

# STRONGER TOGETHER.

September 14, 2020 | World Atopic Eczema Day

# World Atopic Eczema Day 2020 Campaign Report



GLOBALSKIN.ORG

International Alliance of Dermatology Patient Organizations

# World Atopic Eczema Day Overview



Atopic Eczema is an allergic skin disease that sits at the center of other health issues: it impacts mental health and leads to the development of other diseases. Atopic eczema is incredibly difficult on patients and their families, seriously impacting daily life. An individual's health and overall wellbeing can be severely impaired by the disease.

World Atopic Eczema Day, an awareness day for atopic eczema, was launched by the International Alliance of Dermatology Patient Organizations (IADPO, also known as GlobalSkin) and the global atopic eczema patient community in 2018. This Day:

- Empowers a cross-sector and multinational community to build a global movement for change to improve the lives of people living with atopic eczema.
- Engages the general public on the topic of atopic eczema by enhancing understanding of the condition's impact on patients' quality of life.
- Empowers patient groups with a set of common messages and materials.
- Supports and honours atopic eczema patients and their caregivers.

September 14, 2020 marked the <u>third annual</u> World Atopic Eczema Day! This year's campaign focused on patients and families and asked the question "How do YOU care for atopic eczema?". Everyone who is affected by atopic eczema was invited to share their experiences, some of which were stories of joy and support, but also included those of suffering and compassion.

GlobalSkin and the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) developed a <u>Communications Toolkit</u> for use by patient organizations to help raise awareness for this disease with a common voice. The toolkit included key messages, event ideas and was made available in 12 languages. Messaging included working together with patient groups across the globe and uniting for action on the disease.

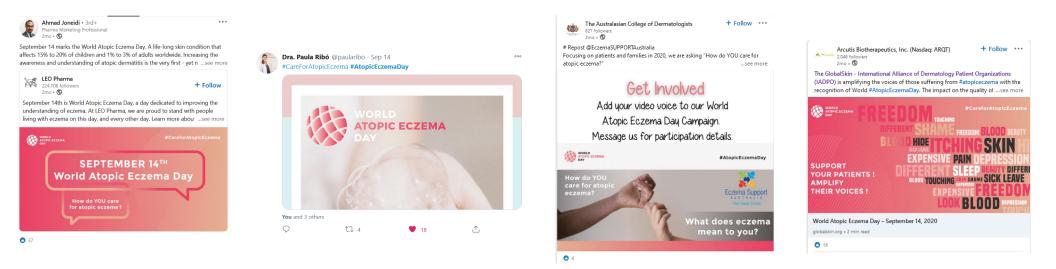


The 2020 Campaign also invited health care professionals and decision makers to join the initiative and to share how they support atopic eczema patients all over the globe.

# Overview – GlobalSkin Campaign



Despite the coronavirus pandemic that has gripped the world in 2020, engagement in World Atopic Eczema Day was far reaching. Participation was seen from patients, patient organizations, healthcare providers, industry partners, dermatology societies and many other stakeholders from the United States, Philippines, United Kingdom, Netherlands, Kenya, Australia and everywhere in between.



In 2020, GlobalSkin ran an extensive social media campaign on existing channels like Facebook and Twitter, but also added two new channels, Instagram and LinkedIn to outreach efforts. The paid portion of the campaign included ads on Facebook, Twitter and Instagram, with an overwhelming amount of engagement. GlobalSkin grew followers on all channels and reached a brand-new Instagram audience.

The GlobalSkin Campaign also included a Care Priorities Survey developed as an initiative of our Atopic Eczema Community. The survey was designed with the purpose of identifying the care priorities, and ongoing care challenges and barriers, for people living with atopic eczema.

The survey was shared globally and was highlighted during GlobalSkin's month-long World Atopic Eczema Day awareness campaign. Over 300 atopic eczema patients and caregivers took part in the survey with particularly high involvement in the Philippines.



