

exchange

FREE TO
MEMBERS

Eczema and work

***Nutrition and
your skin***

**Helping
children with
eczema at
secondary
school**

***Could
complementary
therapies help
you?***



EmolliZoo App

Updated and Improved!

A free app for children and families to help manage eczema



Includes educational information, gameplay and rewards to encourage your child to follow a good emollient routine which can help to protect their skin.

In a separate section, parents can personalise the treatment calendar to receive gentle emollient application reminders, monitor eczema, and access helpful information on eczema.



Provided by Dermal Laboratories Ltd.



www.dermal.co.uk



XISPR159/JUN24



For further information scan the QR code or visit www.emollizoo.co.uk



The information about eczema in this app has been accredited by National Eczema Society.

National Eczema Society does not recommend or endorse any specific products or treatments.



Exchange is the National Eczema Society's biannual magazine, produced to keep members up to date with the management and treatment of eczema and to provide a forum for an exchange of news, ideas and information. If you'd like to join us, go to www.eczema.org/become-a-member

11 Murray Street, London NW1 9RE
Tel: 020 7281 3553
Email: info@eczema.org

Company Registration No. 2685083. Charity Registration No. England & Wales 1009671
© The National Eczema Society 2024

EDITOR Eleanor Stanley

WRITER Claire Moulds

DESIGN HKA Design

PRINT Whittington Moor Printing Works

THIS EDITION

No. 191 Spring/Summer 2024

NEXT ISSUE

Copy date: October 2024

Publication: Autumn/Winter 2024



When you have finished with this newsletter please recycle it.

All rights reserved – no part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise without the written permission of the copyright holder.

DISCLAIMER The opinions stated in this journal are not necessarily shared by the Society and the Society does not accept any liability in respect of them. Likewise, the Society does not endorse, recommend or accept any liability for or in respect of any product mentioned in the journal or included with it as a sample. The inclusion of promotional features does not represent or imply any endorsement of the contents or cost on the part of the Society. They are included to generate revenue to help cover the costs of production of *Exchange*.

Contents

- 4** Introduction Stephen Pugh, Chair
- 5** NES news and views
- 7** Meet our medical adviser
Dr Mark Turner
- 8** Research round-up Julie Van Onselen
- 11** Ask the expert
Helen Dennis and Julie Van Onselen
- 15** The RAPID 'citizen science' eczema trial
Dr Emma Campbell
- 18** Eczema and complementary therapies
Julie Van Onselen
- 21** Managing your eczema in the workplace
Helen Dennis
- 25** You are what you eat – nutrition and eczema
Dr Angelika Razzaque
- 29** Helping children with eczema make the leap to secondary school
Claire Moulds
- 33** 'Like trying to put out a forest fire with a watering can'
My eczema story, by James Stanyer
- 37** Readers' letters

Cover: Alice (pictured) having completed the London Marathon this year. We had a team of supporters taking part in this prestigious event, raising funds and awareness of eczema and topical steroid withdrawal. Photo credit: Scott Seath/Espy Media.

Warning: Products, treatments or other forms of medication that suit one person may not suit another. It is advisable to test different skin products on a small patch before general use. If possible, you should also consult your doctor before changing eczema treatment and should also do this if in doubt regarding a treatment or proposed treatment. The Society cannot accept any responsibility for failure to take medical advice.

Policy: The Society's general approach is to encourage active partnership between patients and healthcare professionals and the discussion of all available options, in the interests of informed choice on the part of the patient.

Making a greater impact

National Eczema Society's Trustees have been reflecting on what role the charity could and should have in today's world. How can we make the biggest difference for eczema sufferers? The Society was formed almost 50 years ago, initially as a support group for people affected by eczema, and to share information about eczema and best treatments. This was a time before the internet, when information was much harder to find. Since then the Society has sought to broaden its work to address other unfulfilled needs of the eczema community.

The requirement for good and reliable information has not gone away of course, not least because eczema is a complex medical condition and very challenging to manage. Our website, booklets, factsheets, videos, webinars and podcasts provide a rich resource of reliable self-management information. We plan to grow these resources that are widely used. We have also operated a helpline giving one-to-one advice about eczema provided by our staff and nurse advisers.

We are of course the **National** Eczema Society. In the UK, around eight million children and adults have eczema and many more are affected in their wider families. We see it as our role to support as many in the eczema community as we can. In particular, we want to become a stronger collective voice for eczema sufferers and do more to support research efforts to improve the life of future generations.



Our challenge is that we are a relatively small charity and we face tough choices over how we allocate our limited funds. A lot of our resources have previously been channeled into our helpline. In order to do the job that we believe will have the greatest benefit for the wider

eczema community, we must devote more resources to campaigning and research. This led us to the difficult decision to close our helpline service in March this year. We appreciate how valuable the helpline has been to its users, but we are also mindful we can only support around a thousand callers per year. We must contrast this with our ambition to support eight million eczema sufferers and their families.

It would be wonderful if the country's dermatology services were such that everyone affected by eczema received the level of support that our helpline has given, but with our current resource we cannot provide such a service to all those who would benefit. We can, however, be a powerful voice for the eczema community and a force for a better future. This is what we are setting out to do.

Best wishes,

Stephen

Stephen Pugh | CHAIR

NESNEWS

New treatment for eczema

National Eczema Society has been pleased to contribute to the assessment by the National Institute of Health and Care Excellence (NICE) of a new treatment for adults and adolescents with moderate to severe atopic eczema. Lebrikizumab is a type of biologic treatment called a monoclonal antibody. It targets and blocks a specific protein in the immune system called interleukin-13 (IL-13), which influences the progression of eczema. In research trials, Lebrikizumab has shown to be effective in reducing eczema inflammation and in quickly reducing itch. We await the decision by NICE on whether this treatment will be made available for use by the NHS.

Atopic eczema affects people in different ways, and we want to see a range of medicine options, so patients can find a long-term treatment that is effective for them.



Fantastic fundraising

Thank you to all our wonderful supporters who are taking part in various challenges this year to raise much-needed funds for the Society.

Emma Inch took part in the London Landmark Half Marathon in April raised £465 for NES. Emma says: "I've had eczema all my life and I was not allowing this to stop me from achieving a goal and raising money for a charity that means so much to me!" **Saritha Visvalingam** completed the Brighton Marathon in the fantastic time of 3 hours and 53 minutes, on a particularly hot and windy day. Saritha was running for her daughter Mila who has difficult eczema. She raised over £1900 and said: "the only thing keeping me going towards the end was supporting NES, especially as my legs started cramping and I wanted to walk!"

Thank you to our fabulous team running in the London Marathon – **Alice** (pictured on the cover of Exchange), **Charlotte, Harry, Honor, Jack, Jamie, Liana, Rachel** and **Trista**. And finally, big thanks to **Vicky Robinson, Lindy Mitchley** and **Susan Kay-Attwood** and other supporters, including Archie the dog, for taking part in the 10km Guildford Charity Walk once again in May.

National Eczema Week 2024

7-14 September

➤ This year we are focusing once again on the impact of eczema on people's mental health and emotional well-being.

