

# What we did in 2020/2021 and why it mattered



Registered Charity SCIO SC042392

## **Our Vision**

"Families with eczema flourish in a society where they can lead healthy and fulfilled lives."



### Foreword by our CEO Magali Redding

Our Chair Steven MacDonald and CEO Magali Redding

*"COVID-19 had a disproportionate impact on our families. We quickly had to find news ways to support them now, and in the future."* 

As EOS is about to celebrate its 10<sup>th</sup> anniversary, never has it been more challenging yet needed to support families with eczema in the UK, who were disproportionnaly impacted by the global COVID-19 pandemic due to the reduced access to healthcare provision, increased isolation and anxiety-induced flare. Having paused our face to face activities, we rapidly set-up new ways of delivering our services, while remaining the "knoweldgeable friend" that our families desperatly needed in these difficult circumstances.

As a result, over 2,600 families from over the UK accessed our help in 20/21, through an online version of our welcome pack, virtual dermatology events, videos created by and for our young children, and much more. With our young people, we were also able to create an eczema animation and training resource for secondary schools, set up the EOS Youth Panel and launch a research project with healthcare and academic partners across the UK, while carrying out a health psychology and diveristy review.

As our families will continue to suffer more than others from the long-term impat of COVID-19 our promise is to offer a growing range of inclusive services and thrive to work with others in order to reach out to the most in need of our help.

#### Why we exist Atopic Eczema: more than a patch of dry skin...

Although eczema affects 1 in 5 children in the UK and is on the increase, its impact is vastly misunderstood by the general public. The reality for families living with the moderate to severe form of this chronic skin condition (about 20% of sufferers) can be shaped by painful flares and constant itch, infections, timeconsuming treatments, sleepless nights, days off school/work, low confidence and social isolation.





Studies show that a fifth of children with eczema are bullied at school and 1 in 2 has low selfesteem; there is a sense of desperation and frustration in families with skin disease. 1 in 5 mothers feel like a failure due to eczema.

There is no cure for eczema. Eczema can only be managed with treatments and on-going support.

## **Our Aims and Activities**

By accessing our services, children with eczema and their families in the UK will be:

- Confident Children of eczema and their families increase their confidence in their selfmanagement and coping skills.
- 2. Supported Children with eczema and their families feel more supported in regards to dealing with the condition and its impact on life, including at school and with their healthcare providers.

How do we do it?

**3.** Connected – Children with eczema and their families feel more connected with others by having access to a community of peers



We offer direct support and empower families with eczema so they can cope better with the impact of the condition on their life.

**1-1 support** from a team of Family Support Workers

**Tailored welcome pack** for the whole family

School workshops and help with 1-1 school healthcare planning



We encourage children and adolescents with eczema to engage in their own care and build confidence together.

**High 5 Club** for children aged 3 to 10 : fun eczema resources, competitions and workshops at events

**XY Club** for young people aged 11 to 17 : eczema guides, teen app, Instagram group, outings and selfmanagement events



We break the isolation of families with eczema through opportunities to meet, learn and support each other.

Learn & Share events for families and healthcare professionals to gain knowledge and meet others

Online meet-ups and webinars

**Online community** 

We carried out a review of all our services based on our underpinning priorities: Inclusive and accessible to all, impactful, safe & compliant and evidence based. With a focus on: Equality, Diversity and Inclusion and Health Psychology.

4. Improving healthcare, support at school and society - Our aims are:

Improved **healthcare** services Increased education chances through a better support provision at school Increased awareness of eczema with policy makers and the general public Increased impact of other organisations through sharing our delivery model

## Meet our friendly team

#### Newcomers...

- We were delighted to welcome our new **Head** of Services Suzi Holland in August 2020.
- As part as our new Volunteering programme, Angela Ward kindly came to our office every week to help with our welcome packs (except during lockdowns periods).







