Eczema Outreach Support

Our impact and achievements in 2021/2022



Foreword by our Chair, Steven Macdonald

In 2021 we said goodbye to Magali Redding, CEO and Founder of EOS, as she left the charity to take on a new challenge. She leaves the charity in great shape.

The Board of Trustees thank Magali very much for the work she has put in since founding EOS and acknowledge her dedication and commitment to the charity. We are looking forward to working with Christine Roxburgh, our new CEO, to continue meeting the needs of children and young people with eczema. This is an exciting time for EOS.

We have continued to see the impacts on COVID-19 on daily life and I am thankful to the dedicated members of staff and volunteers for all their hard work over the last year.

Thanks,



Foreword by our CEO, Christine Roxburgh

Eczema Outreach Support (EOS) celebrated its 10th birthday in 2021. Having grown organically from a small grassroots charity in Scotland to a successful UK-wide charity in 10 years is remarkable. The charity's development and growth has always been based on the needs of the families we support, and we are currently helping over **3,500** children and young people struggling with eczema in England, Wales, Northern Ireland, and Scotland.

2021 was also a year of change for the charity as the Founder and CEO, Magali Redding, left in the summer. Having led the charity through its incredible growth, Magali decided the time was right to pursue new career aspirations. I took up post as the new CEO in January 2022 and I'm looking forward to leading the charity into a new chapter.

2021/22 was an exceptionally busy year for EOS with more families than ever joining the charity. The impact of the pandemic continued to affect our membership, with reduced access to healthcare, increased isolation, and anxiety causing an increase in eczema flares for many.

Foreword by our CEO, Christine Roxburgh

Our services continued to be delivered successfully online with peer support, events, webinars, one-to-one support, and school workshops supporting families across the UK. In early 2022 we were able to start delivering school workshops in person again which felt a milestone in transitioning back to some face-to-face support.

We wanted to ensure our work made a wider impact in 2021/22. We shared the voice of our members in many different forums including a MP Roundtable event in Westminster and launching our 'Time for Change in the UK' report. We have also been raising the issue of eczema and mental health and highlighting the need for more treatment choice for young people with severe eczema.

Thanks,



Why we exist

Although eczema affects **1 in 5** children in the UK, it is vastly misunderstood. The reality for families living with the moderate to severe form of this chronic 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** have low self-esteem. Our *Time for Change in the UK* report highlighted that almost half of children with eczema find it impossible or difficult to access psycho-dermatology services to receive mental health support.

There is no cure for eczema. Eczema can only be managed through a process of trial and error to find treatments that help, and on-going support. Families can feel very desperate, isolated and frustrated.

Atopic eczema is more than a patch of dry skin

Supporting children and young people with eczema to thrive

2021/22 has been a year of growth and development for our tailored support to families across the UK.

Families faced a variety of challenges across the year from managing infected eczema to the impact of the condition on their child's mental health and managing eczema effectively at school.

During the year we saw significant growth in our membership with **834** new families joining the charity from across all four nations of the UK. The largest growth has been with families joining from England. Each family received a tailored welcome pack filled with evidence-based information on eczema and managing the condition, self-management resources and stories from other families.

Volunteer Jamie with the welcome packs



During the year, we also reviewed our one-to-one support and resources using a Health Psychology approach to increase the positive impact of our support on families' lives and began an equality, diversity and inclusion review to deliver on our ambitions to be a charity that is accessible to every child with eczema in the UK.

96%

of our members said that since joining EOS they are more supported or understood in relation to their child's eczema

Our High 5 Club

Our High 5 club welcomed **408** new child members aged 3-10 this year taking our total Club membership to **2,383**. Each child received a personalised activity pack filled with information and resources and had access to a range of activities to help them connect with other children and reduce isolation.

During the summer we worked with families to create a collage of videos with High 5 Club members sharing pictures and messages of support and positivity with each other. Families told us it helped their child understand they were not the only ones with eczema and that they were not alone.

"We all really enjoyed seeing the summer video. The girls especially liked seeing themselves, but it was also great for them to see other children talking about having eczema. It really made us smile. Thank you for putting it together and well done to all the H5C kids."

Parent of High 5 Club member

Festive fun!

In December we brought High 5 Club members and their families together for an online scavenger hunt and some festive fun. It gave children the opportunity to meet other children with eczema and feel less alone in their diagnosis.

Our High 5 Club animation

In December 2021 we started work with families to develop an animation for the High Five Club to improve children's understanding of the condition, reduce isolation and encourage treatment compliance.

Following input from a Health Psychologist, the animation is underpinned by health psychology approaches and techniques to increase its impact. The animation will be completed in Summer 2022, and we look forward to launching it in the Autumn.

