\_trial</a>
- 14. Schram M., Roekevisch E. and Leeflang M., "A randomized trial of methotrexate versus azathioprine for severe atopic eczema", J Allergy Clin Immunol, vol. 128, no. 2, pp. 353-359, 2011. Available: <a href="https://www.sciencedirect.com/science/article/pii/S0091674911005033">https://www.sciencedirect.com/science/article/pii/S0091674911005033</a>
- 15. 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. Available: <a href="https://link.springer.com/article/10.2165/00128071-200405040-00006">https://link.springer.com/article/10.2165/00128071-200405040-00006</a>
- 16. Jain, N., Sanchez, O. and Attarian, H., "Sleep-Related Disorders Associated with Atopic Dermatitis. In Allergy and Sleep, pp. 295-305, Springer, Cham, 2019. Available: <a href="https://link.springer.com/chapter/10.1007/978-3-030-14738-9\_22">https://link.springer.com/chapter/10.1007/978-3-030-14738-9\_22</a>





MEDIA OUTREACH



# MEDIA OUTREACH

#### 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. 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.
- Copy supporting content into the body of the email (attachments often don't get through the firewall!)
- Include appropriate links and contact information, and ensure you have spokesperson availability to hand.
- 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.

#### TEMPLATE MEDIA PITCH EMAIL

SUBJECT: ATOPIC ECZEMA PATIENT COMMUNITY MARKS WORLD ATOPIC ECZEMA DAY

Dear [name of media contact],

Each year, we mark September 14 with World Atopic Eczema Day to raise awareness and understanding of atopic eczema and the people living with it.

This year, International Alliance of Dermatology Patient Organizations (GlobalSkin), the European Federation of Allergy and Airways Diseases Patients' Associations (EFA), and [Insert name of organization], a member of [Insert affiliation] are focusing on the impact atopic eczema has on patients and their families.

Please find more information on World Atopic Eczema Day in the Press Release attached. Should you be interested in arranging an interview with GlobalSkin, EFA, or [Insert local spokesperson/patient] for more information, please don't hesitate to contact us me.

Please don't hesitate to contact me for any questions.

[Insert name]



#### TEMPLATE PRESS RELEASE

#### World Atopic Eczema Day challenges patients, healthcare professionals and policy makers around the world to unite for care.

September 14, marks World Atopic Eczema Day - a day where the patient community comes together to raise awareness, understanding and the standards of care for atopic eczema. Atopic eczema is incredibly difficult on patients and their families, seriously impacting daily life. An individual's health and the overall wellbeing of families can be severely impaired by the disease. [Organization name] is proud to join the International Alliance of Dermatology Patient Organizations (GlobalSkin), the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) and the global atopic eczema community to change the way atopic eczema patients are perceived and how care is delivered.

Patients and families are at the core of World Atopic Eczema Day. They endure chronic pain, social isolation and a considerable financial burden to take care of their atopic eczema. Today we come together and unite for action on the disease. All together, we #CareForAtopicEczema.

#### [INSERT GLOBAL, EUROPEAN OR LOCAL QUOTE HERE] [INSERT LOCAL STATISTICS]

Atopic dermatitis or atopic eczema 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 and 20% of children worldwide. Caring for children affected by atopic eczema can be all-encompassing; it can affect personal relationships, decrease psychosocial functioning, bring sleep loss for family members and engender grief 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 parents. Even siblings of affected children find their lives affected. When atopic eczema affects children, it affects the whole family – often profoundly.

On World Atopic Eczema Day [Organization Name] wants 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 gain understanding of the disease impact by sharing their stories. Healthcare professionals and policymakers are also invited to show how they care for patients and families who live with this disease. When individuals living with atopic eczema receive timely and appropriate care, a better quality of life is possible.

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, this movement aims to improve the lives of millions around the world. Join [Organization Name], GlobalSkin, EFA and the growing global community to be part of the conversation on Twitter and Facebook by using the hashtag: #AtopicEczemaDay.



#### **MYTHS AND FACTS**

MYTHS	FACTS
Atopic eczema is an infectious disease caused by bacteria, viruses, fungi or parasites.	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.  SOURCE: "Atopic Eczema." NHS UK. 2016. Click here to view.
Atopic eczema is contagious and can spread to others through physical contact.	Atopic eczema is not contagious. The condition is at times hereditary as it tends to run in families.  SOURCE: "Eczema (atopic dermatitis)." Department of Health & Human Services, State Government of Victoria, Australia. 2019. Click here to view
Atopic eczema only appears on the face, inside of the elbows, or behind the knees.	Atopic eczema can appear anywhere on the body.  SOURCE: Amy Stanway. "Atopic dermatitis." DermNet NZ. New Zealand Dermatological Society. 2004.  Click here to view
Regular baths and showers can make atopic eczema symptoms worse.	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.  SOURCE: "Causes and Triggers of Eczema." National Eczema Association. Accessed 2019. Click here to.
Having atopic eczema is cheap, it just requires an over-the-counter cream treatment.	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.  SOURCE: Itching for Life: Quality of Life and Costs for People Living with Atopic Eczema in Europe." European Federation of Allergy and Airways Diseases Patients' Association. 2018. Click here to view
Food allergies cause atopic eczema.	Food allergies may trigger flareups and make symptoms worse, but foods are not the primary cause of the atopic eczema.  SOURCE: Amy Stanway. "Atopic dermatitis." DermNet NZ. New Zealand Dermatological Society. 2004.  Click here to view
Atopic eczema isn't a serious condition; it doesn't require treatment because it is easily "outgrown."	There are varying severities of atopic eczema. Sometimes children grow out of the condition, but sometimes it carries into adulthood.  SOURCE: Amy Stanway. "Atopic dermatitis." DermNet NZ. New Zealand Dermatological Society. 2004.  Click here to view
Atopic eczema is just a skin condition – it doesn't impact quality of life.	Atopic eczema is a chronic disease. Its itching can harm patients' mental health, lead to depression and social isolation.  SOURCE: Itching for Life: Quality of Life and Costs for People Living with Atopic Eczema in Europe." European Federation of Allergy and Airways Diseases Patients' Association. 2018. Click here to view
Atopic eczema flares are triggered by the same factors for all patients, whether environmental allergens or irritants like latex.	Atopic eczema triggers vary for everyone.  SOURCE: Causes and Triggers of Eczema." National Eczema Association. Accessed 2019. Click here to view
If both parents have atopic eczema, their child will inherit the condition.	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.  SOURCE: "Eczema (Atopic Dermatitis) Causes & Strategies for Prevention." National Institute of Allergy and Infectious Diseases. 2016. Click here to view