See our website for more about the campaign and look out for our social media posts.

You can follow us on Facebook and Instagram (search for 'eczemasociety') and on X (@eczemasociety).



Annual General Meeting

The Society's annual general meeting (AGM) takes place on Wednesday 26 September at 1.30pm. Members are encouraged to attend to hear more about the Society's work over the past year and vote on trustee elections. This will be a virtual AGM again, hosted on Zoom. Joining instructions and meeting papers are available on our website at www.eczema.org/annual-general-meeting.

If you are unable to attend the meeting and wish to nominate a proxy to vote on your behalf, please use the proxy voting form enclosed in this edition of Exchange. The Society's latest annual report and financial statements, covering January to December 2023, will be available on our website in August/September. If you need to request a printed copy, please contact the National Eczema Society office.

Changes to Exchange

A quick reminder that we have moved to producing two editions of Exchange magazine per year. Members will receive a Spring/Summer and Autumn/Winter edition of Exchange magazine from now on. We needed to reduce the magazine frequency from the previous quarterly schedule to better align membership income with the costs of producing Exchange. Thank you for understanding, We very much appreciate your support as a member hope you will continue to enjoy and benefit from Exchange magazine. There are also other ways to keep up to date with news from the Society, by following us on social media (Facebook, Instagram and X) and signing up on the NES website to receive our free monthly e-newsletter.



Better labelling of topical steroids

The Society has been campaigning for better labelling of steroid creams and ointments, which are used by millions of children and adults in the UK to manage eczema flare-ups. This change is important to help the eczema community use topical steroids safely and effectively. We want the UK regulator, the Medicines and Healthcare products Regulatory Agency (MHRA), to introduce clear and consistent potency labelling on all topical steroid medicines. Having had a number of meetings with the MHRA over the past year, we are confident this change will happen in the next few months. Thank you to everyone who supported this campaign and completed our surveys. It's a positive step for patients!

Meet the Society's Medical Advisory Board

Day in the life

Mark Turner
Dr Mark Turner is a clinical psychologist who's been working with London's Guy's and St Thomas' dermatology team for more than 10 years.



8.30 am I arrive at work – luckily, it's a fairly easy commute. I work at Guy's Hospital four days a week and remotely one day a week. Today I'm at Guy's, so I go to the severe eczema clinical multidisciplinary meeting first thing. Skin conditions like eczema can massively impact a person's mental health, so being able to help is really rewarding.

9 am I start seeing patients – a mixture of online and face-to-face. Some of the therapies I offer are eye movement desensitisation and reprocessing (EMDR), cognitive behavioural therapy (CBT), acceptance and commitment therapy (ACT), and habit reversal (for example, to reduce the itch-scratch cycle).

The best thing about my job is when a patient feels I've helped them make positive changes to their life and supported them to cope better with their skin condition.

Patients are the experts in their own lived experiences, so it's extremely important to recognise their journey to help them overcome barriers to accessing treatment and take the next step. My job includes helping other clinical staff understand how to work more psychologically with patients in the dermatology department who've had trauma due to their long-term health condition.

10 am I'm in the severe eczema clinic, and I see some patients while they're already here seeing the dermatologists. It's very rewarding to see a patient's care move forward because of multidisciplinary input. I help staff signpost patients to other services, such as primary care psychology.

1 pm Time for a quick lunch before triaging some referrals from the dermatology clinical team. Most referrals are accepted, so I or a colleague then offer an assessment and make recommendations or provide ongoing psychological therapy.

3 pm I hold a supervision session. On a Wednesday I do this for a psychologist working outside of dermatology. At the moment I then meet colleagues in the hospital trust to develop mental health screening as part of Vital 5 – an initiative in South-East London aiming to help prevent ill health by focusing on blood pressure, obesity, smoking, alcohol use and common mental health conditions.

5 pm I take a moment to read a research article and the papers for the next meeting of the NES advisory board. I'm a new member and I'm enjoying being involved in something so valuable and interesting.

Integrating psychology into dermatology is a fairly unique set of skills, so my role at the NES is to help colleagues understand the psychological needs and barriers of patients with skin conditions such as eczema.



Research round-up

NES Nurse Adviser Julie Van Onselen provides updates and analysis of findings from the latest eczema-related research studies. In this issue, we look at global prevalence of eczema, understanding itch, topical steroid potency and osteoporosis.

The terms 'atopic dermatitis' and 'atopic eczema' mean the same thing. For simplicity, we have used the term 'atopic eczema' throughout.



Atopic eczema numbers worldwide

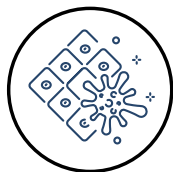
We start with the latest global figures for people

with atopic eczema. Global epidemiology looks at prevalence (the number of people with the condition) and incidence (the number of new cases that develop in a specific time frame). This study looks at the past 40 years, by conducting a systematic analysis of 344 studies.

It finds the global prevalence of people affected by atopic eczema is 2.6% of the total population, affecting 101.27m adults and 102.78m children. Females were more likely to have eczema than males.

The highest worldwide area prevalence figures were in Central Africa (at 6.5%), Australasia (4.5%) and Central Europe (2.3%). This confirms that atopic eczema is a major worldwide health concern, affecting a wide variety of ethnicities.

Tian J, Zhang D, Yang Y, Huang Y, Wang L, Yao X, Lu Q (2024). Global epidemiology of atopic dermatitis: a comprehensive systematic analysis and modelling study. *British Journal of Dermatology*. 20;190(1):55-61.



Bacteria drive itch and scratch-induced skin damage

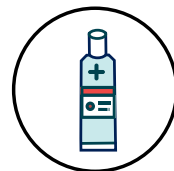
For people with eczema, itch is perhaps the most difficult symptom to cope with. It is

thought to be affected by multiple factors. Antihistamines are often prescribed to address it, but actually histamine plays a minor role in this symptom. So itch is complex.

This breakthrough study proves that skin microbes play a role in generating itch – specifically, *Staphylococcus aureus* (*S aureus*). This is a bacterial pathogen associated with atopic eczema. We already know that its count is higher in the microbiome of people with eczema. This study found that *S aureus* directly activates pruriceptor sensory neurons that drive itch. This is done via a *S aureus* protease V8 mediator, which in turn activates a receptor called PAR1 (already proven to evoke spontaneous itch).

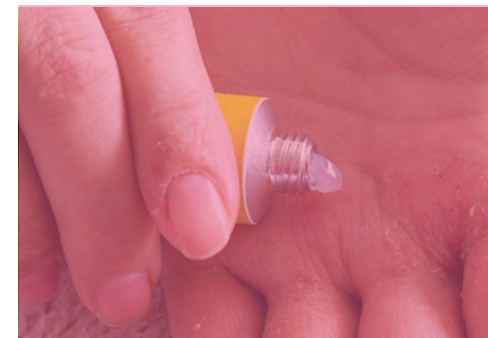
This is a significant finding in understanding key symptoms of itch in eczema. Future research can now focus on treatments that can treat itch by interfering with V8-PAR1 signalling.