Meet the main characters:



Our XY Club



This year 65 new members joined the XY Club for 11-17 year olds with eczema, taking the total club membership to 689.

Members have accessed our XY Self-management App, the EOS Instagram group chat where they can connect with other young people with eczema and a range of resources to support their experiences at school and with self-managing their condition.

Our Family Support Team also provided one-to-one support to members aged 16 and 17 offering them the opportunity to talk about their worries and challenges and receive tailored emotional and practical support on topics like eczema at school and how to prepare for their transition to adult healthcare services.



Connecting families

Peer Support

Over the year, our team has focused on increasing the amount and type of peer support available to families in response to the insights we've gathered during the COVID-19 pandemic. We have been working with other organisations to learn from their experiences and piloted an online peer-support session in December for parents and carers. Peer Support is an exciting area of development for EOS and we plan to deliver sessions across 2022/23 with a key focus on creating a safe and supported space for members to share their worries and solutions, feel more connected with others and get useful tips and support.

Closed Facebook group

Our closed Facebook Group remains a key place for parents and carers to connect and support each other in a safe environment. With **1,483** members, almost **50%** of our membership are part of the group sharing tips with each other anytime from anywhere in the UK. Throughout 2021/22, we continued to invest time in ensuring that the group remained a safe and supportive place for parents/carers to access peer support.

"I have been able to reassure my son him that he is not alone by showing him photos of other children on the Facebook group. He has stated a few times that 'that is like mine'. He was feeling alone and kept asking 'why do I have it and nobody else does' so EOS has helped greatly."

EOS member

Connecting families

Webinars

With several planned events for families having to be cancelled and postponed due to continuing COVID-19 restrictions, we focused on delivering webinars aimed at parents and carers of children with eczema. These popular online events connected families with healthcare professionals whilst giving them the chance to learn more about how to manage the condition and received guidance on topics that mattered most to them.

We look forward to bringing back our face-to-face events in 2022/23.

"The webinar by Dr Segher was AMAZING."

EOS member





Lynne's story

Lynne lives in Northern Ireland with her husband and two children, one who has severe eczema. She doesn't have family close by and she feels none of her friends understand how bad eczema can be. She feels very isolated. She joined EOS and after receiving her welcome pack she told us "I just got the welcome pack this morning and I can't thank you enough. I literally cried when I read the book and my boy loved the cold pack and twisty toy."

Jean, one of our Family Support Workers spoke to Lynne about her situation. They were able to discuss many topics, including her feelings about steroids and the challenges Lynne was having with her child's nursery. Jean was able to signpost her to various resources and guide her through the process to get support from the nursery.

After the call she told us: "I really appreciate all the links sent and the time you spent talking to me this morning. It was very informative and I'm sure I'll find lots of useful tips in all the information you gave me. I think it's amazing what you do and I really hope you can grow and prosper and reach a lot of people that, like me, could have used this kind of support and useful information at the beginning of their eczema journey."

Supporting children and young people at school

Following their launch, our school resources continued to be promoted and accessed by families and schools from across the UK. Feedback from our continuing professional development training for school staff showed us that:

- 68% of staff said they knew little or nothing about eczema before the training and 100% said they understand a lot or a moderate amount about the difficulties a young person with eczema can face after completing it
- 100% said they now understand what can trigger eczema
- 93% said they felt better able to support a young person with eczema moving forward.

"EOS did a workshop online with the children in my daughter's year group. I was so happy and proud both of the school and EOS to connect together.

Thank you again for all your support and hard work that you all are doing."

EOS member

Our Youth Panel



2021/22 marked our Youth Panel's first year. The Panel is formed of a group of young people aged between 16 and 24 from across the UK. All members have eczema and want to make a positive difference to the lives of children and young people with the condition. They work with the EOS Board of Trustees, staff and members to ensure that children and young people with eczema remain at the heart of everything the charity does.

The goal for the Panel's first year has been to agree their overall focus. They also contributed towards the resources for the XY Club for 11-17 year olds, reviewed online eczema resources being developed for young people with eczema, and cultivated a social media presence sharing a 'Day in the Life' and other spotlights on being a young person with the condition.

Their most recent work has been a collaboration with Dr Tess McPherson, a Consultant Dermatologist and Senior Clinical Lecturer at Oxford University Hospitals, to understand the struggles faced by young people with eczema and find solutions to address them. This project will culminate in a presentation at the British Association of Dermatologist's Annual Meeting in July 2022.

Our online presence

Our followers on social

2,991 1,479 1,501 2,820
Facebook Facebook Instagram Twitter
Group

- In November 2021 Jo, a member of our youth panel, did a successful takeover on Instagram Stories. Her posts were seen by **464** people. Previous stories we had posted were seen by **150** to **300** people.
- Our animation *Eczema: More Than Itchy Skin* had over **35,000** views on Facebook.
- We created our first ever Instagram reel for World Book Day. It received over **3,300** views.
- We created a series of blogs providing tips and tricks for handwashing, swimming with eczema and busting common eczema myths.