# Overview – GlobalSkin Social Media Campaign



#### **KEY SOCIAL MEDIA METRICS:**

- 2.72M Total Impressions (Twitter, Facebook, Instagram)
- 1.81M Impressions Twitter
- 1.2M Impressions Facebook/Instagram
- 24,190 Post Engagement Facebook
- 25 countries reached by GlobalSkin posts
- Most impressions in Philippines, US, Canada, UK, France, Australia, Netherlands, Kenya
- Increase of 8352 Followers on Facebook (Totalling 25,155)
- Increase of 854 Followers on Twitter (Totalling 1875)
- New Instagram Channel (115 followers)
- Re-engaged LinkedIn Channel (185 followers)
- 300 Completed Patient Care Surveys Worldwide

LEO Pharma 🥝 @LEO Healthy Skin - Sen 15



Semana mundial de la dermatitis atópica Didos

odemos lograr cambios más grandes 👭

LEO Pharma © eLEOHealthysion : sep 15 " Receive the second seco Allergy UK @AllergyUK1 - Sep 14

Having a child with atopic eczema is tough on parents as many experience feelings of helplessness. This #AtopicEczemaDay

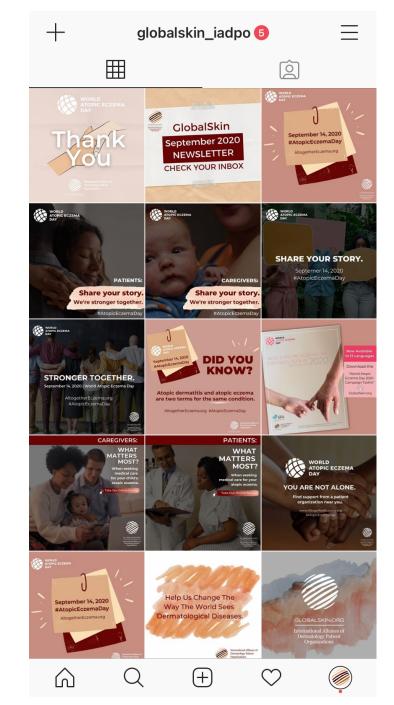
ing you to join the conversation and share your stories ab

we are

AllergyUK

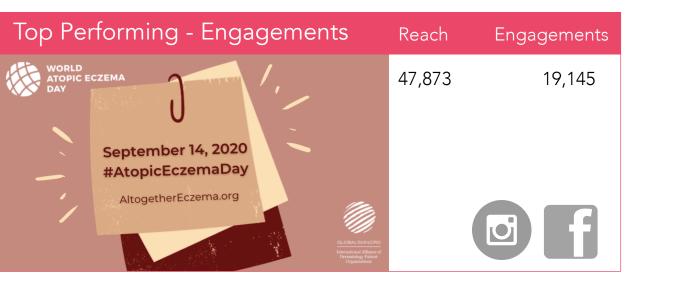
Condation Eczéma @FondationEczema -Sep 7 #Swoffbatte @ref1Lund14/09, crest la Journée Mondiale de Récomationaux de la Sectionaux vivre l'eczéma" pour suivre Facebook Live. Des risolgnants et des épatients partageron leurs vérsis: conselle et méthodes pour miser vivre l'éczéma"





# GlobalSkin Social Media Campaign Reach



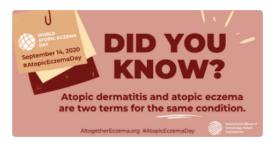


Top Performing - Reach	Reach	Engagements
CARECIVERS: CUCALSING DECIMINATION DECIMI	699,137	10,169

#### Top Tweet

#### Top Tweet earned 8,203 impressions

Did you know that #atopicdermatitis and #atopiceczema are two terms for the same condition? #AtopicEczemaDay is coming up - learn more about this campaign and show your support. #eczemaawareness #eczema pic.twitter.com/jzr8xj8D5I



SEP 2020 SUMMARY

Tweets 40	Tweet impressions	
Profile visits 6,900	Mentions 80	
New followers 832	Y	

Increase of 8352 Followers on Facebook (Totalling 25,155) Increase of 854 Followers on Twitter (Totalling 1875)

# Patient Organization Participation



The World Atopic Eczema Day Communications Toolkit was made available to GlobalSkin Members and any organization, patient or stakeholder that wanted to participate in this important awareness day. The toolkit included key messages, press release templates, event ideas and suggested social media posts. The following is a list of patient organizations that utilized the toolkit in their 2020 campaigns.