#### PARTNER OUTREACH TEMPLATE

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 ATOPIC ECZEMA PATIENTS CONTINUES TO BUILD ON WORLD ATOPIC ECZEMA DAY

Dear [name of partner organization],

We are writing you because September 14 marks World Atopic Eczema Day; a day where patients raise awareness and understanding of atopic eczema. 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 World 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]



## SUPPORT FROM HEALTHCARE PROFESSIONALS AND MEDICAL SOCIETIES

Patients and families are at the core of World Atopic Eczema Day. Working together with patient organizations across the globe, on September 14th we will come together and unite for action on the disease.

Patients and families cannot face the disease alone, we need healthcare professionals guiding our care and supporting us to live with atopic eczema.

On World Atopic Eczema Day, we invite healthcare professionals to join patients and caregivers all over the globe to tell us how they support atopic eczema patients and research to advance on care for this chronic disease.

Healthcare Professionals and Medical Societies Can Support Atopic Eczema Patients on World Atopic Eczema Day

#### CALL FOR CHANGE



Help
call for
change for better
care and appropriate
treatment options
for patients through
messaging on
social media

Amplify
your patients'
voice, by pointing
publicly to the needs
and experiences of
your patients (with
interviews, op-eds,
references in
scientific talks)

#### SUPPORT PATIENTS



Show

your support
to patients with
atopic eczema, through
activities that help patients
connect and better live with
their diseases (peer

groups, advising patient groups and associations)

Acknowledge and validate the experience of families and caregivers, caring for your patients having in mind the full range of symptoms atopic eczema can bring beyond skin.



**AMPLIFY PATIENT VOICES** 

VALIDATE EXPERIENCES



### 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 OFFICIALS 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 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 International Alliance of Dermatology Patient Organizations (GlobalSkin and the European Federation of Allergy and Airways Diseases Patients Associations (EFA), is September 14<sup>th</sup>.

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]



### TEMPLATE WORLD ATOPIC ECZEMA DAY PROCLAMATION

#### SAMPLE WORLD ATOPIC ECZEMA DAY PROCLAMATION

#### Greetings:

It brings me great pleasure to mark today, September 14<sup>th</sup>, as 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





MEDIA OUTREACH





#### WORLD ATOPIC ECZEMA DAY LOGO GUIDELINES

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 globeshape 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.





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



For coloured backgrounds







For white backgrounds

For white backgrounds

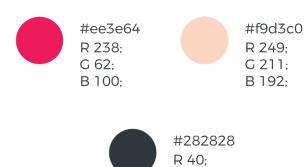
#### **OUR FONTS**

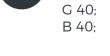
Find these available for download here.

#### Montserrat

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**







# EVENT

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. Many of the examples included can be adapted to virtual activities.

#### PLANNING YOUR ATOPIC ECZEMA DAY CAMPAIGN



#### **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.

#### **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.



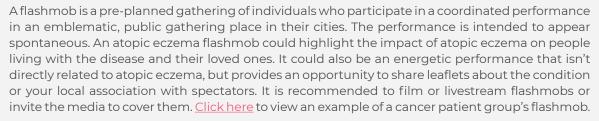


#### PHOTO EXHIBITION:



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.

#### **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.



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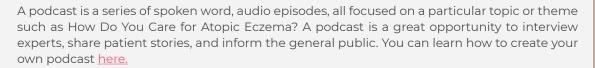


#### PANEL DISCUSSION:



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.

#### **PODCAST:**







#### **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:**







#### **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.

#### **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.





#### PLANNING YOUR ATOPIC ECZEMA DAY CAMPAIGN



#### **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.





#### **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.

#### **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.



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.

#### **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.

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



#### 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.

- 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.



### 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.

- 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.



#### **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.

- 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.





MEDIA OUTREACH



Twitter

## SOCIAL MEDIA

#### TIPS FOR DEVELOPING SOCIAL MEDIA 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 & 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



#### FACEBOOK AND TWITTER 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.

#### 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.

#### **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.

#### **HASHTAGS**

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



#### 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.

#### "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.

#### 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.

#### **HASHTAGS**

Join the conversation by using #AtopicEczemaDay