Magali Redding Chief Executive Officer



Suzi Holland Head of Services



Dorte Al-Gailani Head of Finance and Administration



Jean O'Hara Support Worker



Cheryll Alomai Senior Family Support Worker



Lynne Hogg Family Support Worker



Kirsty Ure Communications and Fundraising Officer



Lyndsay Noon National Outreach Coordinator

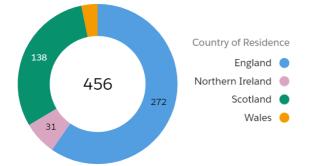
"I feel like we are going in such a **positive direction**. I'm so **grateful** for all your **advice** and **support**. Eczema is still very much a part of our daily life but it is starting to feel so much more **manageable**. I don't think we would be in such a **positive place** without the **help** of yourself, your website or the support group."

Mother of a child with eczema, member of EOS

## **Personalised Support**

This year, we welcomed 456 new families, making a total of 2,659 families supported by the charity since its launch in June 2011.

New members 20/21 by nation

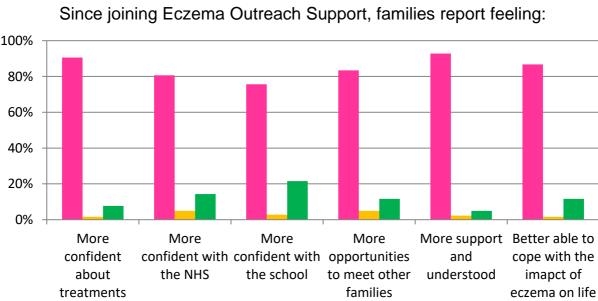


Each family received a tailored welcome pack filled with evidence-based information on eczema and its treatments, self-management resources, other families' stories.

"I was somewhat overwhelmed to receive such an **amazing pack** through the post today from EOS. I have at times felt so exasperated and sad about my son's eczema and to receive so much information was wonderful."



Our team of Family Support Workers supported families through calls, texts and social media, discussing all aspects of life impacted by eczema, treatment choices, practical tips, and encouraging them to engage with the NHS, while providing much needed emotional support.



"It's given me a real confidence boost as I have been feeling lost and confused."

Members' survey March 2021

Yes No Don't know or N/A

## Edha's story



Edha is mum to six-month-old Mila whose eczema was inflamed and itchy and causing her some distress. When Edha contacted EOS she felt alone and didn't know how to get the help she needed.

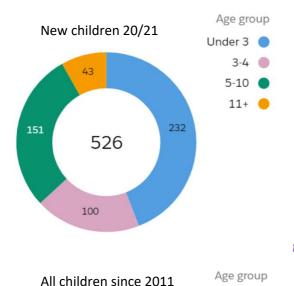
Family support worker Jean helped Edha work through some of the challenges she was facing and focus on the questions she wanted to ask at her next healthcare appointment. As a result of Jean's support, Edha typed up a list of all her daughter's medications, her medical history and questions, to take with her at each appointment. This helped her feel more confident and able to access the right care for the first time.

Edha said, "I really appreciate all your support. You've got so much knowledge! My husband is already talking about doing a fundraising event for EOS so that says a bit about how much we appreciate your help."



"Thank you so much for your call it was so nice to have **the friendly ear** of someone who knows what I am talking about, I can't tell you how much it **helped me** being able to talk through everything with you. It's certainly given me more **confidence** and **clarity**. Thanks for passing on all those handy links. Such **great information**. I appreciate knowing you and the charity are there."

## **Our children's activities**



Under 3 3-4 🔵 498 580 5-10 🔵 11+ 🛑 2.9ĸ 588 1.3ĸ

This year, we welcomed 526 new children, 44% of them under 3, which is a significant increase compared to past years. Helping families at point of diagnosis means that we can provide support early and prevent future struggles, improving our families and children's chances to thrive.

#### Total number of EOS children: 2,948!

*"My son Ethan aged 3 1/2 suffers with atopic"* eczema covering his entire body which gets him down because he's very sore, tired and itchy. On top of that he is noticing people **staring** and he has other kids poke fun of his "dirty face".

His welcome pack came today and I wanted to email to let you know how grateful we are. It's really lifted his spirits, he put the cool pack straight into the fridge, he's keeping his fidget blocks in his pocket to use when he feels angry or itchy and he loves the book.

We've looked through the leaflet of other kids with eczema and he can see that it is not just him.

What a lovely, helpful and encouraging box for him to come home from preschool!"