33 PATIENT ORGS 20 COUNTRIES 4 REGIONS

Argentina

Australia

Belgium

Brazil

Canada

Colombia

Czech Republic

Denmark

France

- Allergy UK (United Kingdom)
- Allergy Foundation South Africa (South Africa)
- Alergija i ja (Serbia)
- Asociación de Afectados por la Dermatitis Atópica AADA (Spain)
- Associação Dermatite Atópica Portugal ADERMAP (Portugal)
- Asociación de Dermatitis Atópica ADAR (Argentina)
- Association Francaise de l'Eczema (France)
- Associazione Nazionale Dermatite Atopica ANDeA (Italy)
- Atopikerna (Sweden)
- Atopic Eczema Association AEF (Denmark)
- Autoimmune Related Diseases Association (United States)
- Brazilian Society of Dermatology (Brazil)
- Canadian Skin Patient Alliance (Canada)
- Asociación Civil para el Enfermo de Psoriasis AEPSO (Argentina)
- Eczema Support Australia (Australia)

# Patient Organization Participation



33 PATIENT ORGS 20 COUNTRIES 4 REGIONS

Ireland

Italy

New Zealand

Russia

Serbia

South Africa

Spain

Sri Lanka

Sweden

United Kingdom

United States

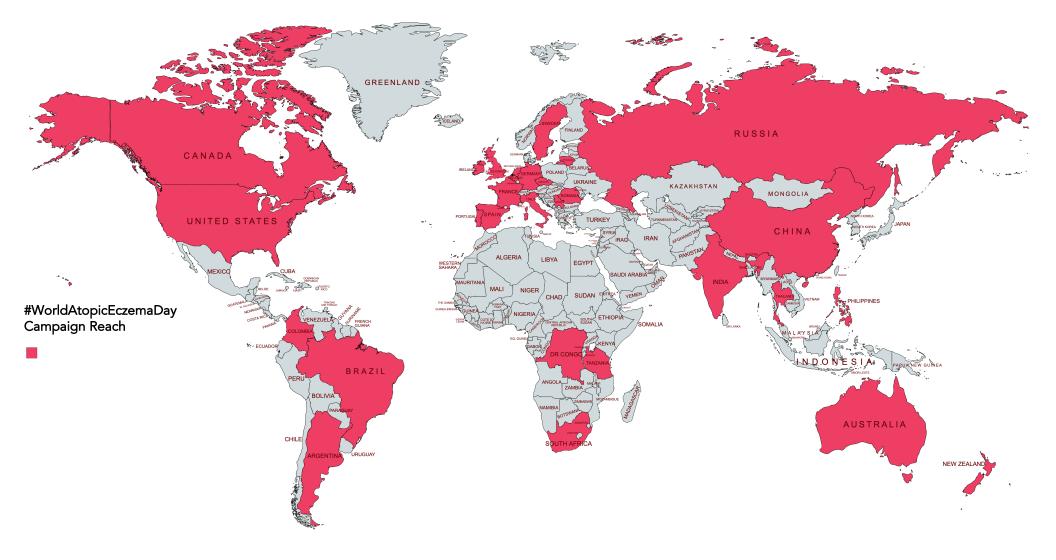
- European Federation of Airways and Allergies Patient EFA (Belgium/All Europe)
- Eczema Association of New Zealand (New Zealand)
- Eczema Association Australasia Inc EAA (Australia)
- Eczema Outreach Support EOS (United Kingdom)
- Eczema Society of Canada (Canada)
- Fundacion de Apoyo al Paciente con Psoriosis y otros Enfermedades de la Piel FUNDAPSO (Colombia)
- Global Allergy and Asthma Patient Platform (Global)
- Investigación en Alergias y Enfermedades respiratorias INAER (Argentina)
- Irish Skin Foundation (Ireland)
- International Topical Steroid Awareness Network ITSAN (USA/Global)
- National Eczema Association (USA)
- Ospedale Israelitico (Italy)
- Respiriamo Insieme RI (Italy)
- Skin Sri Lanka (Sri Lanka)
- Skin and Allergic Diseases (Russia)
- Sociedad Latinoamericana de Alergia, Asma e Inmunologia SLaai (Ibero-America)
- Spanish Association of People with Food and Latex Allergy AEPNAA (Spain)
- Topical Steroid Withdrawal Syndrome Support ITSAN (United States)

# Worldwide Impact



The below map demonstrates the worldwide reach of the #WorldAtopicEczemaDay campaign through engagement on social media. GlobalSkin, our Members and other patient organizations around the globe participated in using the hashtag #WorldAtopicEczemaDay #CareForAtopicEczema in their online support efforts.

Campaigns were connected online using the hashtag alongside other chosen elements such a live/virtual events, paid multi-media, giveaways and even professionally produced videos.