Deng L, Costa F, Blake KJ (2023). *S. aureus* drives itch and scratch-induced skin damage through a V8 protease-PAR1 axis. *Cell*;186 (24): 5375-93.



Do people with eczema really understand topical steroid potency?

Topical corticosteroids are first-line treatments for eczema, but patients and carers often worry about this treatment. In the UK, there are four potencies of topical corticosteroids: mild, moderate, potent and very potent.



Topical corticosteroids come in a wide range of preparations, but none has the potency printed on tubes. The NES finds this concerning, as patients need their treatments to be clearly labelled.

This paper, co-authored by NES Chief Executive Andrew Proctor, reports back the findings of two online surveys devised with the NES and circulated to NES members, patients and carers of people with eczema. Results of both surveys highlighted confusion around potency, with only 17% of the 984 respondents knowing how many potencies there are.

In the second survey, respondents were asked to assign topical corticosteroids to potency. Of these, 55.5% were correct, 21% were underestimates and 23.5% overestimates. Some errors were extreme: 12 (8%) of those who were using a very potent TCS considered it 'mild' while nine (27%) using a mild TCS considered it 'potent' or 'very potent'.

In the free-text survey comments, participants expressed wider concerns about

inadequate and conflicting advice and lack of warnings about long-term effects – particularly topical steroid withdrawal. An overwhelming 95% of respondents wanted clear labelling with potency. The NES has responded by leading a campaign to have potency labelled on every tube of topical corticosteroid to help improve understanding of topical corticosteroid treatment.



Moss C, Haider Z, Proctor A (2024). Do people with eczema and their carers understand topical steroid potency? Results of two surveys. *Clinical and Experimental Dermatology*; 49 (3):267-70.



Increased risk of osteoporosis and bone fracture

Several studies have reported on this topic over the past decade. The conclusions are that osteoporosis and bone fracture are indeed more common in post-menopausal women with atopic eczema. The previous studies concluded that this was not due to a specific mechanism and was likely to be associated with use of topical and oral corticosteroids and restricted diets.

In contrast, this most recent paper identifies a molecular basis (genetic and cells) to explain

the association. It looks specifically at the receptor activity of nuclear factor Kappa-Beta Ligand (RANKL) and osteoprotegerin (OPG). It spotted a change in the ratio between RANKL and OPG in older women who have atopic eczema and fracture risk.

It also identified inflamed skin (for example, from eczema flares) produced more RANKL. This provides further evidence that women with atopic eczema are at higher risk of osteoporosis. More research is needed, but these findings may help scientists develop new drug treatments to reduce osteoporosis in women with eczema.

Sakai T (2023) Fracture risks and their mechanism in atopic dermatitis focusing on receptor activator of nuclear factor kappa-B ligand. *Clinical and Experimental Dermatology*; 48:1209-13.

Ask the expert

Welcome to our panel of experts



Helen Dennis
DERMATOLOGY NURSE ADVISER

Helen has worked as a dermatology nurse practitioner in the community and as a sister at St John's Institute of Dermatology. She is a keen educator of parents and healthcare professionals, and was coordinator for the Eczema Education Programme, a service training parents to self-manage their child's eczema. Until recently, she was a dermatology nurse adviser to National Eczema Society.



Julie Van Onselen
NES NURSE ADVISOR

Julie is a dermatology lecturer practitioner with 32 years' clinical experience working in dermatology clinics and education. She is passionate about improving care and support for people with skin conditions and educating patients and healthcare professionals. Julie is a dermatology nurse adviser to National Eczema Society and sits on the Primary Care Dermatology Society executive committee.

Can I claim Personal Independence Payments (PIP)?

Q I have severe eczema and have reduced my hours at work to give me more time to look after my skin. I have heard of PIP. How does it work and is it worth applying?

Helen Dennis says: Personal Independence Payment (PIP) is a government payment designed to help cover the costs of supporting everyday tasks for people with a disability or long-term medical condition. There are eligibility criteria, so you'll need to check the details. But if you are over 16 with a long-term physical or mental condition that causes difficulty with everyday tasks or mobility, and if it's likely to continue for at least 12 months, you may be entitled.

The assessment is divided into two areas of need: first, your ability to manage daily living tasks, and second, how able you are to get around. First, you complete a detailed questionnaire online or by post. Then further assessment takes place by phone or at an assessment centre.

Filling in the form may take many hours, depending on your situation. Before you start, gather any documents you have, such as doctors' letters, prescriptions and a calendar to help jog your memory.

The daily living section asks questions to assess how well you function with everyday tasks such as preparing food, eating, dressing and washing. Example questions include 'Do you use an aid or appliance to eat and drink?', 'Do you need help from another person to dress?' and 'Can you stand without help?'

Answer the questions keeping 'the majority of the time' in mind. You need to specify the frequency of issues in each answer you give. This may mean that you find yourself repeatedly writing '5 days out of every 7' or 'every day' in each sentence. Don't worry about sounding repetitive. What matters is that you show exactly how far your daily living is affected by the condition.

Many people score high in some areas and low in others. Eczema alone does not usually elicit high scores, despite its huge impact on sleep, mental health, employment and the financial burden. This is because PIP focuses on people's ability to function with daily tasks, and with eczema these are usually achievable as long as the person is otherwise in good health.

If you have other medical conditions too, the combined impact may increase your scores to the payment threshold.

If your claim is successful, you will be allocated one of two rates of payment (higher and lower) for daily living, mobility, or both.

To find out more, download the forms and guidance at gov.uk/pip or watch the Department of Work and Pensions films about the process at tinyurl.com/pip-films



Food allergies

Q My son is aged two and has had eczema since he was six months old. I would like to find out if food allergies could be part of the problem, but the GP says they cannot refer him for allergy testing. Is it worth going private?

Helen Dennis says: It can be distressing seeing your child struggle with eczema and it's understandable you are eager to look for solutions. Only a small proportion of children with eczema have allergies, but it is possible your son is one of them.

Most food allergies occur during the first two years of life, when multiple new foods are being introduced. There are two types of food allergy: type 1 (immediate or 'IgE mediated') and type 2 (delayed or 'non IgE mediated').

There are tests available for type 1 but not for type 2. Food allergy testing may be helpful where certain food groups seem to trigger immediate symptoms, such as lip or tongue swelling, hives, vomiting or nappies streaked with mucus or blood. But eczema alone is not sufficient to qualify for tests on the NHS.

Atopic eczema often develops in babies under one year of age, which means it can coincide with weaning. This often leads parents to wonder whether the eczema was triggered by a particular food. However, this is not usually the case. Only around 14% of children with eczema have a food allergy – so although it is possible, it is not especially common.

You need to consider whether your son may have additional symptoms of type 1 food allergy and whether testing is worth pursuing.



Accurate allergy testing is done by hospital teams. For food allergies, there are three different tests available: skin-prick tests, blood tests (RAST) and challenge testing. Each of these has its limitations and it is not possible to test for everything, so patient history plays an important part in narrowing down which groups to focus on.