Our online presence





"EOS really have supported me and my son though his continuing eczema journey."

"Found all these Instagram posts so helpful ... Seeing your posts today and the way you manage things gives me hope for my son later in life, thank you."

(In response to a youth panel Instagram takeover)

"The Facebook group is a great community with helpful hints and friendly tips."

"This is really interesting to read. Thanks for sharing your story, it's been helpful!"

(In response to a parent Instagram takeover)

"EOS is a charity supporting families going through the same journey as us ... They offer reliable information and give you the chance to speak to others going through this. As a family we have learnt so much through the Eczema Facebook page and learned things we would of never considered, but almost everything we have learned is inside the booklets that are sent out. I can't recommend this enough, for anyone needing that extra bit of support definitely sign up to this page "

(The user shared this post on her own account)

We wanted to ensure our work made a wide impact in 2021/22. We shared the voice of our members in many different forums to influence change for the benefit of children, young people and families struggling with eczema. We focused on four key areas:

1.

Improved healthcare services

3.

of eczema with policy makers and the general public

2.

Increased

education chances

through a better

support provision

at school



Increased **impact** of other organisations through sharing our delivery model



Healthcare improvement updates:

- We presented at a parliamentary MP Roundtable event in March 2022 focused on 'Supporting NHS pandemic recovery: the future of services for long-term conditions'.
- We have been progressing our ecZema cAre Plan (ZAP)
 Project: This UK-wide project aims to create the best possible written treatment plan template for use in clinics and at home helping families manage eczema. In 2021 we consulted with dermatology professionals, GPs, families, young people, and academics to inform the content of the treatment plan. Our academic lead and graphic designer are now working on the treatment plan template.
- We co-authored **2** chapters of the revised European Eczema Guidelines. They will be available in 2022.
- We contributed to the National Institute for Health and Care Excellence (NICE) and Scottish Medicines Consortium (SMC) consultations for new treatments for adolescents with severe eczema.
- We presented at the BSPAD psychological workforce meeting to share the thoughts of our members and discuss developing guidance for dermatologists to ensure the mental health impact of the condition is considered.

We attended the c4c multi-stakeholder meetings on Atopic Dermatitis in children to develop a strategy to improve the timely development of therapeutic innovations for children and adolescents with AD (Atopic Dermatitis) across Europe.

Contributing to clinical and patient networks:

- British Association of Dermatologists
- Scottish and English Dermatology Councils
- Appearance Collective (Centre for Appearance Research)
- 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)
- TREAT study
- HOME (Harmonising Outcomes Measures for Eczema (Global)),
- BIOMAP biomarkers of eczema and psoriasis

Supporting children and young people at school

Primary school workshops

Despite ongoing restrictions and schools facing significant challenges brought on by the Covid-19 pandemic, our sessional workers delivered **23** workshops in primary schools across the UK, including three face-to-face sessions in Wales in March.

"Hector, our pupil who the workshop was organised by, was a little shy to begin but quickly became confident in sharing his own experiences. The workshop provided a platform for him to share this, and also for his classmates to develop a greater understanding and compassion."

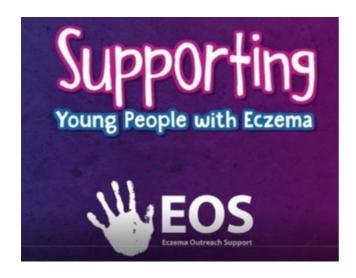
Primary School Teacher

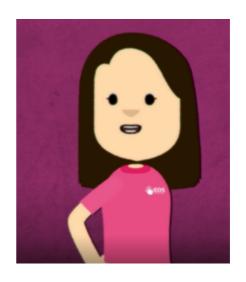
100% of schools told us that following the workshop they believe that the children in their class now have a better understanding of eczema and almost **60%** said their learning would change the way they supported children with the condition in their classes. In 2022/23, we will be focusing on increasing the reach of our workshops, rolling out more face-to-face sessions and developing our monitoring and evaluation processes.

Supporting children and young people at school

Secondary school resources

Our *Eczema: More Than Itchy Skin* animation and accompanying Continuing Professional Development (CPD) training resource for school staff were formally launched in September 2021 and are aimed at children attending secondary school, their families and school staff





"The school staff team will now be much more aware of the wide variety of eczema triggers which will help us have better conversations with the children about how we can support and help them at school."

Secondary school teacher

ALLIANCE Live

On 23 March we were delighted to take part in an ALLIANCE Live session delivered by the Health and Social Care Alliance Scotland (the ALLIANCE). Cheryll and EOS Youth Panel member Sylvia talked about the challenges young people with eczema face at school and promoted our animation and CPD resources for secondary schools, which were funded by the ALLIANCE.