# World Atopic Eczema Day Fund



2020 marked the second year of the GlobalSkin World Atopic Eczema Day Fund. This fund was created to financially assist GlobalSkin Member organizations in the planning and execution of events and activities around this important day. We are grateful to Sanofi Genzyme Regeneron, LEO Pharma, Pfizer, and AbbVie for your support.

Grant applications were submitted from GlobalSkin Members in the lead-up to World Atopic Eczema Day on September 14, 2020. Projects that supported raising awareness of and/or contributed to building the community during World Atopic Eczema Day were considered for funding. Funded projects fell into two categories: Planning/Hosting Events and Marketing Support.

The 2020 World Atopic Eczema Day Fund Supported:

- 14 Patient Organization Projects
- Located in 10 different countries: China, Slovenia, USA, Kenya, Sri Lanka, UK, Serbia, Australia, Belgium and Austria
- Each project was funded up to 2000 CAD each

Thanks to this Fund, we were able to create higher quality content for our members which was particularly significant this year with our campaign being fully virtual.







#### China AD Family (China)

Online Presence: WeChat Channel 7 posts, 2046 views, 100 shares

How the Funds Helped: Website build, design and operation; article-writing; data analysis <u>https://chinaadfamily.org.cn/sy</u> Image: state state

We launched the China AD Family website on the day in order to touch more potential atopic dermatitis patients and enhance public and patient's atopic dermatitis disease awareness, improve diagnosis and evaluation and self-management capability. Several activities were posted on the website and WeChat including Real Patient Stories, Patient Education, and a Junior Dermatitis live broadcast. Many thanks for your full support on World Atopic Eczema Day in China.

#### Drustvo Atopijski Dermatitis (Slovenia)

Online Presence: Facebook 33 posts, 64,970 views, 746 likes Instagram 20 posts

How the Funds Helped: Printing costs of brochures and books of patient stories

We conducted interviews with patients and caregivers and put them together in a book of stories which we also gave out to decision makers, companies, doctors, and pharmacies. We made an online campaign with T-shirts, which we turn inside out for the support of all the atopic patients. We also appeared in the paper, on radio and TV to give statements about atopic eczema, about World AD Day and about our association.

To be able to communicate with different decision makers and doctors really pointed out where our challenges lie. Finally, a center for atopic dermatitis in Slovenia is being considered, which was an idea that came from us "being loud".







#### Global Parents for Eczema Research (USA)

Online Presence: Facebook 36 posts, 13,000 views, 966 likes Instagram 36 posts, 2112 likes, 710 comments, 89 shares

How the Funds Helped: Graphic design of social media posts, prizes for caregivers, paid boosted posts, postage.



mean to YOU?

We invited caregivers of children with eczema to share their personal stories and experiences on their public timelines on Facebook and Instagram on Sept. 14 and offered prizes for the most impactful posts. These were incredibly emotional, moving, and raw stories that generated a lot of interaction and traffic. All were reposted to the GPER Page and shared as Instagram stories as a "gallery" of stories, which we invited people to view via Twitter as well.

We had a big turnout and lots of engagement. We were really happy with how the day went. Please check out our caregiver stories at: <a href="http://www.facebook.com/parentsforeczemaresearch">www.facebook.com/parentsforeczemaresearch</a>.

#### International Topical Steroid Awareness Network (USA)

Online Presence: Facebook, Twitter and Instagram 12 posts, 1000+ impressions per post

How the Funds Helped: We hired a film maker to produce 5 short videos, as well as 5 print ads, "boosted" Facebook ads, Zoom platform.

We held a webinar and live Facebook stream, as well as posting short videos and memes. Our webinar featured an eczema/topical steroid withdrawal sufferer with a large social media following. She has appeared on TLC's "Save my Skin" and is creating a documentary chronicling her eczema/TSW journey. Our posts featured myths vs facts to share with friends and family, and short videos highlighting the eczema experience socially, financially, emotionally, and physically.

We are a small non-profit, and to see numbers in the 20 - 40 thousands engaging with us was a real treat. We are so grateful that this grant allowed us to reach more people and raise awareness.