Because no test is 100% reliable, specialists combine different tests and then carefully interpret the results. Once you have the results, it is extremely important to follow the advice carefully. This may not be as simple as excluding the food, which can sometimes make people more allergic.

Allergy testing is available privately. If you choose to explore this option, search online for 'allergist' and your postcode to find a local private hospital offering this service. The fees may be covered by a private medical insurance policy, or you can self-fund. Ask about the likely cost before making an appointment. Food allergy testing advertised in other places, such as high-street shops or online, is unlikely to be accurate and is best avoided.

Nipple eczema

Q I'm breastfeeding my four-month-old daughter and in the past few weeks, I have developed an eczema flare on my nipples. I've had atopic eczema since childhood, but it has never affected my nipples before. I am really concerned about emollients and treatment. How can I continue breastfeeding and treat my eczema without harming my baby?



Julie Van Onselen says: Nipple eczema usually affects the nipple and areolae only and not the surrounding breast skin. It can cause redness or darkening skin, along with oozing, crusts and cracks, and can be itchy and painful. Eczema does not affect your baby or breast milk, so it's important to try and continue breastfeeding and treat the eczema.

Emollients can be safely used when you're breastfeeding – use them for washing and moisturising. With demand feeding, it is difficult to predict timings, but aim to leave a gap of at least 30 minutes between moisturising and breastfeeding. This will allow the skin to absorb the emollient. It's a good idea to moisturise immediately after breastfeeding to try to prevent your nipples becoming sore and this will also help avoid cracks. If you use breast pads between feeds, change them regularly so that they don't get too damp as this could cause irritation.

As this is a sensitive area, the standard flare treatment for nipple eczema is a mild-to-moderate topical steroid, used for a short treatment burst – generally daily, every day, for 5–7 days and then every other day for a week.

Rarely, if the eczema is severe, a more potent steroid may be prescribed for a short period.

Be aware that any yellow crusting and oozing may indicate infection, so do seek advice from your healthcare professional. If the eczema is not adequately treated, there will be more redness, itching, soreness and cracking, so it is better to treat promptly.

Topical calcineurin inhibitors (tacrolimus or pimecrolimus) are another treatment option. If your nipple eczema is more problematic and long term, these can be used twice a week, as an ongoing maintenance treatment.

With all topical treatments, aim for a long gap between application and feeding. Always apply your treatments just after breastfeeding, ideally before the longest stretch of time your baby has between feeds.

It's a good idea to use expressed breast milk to wipe the breasts before feeding. This will help prevent irritant dermatitis, which can be triggered by regular wiping and washing. Also, the fat contained in breast milk helps retain moisture in the nipple and minimise dryness, alongside your regular emollients.

Hopefully, your nipple eczema will respond to treatment quickly and then you can prevent and control nipple eczema with emollients and breast milk only.



Answering the eczema questions that matter

Researcher Dr Emma Campbell introduces an innovative research project that is designed with people with eczema, for people with eczema.



How often do you turn to Google or eczema support groups to find ways to stop eczema itching, to see if stress might have caused a flare-up, or to search for products that might help someone with eczema get a better night's sleep?

These are just some of the questions that matter to people living with eczema. But despite people's need for information, many of these questions have still not been fully answered by research studies. We are working to change this through our project Rapid Eczema Trials.

Our project is using high-quality studies to answer questions that impact everyday life for people living with eczema, such as 'How often should I bathe?' and 'Will meditation help my eczema?'

Amanda Roberts and Kim Thomas are co-leads of the five-year research programme. Amanda has been a key patient voice in many research projects. She has eczema herself, as do her children. Kim is a world-leading eczema researcher, who also has eczema. Together, they have many years of lived experience of eczema and of dermatology research.

Amanda and Kim were becoming increasingly fed up with the lack of answers from research to questions that are important to people with eczema. So they decided to do something about it. The result was a proposal for a project



RapidEczemaTrials.org

– Rapid Eczema Trials – that would enable some of these questions to be asked in high-quality clinical studies.

The voice of people with eczema is key to the questions the project is seeking to answer. Because of this, Amanda and Kim designed Rapid Eczema Trials as a citizen science project. This means involving people with eczema, and parents of children with eczema, every step of the way.

‘Being involved with Rapid provides a real opportunity for people without a scientific background to make a meaningful contribution to research,’ says citizen scientist Tressa. She adds: ‘Rapid has helped me to take back control.’ Fellow citizen scientist Hugh describes how the project has ‘made me think about how I treat my eczema, which I’d just given up on.’

How does citizen science work?

In our Rapid Eczema Trials community, people with eczema and parents of children with eczema decide what topics are most important to them and what questions should be answered through research. Smaller groups of these citizen scientists then work together with healthcare professionals and researchers, through online meetings, to design the research study.

Once a study has been approved, people living with eczema in the UK can take part in the research.

‘None of the citizen scientists are experts in research,’ explains citizen scientist Kelly. ‘We are ordinary people living with eczema all over the country. The only reason we got together and worked on the panel is the determination we must fight eczema.’

As well as being led by citizen scientists, another ground-breaking aspect of Rapid Eczema Trials is that the studies themselves are run entirely online. People taking part monitor their own eczema and fill in online questionnaires to record any changes they notice during the study.

This means there are no geographical boundaries to taking part and no need for participants to make their way to extra GP or hospital appointments for assessments. These really are studies people can do from the comfort of their own home.

‘It feels good to be able to try and do something positive for people with eczema and be listened to.’

Rapid Eczema Trials citizen scientist Aaron

What’s happened so far?

The Rapid Eczema Trials project started in September 2022, and three topics have been prioritised:

- Best ways to bathe when you have eczema
- Best ways to keep control of eczema between flare-ups
- Psychological interventions for people with eczema.

Our first study will answer the question: ‘Is it better to bathe daily or weekly when you have eczema?’ This study is now open and will recruit 390 people with all severities of eczema, and of all ages, to take part for a period of four weeks.

Once the results are known, our citizen scientists will help us work out the best way to share the findings with the wider eczema community, including members of the public and healthcare professionals.

If you’d like to get involved in any way, we’d be delighted to welcome you to our community. Anyone in the UK who has eczema, or who cares for someone with eczema, can join the Rapid Eczema Trials community. This is your chance to help research for the benefit of everyone living with eczema.


Rapid Eczema Trials citizen scientist Mars explains: ‘[It’s] very good to see those doing research really care about what will be useful

to people with eczema.’ Fellow citizen scientist Tracy adds: ‘It’s the most exciting part of my life to know that I’m working with a massive group of people that can make a difference to those suffering with eczema.’



Join to be part of the change!

 Sign up for the newsletter at <https://RapidEczemaTrials.org>. You’ll hear about project updates and opportunities to get more involved. You’ll also have the chance to vote on topics and feed into surveys.

 Take part in the eczema bathing study at <https://RapidEczemaTrials.org/eczema-bathing-study>



Complementary therapies for eczema

Is it worth exploring complementary therapies alongside medical treatment for eczema? Julie Van Onselen investigates.

People with eczema are often interested in seeking complementary therapies. It is important to understand there is no cure for eczema, whether with complementary therapies or with any current eczema treatment in dermatology.