### (old enough to have benefited directly) 0% 80% 100% 20% 40% 60% Understands eczema and treatments better Feels more supported/understood Feels less alone in regards to having eczema. Talks more easily about their eczema with More engaged in treatments Feels better about themselves

## The difference EOS made to children with eczema

others

More confident to ask for help from others (school, etc).

Is better looked after at school/nursery



Yes No On't know



In 20/21, 1,870 children aged 3-10 were part of our High 5 Club, which includes our H5C pack.

"We received our **box** [welcome pack] on Friday and I can't tell you how **positively** Esme in particular has **responded** to it. She's clearly so **relieved** to find pictures of **other children** like her and facing the same **challenges**.

She loves the concept of being in **an 'eczema club**' and I'm hoping we can use some of the material to **educate** her peers at **school**. I cannot thank you enough."



Last year, we ran **competitions** and facilitated **22** penpal pairs to foster friendships and peersupport among our youngsters.



"He's made up! We've been shielding for a year now for his dad so this is such a boost for my Josh."

In December, we created a Festive celebration video by putting together 20 clips from young members of the High 5 Club, with an extra message from Santa!



"This is **marvelous**, we all loved it, I am **crying watching it**. Ella will ask to see it over and over again." "The video is a lovely balance of **cheer**, **hope** and also **acknowledging** how **difficult** this year has been and how difficult it is to have **eczema**!"

"My daughter watched the video with so much **amazement** and loved it so much. Seeing the other **children** talk about their eczema was a real highlight because she said "**they use cream like me mummy**"! The ending was a real **bonus** too seeing **Santa talk about eczema**, how **wonderful** and **thoughtful** to produce this video, you are all amazing."



The XY Club supported a total of 580 young people aged 11+ in 20/21. A tailored self-management pack was sent to each young person joining EOS.

#### **Online Events for young people**

- "Understanding Stress" 4 July 2020: 11 participants and a guest dermatologist.
- "More than itchy skin" 19 Sept 2020: 11 participants Launch of our secondary school animation.



#### The EOS youth panel: putting young people with eczema at the heart of EOS

The recruitment campaign was led by two young people with eczema and we now have 9 members from England, Scotland and Wales between 16 and 24.



*Speaking to others* and *being able to neip* has *boosted Kira's confidence*. She is an *ambassador* for EOS now."

## **Connecting Families**

#### Webinars

"Starting from scratch" – 14 Sept 2020: World Eczema Day event attended by 72 families



Speakers: EOS staff and Dermatology Nurse Sandra Lawton



"My mum & I attended together & found it so informative, as well as reassuring when Sandra recommended treatments we're already doing."

"I have attended the dermatology clinic with my daughter many a times but having a professional speak like this on zoom, **I take more in** than when at the appointments."

"I just wanted to say thank you so much to EOS. I received my welcome pack in the post recently and also **watched the webinar** last night. The best thing about it I found is that all the questions asked were ones I've asked myself so **you know you're not alone**."

"Coping with eczema" - 17 Sept 2020 (EOS chief Executive Officer as a guest speaker), organised by the Centre for Academic Primary Care in Dermatology (University of Bristol).

#### Our closed Facebook group counts 1,200

**members** who share tips and support each other at any time of the day, from anywhere in the UK.



#### Key issues being discussed by group members

- Children on immuno-suppressants returning to school
- Concerns about infection especially when children are not being seen face to face by GPs
- Opportunity to vent and let off some steam with people who understand
- Looking for advice in the absence of being able to see medical professionals
- Members' experiences of different emollients
- Recommendations for **clothing** and shoes for children
- Eczema on the scalp and hands, particularly as a reaction to increased handwashing

"Honestly it's such a **relief** to know that there is a **community** out there who **understands** somewhat what we as a family go through on a daily basis."

"The group is **amazing**. Although I felt very overwhelmed with everyone being so **supportive** and **nice**... the other eczema groups I'm in they all jump on telling you try this stop that etc... very grateful for finding this **wonderful group** and getting such positive comments back."