#### Eczema Society of Kenya (Kenya)

Online Presence: Facebook 35 posts, 418 likes, 130 shares Whatsapp 180 views Webinar 427 attendees

How the Funds Helped: Zoom account, paid media outreach, incentive materials, internet costs for participants

We held a two-day virtual event held on 14th and 15th September 2020, from 12:00pm - 2 pm, streamed live on zoom and Facebook. The objective was to mark World Atopic Eczema Day for 2020, whose theme was "How do you take care of your atopic eczema?" We were able to bring together a team of eight panelists participating on both days, sharing their expertise, knowledge, experiences, answering questions, concerns, and emerging issues.

Participants commended the Eczema Society of Kenya for the good advocacy work, they are doing. They advised that they should target a wider audience - the vulnerable groups in the society who do not have access to such opportunities. The guest dermatologist advised participants on the importance of knowing your triggers and observing proper diet and hygiene, and the need to take an allergy test for identifying Eczema triggers. We had participants volunteering to share their experiences and journey with atopic eczema on both Facebook and zoom (as a panelist), highly motivating others who identified with their stories.

#### Skin Sri Lanka (Sri Lanka)

Online Presence: Facebook 4500+ reach

How the Funds Helped: Hosting in-person clinics in remote regions, boosted posts

We started our WAED program one month before, with the education of our community with the everything about Atopic Eczema in our native language (Sinhalese) on our official FB page SkinSriLanka. We gave a media conference about the importance of WAED and good media coverage through the TV and prominent news papers in Sri Lanka. Our special Atopic eczema clinic on the WAED held in deep down south of Sri Lanka place called Morawaka in Galle district where the health facilities are very poor. More than 200 atopic eczema patients were attended with about 100 care takers. All most all patients were seen by a Dermatologists and treated accordingly with specific advice related to atopic eczema.



Eczema Society Kenya (ESK) @EczemaSocietyKE · Sep 14 Know your triggers in order to buy the specific products for your skin. #Eczema.#livingwithEczema@EczemaSocietyKE @Hot\_96Kenya @eczema\_less @oureczemastory1 @EczemaNoMore







#### Allergy and Asthma Network (USA)

Online Presence: Facebook 2118 reach, 15 shares Twitter 2202 engagements E-newsletter 38 000 deliveries, 5880 opens

How the Funds Helped: Paid social media ads, boosted posts



We worked with allergist Purvi Parikh, MD, to post an article titled "What's Causing My Eczema? 6 Common Triggers," highlighting that Sept. 14 is World Atopic Eczema Day. We also spotlighted an "Ask the Allergist" video with allergist Stanley Fineman, MD, who discussed how to stop the itch-scratch cycle associated with chronic eczema. We posted the content on AllergyAsthmaNetwork.org, promoted it on social media and shared it in our monthly E-newsletter. We supplemented our own World Atopic Eczema Day messaging and social media posts – Facebook, Twitter and LinkedIn – with posts provided by GlobalSkin.

#### Eczema Outreach Support (UK)

Online Presence: Facebook and Instagram 221 601 reach, 520 shares

How the Funds Helped: Facebook and Instagram ads, plus boosted posts Eczema Outreach Support @EczemaOutreach - Sep 12 You can show your support for World Eczema Day on Sep 14 by adding our frame to your Facebook profile picture. Just click the image and select 'use frame' to add to your photo. #eczemaoutreachsupport #eczema #eczemahelp ow.ly/dWZL50BeArU @IADPO

Eczema Outreach Support held an online webinar with a dermatology nurse consultant for members and the general public. We also filmed a follow up video with the nurse, answering additional questions and posted on YouTube and our website. We also held an online event for members aged 11-17 with a dermatologist answering their questions and we premiered our new school animation on eczema that will be shown in secondary schools which featured the voices of some members. When polled, 89% of webinar attendees said it helped them to feel more supported to deal with their child's eczema. We had national newspaper coverage in The Mirror and Belfast Telegraph. As a result of this, Eczema Outreach Support had new members join having seen the news articles.





#### Allergy and Me (Serbia)

Online Presence: Facebook 49 posts, 59 183 views, 3968 likes, 96 shares Instagram 38 posts, 79 105 views, 3985 likes, 79 shares Twitter 17 tweets, 1626 impressions

How the Funds Helped:

Equipment and scenography rental, media wall, atopic eczema brochures, printed materials, photo exhibition, materials for kids' workshops, designer for printing and publishing materials.