‘Complementary therapies’ are therapies used alongside conventional medicine, while ‘alternative therapies’ are those used instead of medical treatment.

We never recommend using alternative therapies instead of medical treatment. If you decide to add in any complementary therapies, it is always important to discuss this with your healthcare professional. However, complementary therapies can be helpful – especially in improving quality of life and overall well-being.

Is there evidence that they work?

Unfortunately, there are few clinical trials on individual complementary therapies, and research in this area is limited. Many therapies simply do not have enough evidence to prove that they are effective eczema treatments.

The complementary therapies that have been researched do have proof for general well-being benefit (but not specifically for eczema). These well-researched complementary therapies include acupuncture and acupressure, hypnosis, massage and herbal preparations.

One positive advantage of complementary therapies is that they may offer longer appointments and practise holistic care. This allows the person with eczema (and their carer) more time to talk through physical and emotional issues. These factors in themselves may help improve well-being.

Are complementary medicines regulated?

All conventional medicines and medical devices are regulated by the Medicines and Healthcare products Regulatory Authority (MHRA) – the government agency that checks quality, performance and safety standards. Complementary therapies are not categorised as medicines, but the MRHA does run a traditional herbal registration scheme, which sets safety standards for herbal medicines.

Choosing a practitioner

In conventional medicine, healthcare practitioners must be qualified and listed on a professional register. They follow a code of conduct and have continuing professional development.

Regulation for complementary practitioners offers less assurance: anyone can set themselves up as a complementary therapist or sell products on the internet claiming to cure eczema. However, many complementary practitioners have undergone training and are registered with the Complementary and Natural Healthcare Council or other professional organisations.

Questions to ask a practitioner

- What training have you done?
- What is your experience in treating eczema?
- Do you have professional indemnity insurance?
- How much is a session and how long are courses of treatment?

Which therapy is which?

There are numerous complementary therapies and new therapies emerging all the time. We set out a few of the therapies that you may encounter.

Acupuncture is a well-known holistic treatment method that originated in Asia but is now used around the world. The practitioner inserts needles in the skin at particular points to stimulate, circulate, and steady the movement of energy known as ‘chi’ around the body to restore balance.

Non-needle treatments include cupping, acupressure and moxibustion. There is some evidence that acupuncture can reduce the intensity of itch.

Aromatherapy uses essential oils, distilled from plants, to improve emotional states such as stress and anxiety and treat a wide range of conditions. Oils are applied either by being massaged into the skin, inhaled, or distilled in baths. Aromatherapy is often used alongside other therapies such as acupuncture or herbalism.

Balneotherapy involves immersing the skin in baths or soaks containing substances such as salts and minerals. It may help alleviate itch and inflammation or aid cleansing by removing crusts and scales.

Balneotherapy was first used for arthritis and trials have found it more effective than



no treatment. It can be done at home or in hydrotherapy pools, sometimes alongside chromotherapy, which uses colour and light to reduce tension and stress.

Herbalism Also known as phytology, this therapy uses plants, herbs or plant extracts for medicinal purposes. Some of the extracts in the box are registered by the MRHA as traditional herbs.

Chinese medicine falls into this category and there have been some validated trials for certain treatments. However, some Chinese medicines have been found to contain topical steroids without labelling and some treatments may require regular blood tests to check kidney and liver function. If you are considering treatment, talk to your doctor first.

Some of the botanical extracts that are used to treat atopic eczema

- Arnica
- Calendula
- Camomile
- Gotu kola
- Liquorice
- Oolong tea
- St John's wort
- Tea tree oil
- Oregon grape root
- Pansy

Homeopathy involves administering chemical preparations made by diluting preparations to the point only minuscule – or none – of the substance remains and shaking them in a particular way.

In 2017, NHS England stopped funding homeopathy and recommended GPs and other prescribers stop providing it, as there is no robust evidence to support it in treating any

condition. However, private complementary practitioners continue to provide it.

Hypnotherapy involves using the voice and imagery to induce a semi-conscious state that helps the person become focused, relaxed and open to suggestion. There is evidence hypnosis can have a positive impact for people with eczema – for example, in helping control the itch-scratch cycle and improving sleep and mental well-being.

Massage therapy involves stroking, kneading, pressing or manipulating the muscles and other soft tissue to aid relaxation and well-being. There are many techniques, drawing on Eastern and Western healing practices.

Relaxation techniques include a range of approaches, including sequential muscle relaxation, meditation, yoga, autogenic training, mindfulness, qigong, reiki, shiatsu and tai chi to promote physical, mental and spiritual well-being.

Some techniques induce relaxation or reduce pain, whereas others improve strength and balance. Others address stress or emotional distress. (See the article on yoga, meditation and eczema in the Winter 2023 edition of *Exchange*.)

Find out more

Our factsheet Complementary therapies and eczema is available at: eczema.org/information-and-advice/eczema-booklets-factsheets/factsheets

Working and eczema



Dermatology Nurse Adviser Helen Dennis explores the world of work and eczema, including roles carrying higher risk, employers' responsibilities and ideas for eczema-friendly working.

If you live with moderate-to-severe eczema, you may often need time away from work. Having very sore skin may severely affect your mobility and make everyday tasks, such as walking, bending, reaching up and writing, a struggle. Chronic sleep deprivation can take its toll, too. Nights lying awake tormented by itching may leave you unable to work.

Over time, these effects can result in people simply having to leave their jobs. But a good work match is not always easy to predict. It may be only

with hindsight, after trying a job out, that the workplace obstacles become clear.

What jobs carry higher risk of contact eczema?

Certain jobs carry higher risk of developing contact eczema due to repeated exposure to particular substances such as chemicals. The Health and Safety Executive identifies certain occupational areas as presenting particularly high risk, including catering, health services, dentistry, printing, construction and vehicle repairs. These are explained below.

For someone with existing eczema and already sensitive skin, the risks are even higher.



Catering

Work-related dermatitis is twice the average in catering as in other industries. In this sector, the skin is affected through handling foods, frequent handwashing (to comply with food safety laws) and cleaning equipment and kitchen surfaces.

Some adaptations can help, such as using food processors to chop foods, using a dishwasher where possible and wearing gloves. However, given the high risk, this might be a career to think about very carefully if you have eczema.



Health services

Nurses are reported to have a higher rate of work-related contact dermatitis than the average of all professions. Contact urticaria can be seen in people who are allergic to latex rubber proteins. Frequent handwashing and wet work account for about a quarter of the hand dermatitis cases.

Other hazardous agents hospital staff are exposed to include sterilisers, preservatives, fragrances and aldehydes.

Students often first encounter these difficulties during training. As a result, some are unable to complete their course. This can be a costly mistake, leaving people with student loan repayments and no qualification.



Construction

Several construction-related roles present a high risk for dermatitis. They include roles working with cement (or lime-based products found in cement), as well as mortar, grout and some plastering materials. So, bricklaying, plastering, tiling and groundworks may be

challenging. Many paints contain chemicals that irritate eyes and skin.