## **Our Wider Impact**



Increased education chances through a better support provision at school

Increased awareness of eczema with policy makers and the general public Increased impact of organisations through sharing our delivery model

#### Healthcare improvements

Launching our ecZema cAre Plan (ZAP) project: A UK-wide "Quality Improvement" project that aims to create the best possible written treatment plan template to use in clinics and at home. Funded by the VTCT Foundation, this new partnership between EOS, families with eczema, healthcare professionals, academics and the Centre for Appearance Research aims to increase the self-management skills of families with atopic eczema in the UK and improve their longterm health outcomes.





#### **Co-authoring 2 chapters of the revised European eczema guidelines**

**Contributing to 3 NICE consultations about new treatments** for children and adolescents with eczema in Wales and England, resulting in the release of new biologic drugs on the NHS.

## Sharing the lived experience of families with eczema with healthcare professionals

Talk at the European Academy of Dermatology and Venereology (EADV) congress - 29 Oct 2020.

#### Contributing to clinical and patient networks

- British Association Dermatology: helped design a survey for patients on virtual clinics, led the creation of a new endorsement scheme for patient groups' research projects.
- Scottish and English Dermatology Councils: influenced the revision of NHS England's guidance on the prescription of emollients, which was discriminating against long term skin conditions.
- Appearance Collective (Centre for Appearance Research, Bristol)
- GlobalSkin, a world-wide network of skin patient groups

#### Influencing the design of new research programmes in the UK

- Eczema Care Online (University of Southampton)
- UK Dermatology Clinical Trial Network grant panelist 2021 (Nottingham)
- HOME Harmonising Outcomes Measures for Eczema (Global)
- BIOMAP biomarkers of eczema and psoriasis (IMI funded European project)



#### **Support at School**

#### School resources available online

#### **Primary school workshops**

We recruited and trained 9 sessional workers to deliver school workshops across the UK, as soon as the schools reopen their doors to us.

We created a distance learning version of our workshop, including <u>a new video.</u>









#### New secondary school resource: "More than itchy skin" animation



Our unique animation was created with and narrated by our young people with eczema! Soon to be accompanied by a teacher training module.

"After watching the animation, we felt more **confident** contacting the **school**. They will put a plan in place to make sure my son gets the **support he needs**."



#### **Raising Awareness**



#### "World Eczema Day" campaign - 14 Sept 2020

- Webinar for families 14 Sept 2020, 72 attendees.
- 6 BBC radios interviews 14 Sept 2020
- XY online event 19 Sept 2020
- Press releases featuring Miya (right) in 3 newspapers

#### Video for our very youngest children

Author/Illustrator Rosie Wellesley reads out loud her popular book the **Itchy-saurus** for EOS. Watch them here: <u>Drawing</u> and <u>Reading</u>





#### **Contributions to 2 Netmum blogs**



#### A series of blogs on managing eczema during COVID-19 on our website



#### Hand washing at school when your child has eczema

Now the new school term has started after a long break, children will be needing to get used to the new normal. Kids may be nervous, excited or apprehensive about returning to the classroom but



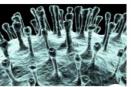
### Latest COVID-19 information from the British Association of Dermatologists

The British Association of Dermatologist has released advice for people on immunosuppressants and biologic drugs regarding the COVID-19 virus. The information is published below. The British Association of Dermatologists The BAD knows that national



#### Face masks for COVID-19 and eczema

Face coverings are now recommended for use every time you enter a shop or travel on public transport to prevent the spread of COVID-19. While there is no doubt this will help to keep shoppers



#### Helping deal with COVID-19 for children with eczema

COVID-19 has reached pandemic stage and as a result all UK schools are closed as well as social spaces like restaurants, museums, cinemas and soft play centres. These measures have never been seen in the

#### Awareness of eczema with policy makers

In Dec 2020, we launched a large **UK-wide survey on the experiences of families with eczema** (4,500 respondents) which will help us highlight the needs of families with UK with policy makers in the future, and we co-authored a **European white paper** to be released in 2021.

## A warm Thank You to...

- ✓ Our volunteers, including our trustees, and fundraisers for their help and enthusiasm
- ✓ Our funders and corporate sponsors for making our work possible
- ✓ Our NHS and university partners for their time and expert advice
- Our staff for their dedication and passion for the cause
- ✓ And of course, our **members**, who are the reason we exist!