59%

of children feel less alone in regards to having eczema since joining EOS

Increased awareness of eczema

General awareness campaigns:

- "World Eczema Day" campaign in September including a webinar with Dr Kanji, a registrar at Imperial NHS Trust and an honorary clinical senior lecturer at Imperial College, London to share her experience and knowledge on treating children with eczema.
- Excellent coverage from the press release about our new CEO raising awareness of EOS and eczema (publications include Charity Digital, Charity Times, Scotsman, Edinburgh Evening News, and local publications around the Central Belt).
- We appeared on the BBC Radio Scotland's Stephen Jardine show on 9th February to talk about the impact eczema can have on an individual and family.
- Our Comms team have been working on a variety of blogs, social media posts and other communications to increase awareness of our work and raise funds.

99% of our members said they would recommend EOS to a friend

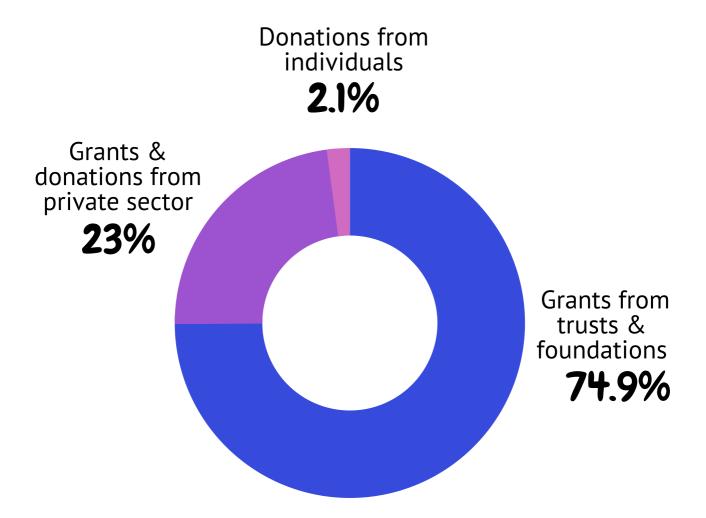
Policy awareness

We launched the 'Time for Change in the UK; The True Impact of Eczema and the Experiences of Children, Young People and their Families in Managing the Condition' report in March 2022, sending it directly to over **40** MPs and other key stakeholders to influence change. The report was also shared widely on social media.

One of the key findings from the report was that support for mental wellbeing can make a significant difference to people with eczema, with 88% of young people who had accessed this support found it helpful. However, many parents/carers found it either impossible (27%) or difficult (19%) to access mental health support for their child.

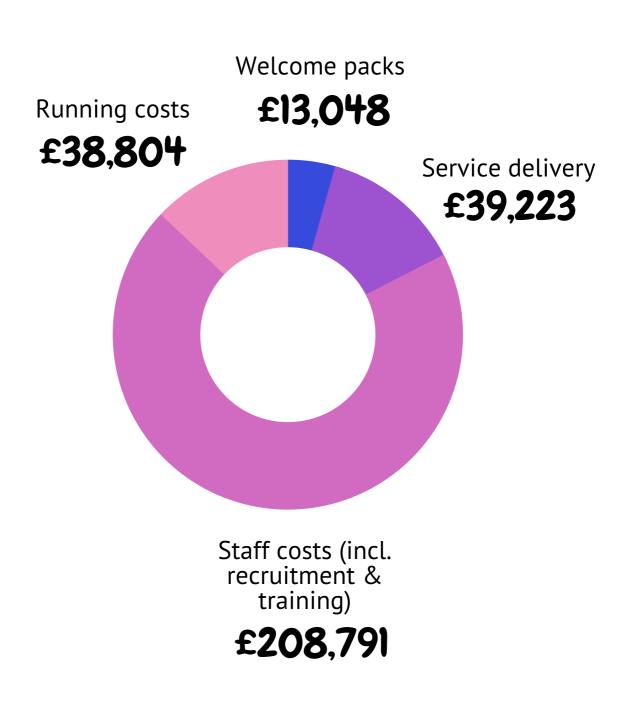
We presented in Westminster at a MP Roundtable event 'Tackling unmet need in atopic eczema – how can we prevent dermatology becoming a Cinderella service in England'.

How we are funded



We are very grateful to everyone who helps fund Eczema Outreach Support and helps us to continue providing an invaluable service to our members.

Our expenditure 2021/22



Our supporters include



The Big Lottery





Health and Social Care Alliance Scotland









Yorkshire Building Society

Thanks for your support

Our supporters include













Thanks for your support









www.eos.org.uk

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