People working in construction are often self-employed and lack access to occupational health advice. Gloves and plastering sleeves are available to protect hands and sleeves, but if you develop a contact allergy you may need to change in trade to an alternative with less risk to skin, such as plumbing and electrical works.



Motor vehicle repairs

The many cleaning and degreasing products in this industry pose a risk. Meanwhile, people working as spray painters are seven times more likely than others to develop dermatitis. Many of the two-part fillers for body works cause skin allergies too.



Printing

In the printing industry, problems arise from wash-up sinks and cleaning solvents, varnishes

and inks, developers, thinners and materials containing isocyanates.

What can I expect of my employer?

Employers have a responsibility to help workers look after their skin. They need to:

- ⊗ provide appropriate washing facilities
- ⊗ remind staff of the importance of washing any contamination from their skin promptly
- ⊗ provide the means to dry the skin after washing
- ⊗ make available (or refund you for) barrier creams and appropriate gloves for the task.

If your workplace has access to occupational health, ask them to advise you and to make sure you have access to the protective equipment needed.

Under the Single Equality Act 2010, you are considered disabled – and therefore protected from discrimination – if ‘your impairment has a substantial and long-term adverse effect on your ability to do normal day-to-day activities’. The definition includes many people with severe or moderate eczema.

The crux of the act is that the employer needs to make ‘reasonable adjustments’ to enable you to work comfortably and efficiently. These might include flexible working, aids to assist you, a review of job duties and allowing time off for medical appointments. Eczema-related adjustments may include adjustments to the temperature you work in, a private space to

Working and eczema

apply treatments, adjustments to uniforms, and personal protective equipment.

What if I develop a reaction?

If you develop an allergic reaction, you need to avoid contact with the materials that triggered it. Protect your skin with gloves and emollients and check for early signs of dermatitis. It is important to treat the dryness and inflammation promptly. If these symptoms continue, see your GP.

If you already have eczema, it can be hard to know if the dermatitis is work related or not. Contact dermatitis is more likely:

- if it is mainly on the hands and face
- if the condition improves away from work and gets worse when you go back to work
- if it affects more than one person in the same work area or handling the same materials.

Testing

Removing the allergen is the key to resolving contact dermatitis, and this may require you to change your role. If you don't know which allergen triggered it, your GP may refer you to a dermatologist for patch testing.

Waiting times for this service can be considerable. Your workplace may be prepared to fund it privately to speed things up, although they are not required to.

The testing involves taping drops of substances onto your back for 48 hours and then

interpreting the skin's reactions to identify the chemical that you need to avoid.

Treatment

Treatments for contact dermatitis are similar to that of eczema, with emollients and topical corticosteroids as the first line in symptom management. Topical calcineurin inhibitors are often prescribed for facial eczema, in particular.

Employers are not generally required to provide paid time off for medical appointments, but if the workplace is contributing to your condition, many will do so. Check your employer's handbook for their policy details on this.

Alternative approaches to working

Many people with eczema find flexible or home working really helps. Flexible working allows you to adjust your hours. This means you may be able to negotiate a longer lunch break to apply creams or a later start if you haven't slept well.

If you work from home, you can control your environment (including room temperature), dress in loose, comfortable clothing, and shower and apply creams easily. Since the pandemic, opportunities for remote working have increased hugely. Today, there are remote office-based roles in many areas, including customer services, human resources, financial services, legal services and business operations.

Eczema does not need to limit your career. But if you're thinking through options, don't forget to factor in your skin.

You are what you eat

With no known cure for eczema, it's natural that people with eczema want to understand the connection between their diet and their symptoms. **Specialist GP Dr Angelika Razzaque** helps us sort the good advice from the bad.





What myths about eczema and nutrition should we be aware of?

Perhaps the most common myth is that a single dietary change can cure eczema. There is a connection between eczema and allergies, and food intolerances or allergies could increase eczema symptoms in some people. However, this is the case only in about 10% of the eczema population, and if nutrition is the cause, it will arise in infancy.

People are often looking for that 'one thing' they can change. And food may contribute to their symptoms – but changing your diet will never be a complete cure for eczema. That's because eczema is complex and needs to be managed holistically.

That said, if there is a genuine link between your eczema and an allergen – dairy or peanuts, for example – then removing the allergen from the diet can help improve symptoms as well as avoiding severe reactions.

How does diet contribute to inflammation in eczema?

Processed foods are common in Western diets. These can contribute to skin issues such as acne, so we can reasonably conclude they affect eczema too, because eczema is also an inflammatory skin condition. So, while there is no definitive evidence linking specific foods to eczema flare-ups, it's advisable to minimise your intake of processed foods.

Similarly, while I don't believe a clear link has been found between sugar and eczema, common sense tells you to keep sugar at a minimum. Sugar spikes cause a huge strain

on our insulin metabolism and our sugar metabolism overall. When this happens, our bodily response can be to release mediators that have an inflammatory effect too. All this could aggravate your eczema.

What role does gut health play in eczema?

The gut microbiome is suspected to have a two-way relationship with the skin, so any changes to the diversity of our gut composition can ultimately result in local or systemic immune dysfunction affecting the skin.

Some studies have shown microbial imbalance of the gut precedes the onset of eczema. Infants who go on to develop eczema have shown to have, for example, lower colonic microbial diversity, including lower levels of Bifidobacterium. Research is continuing to look into which diet has optimal health benefits in people with skin conditions.

When should someone consider allergy testing?

Allergy testing is mostly used for allergic contact dermatitis. If you find certain



emollients or active treatments make your symptoms worse, you may have this type of dermatitis. Another sign can be if topical steroids produce bad side-effects, such as stinging and burning, and are not producing improvements.

Allergy testing may be relevant in these cases or if your skin has become sensitised to certain ingredients. In this case, you will have patch testing, which involves sticking little patches on your back to expose your skin to well-known allergens. After 48 hours, any reactions show up as redness and swelling. Using those results, the team can filter out substances, such as emollients and topical active treatments, which contain those ingredients.

Testing is important if someone has an episode of an alert reaction. For example, if a child has a rash or breathing difficulties, lip or eyelid swelling and the GP suspects that further exposure would cause an anaphylactic reaction, they would do an urgent referral and may do an immediate blood test.

A lot of people spend time and money on private testing or buying kits online when there isn't really an indication to test. If you are in one of the groups described above, you should have an NHS referral to a cutaneous allergy department. Here, the testing is done – and analysed – by a specialist rather than an online self-testing kit.

(I'm very suspicious of what these testing kits actually contain and how accurate they are. The products used in the NHS are standardised and they have gone through rigorous authorisation, so you have that quality assurance.)

How can people manage eczema symptoms through diet and lifestyle?

Even if you don't have an allergy, you could find that certain foods worsen your symptoms. The best way to identify these food groups is by keeping a food diary for three to four weeks. Then map your symptoms to potential triggers – ideally with a healthcare professional or dietician – to discover what foods to reduce or avoid and whether it might make a difference.