We published a Literary Competition in which patients shared with us personal experiences in the form of a story that we published on our website. We have collected 10 quality stories, which we published in an online book. We opened an author's photo exhibition (14 photos + 4 posters with messages) with messages explaining the everyday experience of living with atopic eczema. After the opening, it will be presented at the Clinic for Dermatology of Serbia, and after that in other cities in Serbia. We organized free examinations by dermatologists and allergists for patients, which are the main event for patients this year as well, due to the impossibility of treatment and the difficulty of diagnosis, especially now at the time of Corona virus. A panel discussion was held in which mothers of children with atopic dermatitis shared their stories, and at the end of the event we prepared a motivational speech by a young patient who spoke about her treatment for atopic eczema and supported young people to take care of their skin. Together with our associates and experts, we have written 13 educational texts for our website that will cover topics that no one has previously written about.

I think that this year we have moved the line of understanding atopic eczema in Serbia. I am very proud that our content will continue to live in the future, and not just for one day a year.











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#### Institute Atopika (Slovenia)

Online Presence: Facebook 97 posts, 49 303 views, 9859 likes

How the Funds Helped: Graphic design for event, filming and live stream, event coordinator.

Our event lasted for 3 days. Dermatologist doc. dr. Maruška Marovr, dr. med. gave free consolations for patients. We gave one interview on television, one on radio and 4 interviews for written media. For the educational part of the event, we organized a congress for the patients with atopic dermatitis, their loved ones, the general public and medical doctors. At the congress we held lectures from three dermatologists, allergist, pediatrician, skin- gut microbiota researcher, psychologist and pharmacist. We also hold a round table where adult patients and mother of children that suffer with AD explained how their life looks like and what is the rate of their life quality. We held the congress in person and online. We also had activities take place at the Maribor City Park where we organized numerous workshops. We held relaxing sound bath (with gong, drums and other holistic instruments), foot reflex therapy to aid the organism with atopic dermatitis and guided meditation.

I have to say that everything was successful. The most successful was the round table where patients told their stories. Even the doctors that see those patients every day were speechless. The patients were grateful that all three days they could communicate with the doctor on a personal level.

Zavod Atopika September 14 · S

We started with the preparations. **2 2 2 2** September 14. is here! Come visit us! Freedom Square, Maribor. Atopika Institute with you.

- See original - Rate this translation



Zavod Atopika

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Rdečke 🔮 🔮 🤮 ozaveščamo!!!

See Translation







#### Eczema Support Australia (Australia)

Online Presence: Facebook 18 700 reach

How the Funds Helped:

Video filming, editing and social media planning and implementation. Management and promotion of eczema community participation. Promotion of social media posts.

We invited those affected by atopic eczema to share their experiences on the impact of eczema and how they manage to live with this condition in Australia. Our activities involved collating a number of short video messages from around Australia and sharing these through our social media networks. We made it easy for participation by providing a detailed instruction video and sheet then utilized a professional filmmaker to edit and compile the videos. In total, we produced 10 short videos plus an instruction video and 4 still images to use along with the graphics supplied by Global Skin.

The videos will contribute to more understanding in our community, in our healthcare system and with our policy makers. It was empowering for our members to get involved in front of the camera and share their tips, experiences and challenges.

#### Eczema Association of Australasia (Australia)

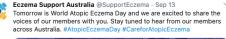
Online Presence: Facebook 3635 reach, 134 engagement Instagram 4159 reach, 3909 engagement Twitter 11700 reach, 221 engagement

How the Funds Help: Preparation and filming of two informational digital videos



Eczema Association @EczemaAu · Sep 13

The Eczema Association of Australasia Inc (EAA) requested funding for professional filming of two promotional informational videos for upload to their AU & NZ social media platforms. One video was for a professional overview of eczema from Dermatologist, Dr Leona Yip and one was a patient case study from EAA member Kerry Patterson who has children with eczema, both highlighting the themes and messages for World Atopic Eczema Day 2020 and encouraging EAA & EANZ members, members of the public in Australia and New Zealand, and other interested parties to reach out for the appropriate help required from the appropriate source – whether locally or overseas via GlobalSkin.









#### Allergienet, Belgium

Online Presence: LinkedIn 1 post, 465 views, 31 likes YouTube 2 posts, 22431 views Facebook 19 posts, 242 comments, 1233 reactions, 55 shares)

#### How the Funds Helped:

We were really challenged due to Covid19 to organize our World Atopic Eczema day. We decided to host our event virtually by organizing a panel talk with caregivers and patients to talk how they care about AD and to share their experiences followed by a presentation about AD. We rented a small hall to guarantee the safety of all panel participants and took extra Covid19 measures and transformed this location into a safe recording studio.