Generally speaking, though, the main advice is to prepare your own food for yourself and your family. That way, you can keep control over what you're putting in your body, which will minimise your exposure to possible causes. A balanced diet rich in fruits, vegetables, lean proteins and healthy fats supports overall skin health and reduces inflammation because it provides our bodies with essential nutrients.

Plant-based diets can be healthy as they cut out a lot of cholesterol-rich food and tend to encourage people to prepare their own food. However, pre-made, highly processed plant-based food can be just as detrimental as other processed food. So cooking from scratch is always best.



Keep it simple. The best approach is a Mediterranean-style diet with fresh vegetables (especially greens), complex carbohydrates and protein, including oily fish, lean meat and legumes such as pulses.

Do you have any advice for pregnant people or parents of children with eczema?

The 'hygiene hypothesis' tells us that early childhood exposure to particular microorganisms helps strengthen our immune system and that in the West, we aren't exposed to antigens early enough.

Studies have shown that if pregnant women use bioactive cultures (such as Lactobacillus) in the last three months of pregnancy, this can prevent their children from developing eczema. This might be particularly helpful where the mother-to-be has eczema, hayfever or asthma herself.

Breastfeeding can help, too. Today, the NHS encourages breastfeeding for at least six

months. Breastfeeding introduces children to allergens through the mother's own body, which can minimise sensitivities.

But don't wait till the six months are up to gradually introduce food groups to children. Doing this from three months onwards could make a huge difference.

Even a tiny taste of peanut butter on the end of a parent's finger is enough for the body to learn that peanuts are food. The gut tells the immune system 'It's okay.' In contrast, if a baby's first contact with peanut is through the skin, their immune system may not recognise it as food and they are more likely to develop the allergy.

How can people navigate dietary restrictions without feeling overwhelmed?

Controlling your food isn't easy and it can become a fixation – forever searching for what we should and shouldn't be eating – when in actual fact, a flare-up may be caused by lack of sleep or stress instead.

Like any chronic inflammatory skin condition, eczema usually benefits from a proactive approach to selecting, and possibly restricting, certain foods or eating at certain times. But it's important to balance out the benefits with the impact on the overall well-being of yourself and those around you.

If you think you might have an intolerance, just try removing that food for three-to-four weeks and see if that improves your symptoms. Most important of all is to enjoy your food. There is an abundance of fruit, vegetables and other foods to try, so treat cooking as a pleasure and make healthy meals a highlight of your day.

MAKING THE LEAP TO SECONDARY SCHOOL

Claire Moulds looks at ways to help your young person with eczema flourish as they navigate the transition from primary to secondary school.

Starting secondary school marks a major milestone in any child's life. It's exciting and just a bit daunting. But add eczema to the mix, and you'll find a whole new range of challenges.

What about applying my emollient?

Will I fit in?

What if I become hot and itchy?



● Talk about it

Even the most confident child may be anxious about some aspects of secondary school life. Encourage them to talk about how they're feeling: including what they're looking forward to and things they're worried about.

For many children, the sheer size of their new school and the fear of getting lost will be a worry. But for children with eczema, the size raises some bigger issues.

At primary school most will have had the same teacher with them all day, who hopefully understood their skin and their triggers. At secondary, they will have a succession of teachers in different classrooms. This may leave your child feeling apprehensive about managing their condition. In particular, they might be worried about having to explain what they need to lots of unfamiliar adults.

Listen carefully to their fears and help them come up with solutions. If neither of you knows how to handle something, plan together to ask a teacher, a school nurse or your GP. It's important for children moving on to become part of the problem-solving process so that, as they get older, they feel confident taking more responsibility for their skin.

● Get informed

Find out what information your child's primary school will pass to their secondary school about your child's health. Ask as early as

possible about the process and how you can contribute.

With many secondary schools welcoming hundreds of new students each year, it's unrealistic to expect each teacher to have an in-depth understanding of your child's condition. Instead:

- ✔ Make sure your child's form tutor is comprehensively briefed, as the main point of contact.
- ✔ Ask for the SENCO (or school nurse, if there is one) to be informed of their condition.
- ✔ Compile a short, bulleted briefing document for other teachers highlighting the key issues in class such as:
 - not seating them near a radiator or window
 - allowing them to wear gloves to handle art materials or cooking ingredients
 - being able to step out of a lesson if the itch becomes overwhelming and they need to compose themselves or apply more cream.

If you can, have a one-to-one meeting with their form tutor before school breaks up for the summer. Hand over any information you've compiled for the teaching staff, for them to circulate. Ask questions, too. For example, if your child has a severe flare up, can school send work home for them so they don't have to come in? If their focus is affected due to interrupted sleep, can they have extra support or catch-up sessions?



Encourage your child to join in, too. The more they practise talking to adults about their eczema, the better prepared they will be for later life.

● Sort out emollients

If your child needs to apply cream during the day, it's important they have a private place to do this. Ask the school to identify suitable locations across the campus and highlight them on a map. If possible, ask to see these in advance.

Decant your child's emollient into a small, discreet pump dispenser – to minimise the risk of infection and to avoid drawing unwanted attention. They can keep this in their bag as they move between classrooms.

Encourage them to start using this in the summer holidays so they get into the habit. If you want them to apply their cream at

lunchtime, encourage them to do this, too. This will be a good test for them, especially if they're with their friends. It mimics the conditions they will find themselves in at school, where there will be lots of distractions.

Make it their responsibility to refill the container, rather than doing it for them, so they learn to check how much is left.

● Heading off new challenges

Secondary school will throw up many new triggers and challenges. Your child probably knows to take their school jumper off if they're overheating, but they may be less prepared for other situations. Talk to them about potential challenges in practical classes such as pottery or sports, like rugby, cross-country running or athletics. Explain how each could affect their skin and what they might need to do.

MAKING THE LEAP TO SECONDARY SCHOOL

Teach them how to scan new environments and to adapt their behaviour accordingly, without adult input. This will help them develop a key life skill.

If your child had uniform adjustments at primary school, be prepared for pushback with their new uniform, as they may be reluctant to wear different clothes from their friends. Involve them in the decision-making process and be prepared to negotiate.

Regardless of school policy, make-up may become an issue, too. If your child's friends are wearing it and they're keen to, restrict it to items with limited skin contact, such as a lip gloss or mascara, rather than foundation, and introduce items one at a time, so you can monitor for any deterioration in their eczema.

● Build a support network

Most children worry about how they will fit in at secondary school, but for those with a visible skin condition, the anxiety is far greater – including a fear of being bullied.

If your child's friends are moving to the same school, ask if it's possible for some of them to be in their form group, so they can navigate the new environment together. This is especially important if your child has been bullied because of their eczema in the past. They may well benefit from being around people who are used to their skin and will stick up for them.

If your child doesn't know anyone, alert the school before transition days so that teaching staff can help them integrate. Also, look for holiday clubs where they can get to know other children starting year 7 before term starts.

Regardless of the size of their support network, make sure your child has a tried and tested answer to any eczema-related comment that will take the heat out of the situation. This might be as simple as "It's eczema. It's not contagious and it just means my skin gets really dry and itchy, which is why I have to put cream on."

● And relax...