We were joined by a Belgian celebrity medical professor who is also AD patient and we called in the help of the co-host of the most popular webcast/podcast show in Belgium (the local Joe Rogan) to help us record and host the panel talk. After the panel talked, we had a presentation by the well know Belgian Dermatology professor Lapeere who presented our audiences with information about AD and about new treatment options now and in the future available in Belgium. We also launched a petition during our première asking for financial reimbursement for moisturizing crèmes for people with AD since these are pricy and are a necessary treatment. We aired our event in première simultaneously on YouTube and Facebook. Which is a first for us. During the premiere volunteers of our organization were interactively answering questions from the audience on both channels. Because of the virtual nature of our event we mainly used internet communication to promote our 'Dag van het Eczeem' We used a campaign website to pre-register participants, made social media advertisements and video clips to announce our event. Although we missed the real interaction of a life event we were very very happy with the results and with the interaction. We received only positive feedback and people asked us to keep our film online with we decided to do. We've learned a lot and hope we can continue this success to the next edition.







#### Global Allergy and Airways Patient Platform (Global/Austria)

Online Presence: Weekly Facebook posts, Website

How the Funds Helped:

We collected patient stories and adjustment the website to accommodate for the panel-discussion.

We also offered translation of the panel discussion to members. Our community has a strong focus on World Atopic Eczema Day and the feedback about the different approaches of "Eastern vs. Western Approach on the treatment of AD" was anticipated very well. It also reflects the global view of disease management and offers the chance to combine different approaches.

A patient told us that having a discussions about AD that day and seeing different activities for AD is so much different than 10-15 years ago when disease was not visible in the public and nobody really understood the problematic of the disease and the burden for patients.



Global Allergy & Airways Patient Platform September 14 · 🚱

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"Eastern vs. Western Approach to Managing Atopic Eczema" Panel Discussion for World Atopic Eczema Day. Dr. Olivia Hsu Friedman will share the Eastern approach to medicine and Dr. Peter Lio will share the Western approach.

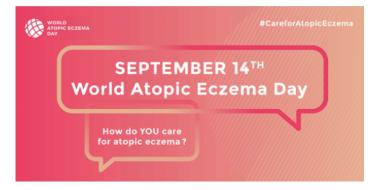




Global Allergy & Airways Patient Platform September 14 · 🔇

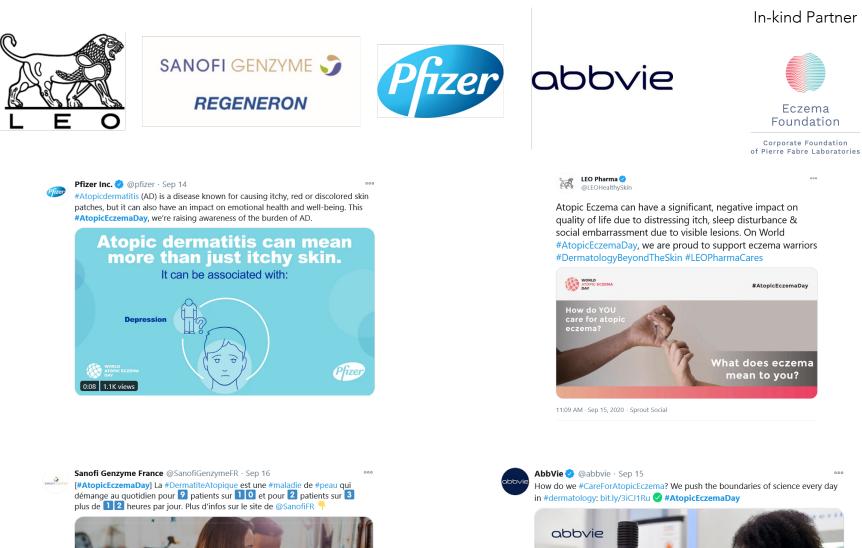
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Today, 14th September is World Atopic Eczema Day, we are expanding the global movement by asking "How do YOU care for atopic eczema". #AtopicEczemaDay #CareForAtopicEczema #awareness International Alliance of Dermatology Patient Organizations - IADPO



### Thank you to our Partners for your support and participation!







La dermatite atopique c'est d'abord une maladie de peau qui démange  $\mathscr{S}$  sanofi.fr