The move up to secondary school can be stressful for children and their parents alike. As stress is a major trigger for eczema, it's important to keep things light. Make sure starting school isn't the sole focus of their summer holidays and that you all get a chance to unwind and have fun.

It's important for your child to have lots of downtime in those first few weeks of term – especially if they're struggling to adjust. They might be tired from longer days, longer journeys and more homework, and may need more sleep. To avoid an eczema flare-up, make time for rest and don't cram weekends with activities until they get used to their new routine.

Finally, mark the transition with a treat or a celebration, such as a family outing or a special dinner, to show how proud you are of the young adult they're becoming.

Living with ECZEMA

'It was like trying to put out a forest fire with a watering can'

James Stanyer (25) talks about the importance of listening to our bodies.

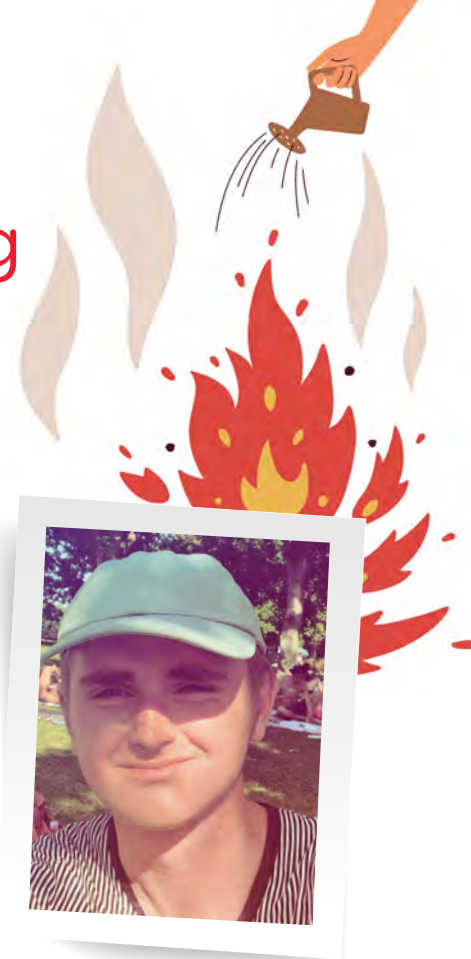
“Despite battling with eczema since I was a toddler, I was still completely unprepared for how much it has affected my life over the last few years.

Having graduated during the Covid-19 pandemic, I was excited to move to London to start my first media job and looking forward to the buzz of a new city. But little did I know that the experience would take my eczema to a whole new level and, ultimately, see me quit my job and return home to Aberdeen.

It's been a horrendously difficult period but one that has, in the end, transformed my life for the better. I'm feeling hugely positive about the year ahead and that I'm the one now in control, not my eczema.

At its worst

Just six months after moving to London, my eczema had spiralled to the point where 80% of my body was covered in raw, flaky, itchy, bleeding, blistered skin.



It was painful to shower and impossible to walk comfortably. I was tired all the time and each evening I felt like a boxer returning home after a fight that's gone the full 12 rounds.

My mental health also took a massive hit. Weekends would consist of lying in bed, listening to the radio and ordering a pizza for dinner, because the thought of shopping and then cooking was just too taxing. I was forced to cancel plans with friends as I was in far too much pain.

It got to the point where my family were concerned about my low mood and well-being. I felt completely helpless.



Growing pains

My eczema had never affected me this badly before. When I was younger it took me a while to even realise that not everyone has eczema, asthma and a peanut allergy!

I grew up in Bournemouth and quickly learnt that sea water was not my friend – it made my skin really hurt. I remember having to have my skin bandaged and how my older sister would distract me from the itch with humour and play.

I was never badly bullied because of my skin, but there would be unwelcome comments and teasing from the other boys when I wore shorts to school, revealing my visibly sore and often infected legs.

When I was 11, I was referred to dermatology at the local hospital and started a course of phototherapy. I don't remember a drastic change, but my parents thought my skin was in a better place afterwards and the consultant must have agreed, as they discharged me.

At secondary school, I discovered the performing arts. In these subjects, the other students were very inclusive and friendly. Unlike when playing sport, I could cover up my eczema with clothes and completely blend in. It provided brilliant respite for me, as well as a creative outlet.

The root of the problem

In London, life was very different. I was living on my own, commuting long distances. My flat was a far from ideal environment for someone with eczema. Meanwhile, the intense heat of summer in the city exacerbated the pollen situation and everything just snowballed, until I found myself back under specialist dermatology care.

When I look back at photos from that time, it's really upsetting. A nine-month course of methotrexate had minimal effect, even though they increased the dose. It was like trying to put out a forest fire with a watering can! Numerous times, I relied on oral steroids coming to my rescue.

At work, I was continuing to make a good impression and could do my job well. But at home, my quality of life, relationships and mental health were all suffering as a result of my skin. I didn't feel settled but I lacked the drive to find a flat better suited to my needs. I knew it would be a hugely stressful and expensive process.

In the end, I knew that if things were to improve, I had to make significant changes to my way of life and mindset.

Full circle

Moving back home to Aberdeen wasn't an easy decision. It was the right one, though. I needed to reduce my stress and improve my living conditions. It was a drastic change and it's made a huge difference.

In January, I started a great new role and I've begun a new course of phototherapy, which seems to be helping. I've also been able to pick up the hobbies and interests that fell away when I was very poorly, such as qigong, running and skateboarding. They provide a welcome distraction from my skin while

helping me stay healthy and reducing my stress levels.

When I was at university, I realised that lots of alcohol can make my skin worse, so I keep an eye on how much I drink. Sugar affects me too – if I eat sugary foods for breakfast, I know I'm going to feel much itchier for the rest of the day. I'll do anything I can to feel less itchy, but it's not about excluding something: I believe in balance. If I've overdone it with sugar, caffeine or spicy foods, then I feel it in my skin.

You can't do it alone

I've always been really open with people about what I go through with my eczema. Family and friends have seen me at my very worst, and when I'm finding things really difficult, I'm not afraid to be honest. When I was living in London, calling home provided me with the vital support I needed to keep going.

I've also been very lucky at work. In my last two jobs, my line managers have been very sympathetic, as people close to them have eczema too. So they completely understood what I was going through.

Giving back

Running has also been an excellent outlet for me, helping with my fitness and my body confidence. I'm now part of a running club where my fellow members are constantly challenging themselves to run different races and distances.

Inevitably, I have also been bitten by the marathon bug and have set my sights on running one in 2025 – either in London or another major city in Europe. As I work towards this goal, I'm hoping the focus and discipline it requires will translate to my self-care and treatment regime, so I can better manage my condition in future. I also want to make every step count and to raise as much as I can for the National Eczema Society.

In the meantime, I recently held a successful 'Spring FUNdraiser' at Aberdeen Squash and Racketball Club with music, quizzes and a tombola, raising £1,585 to help fund the Society's invaluable work and ensure that everyone with eczema can access the information and support they need.



£ Sponsor James
James is running the Budapest marathon on 12-13 October 2024. To sponsor him, go to <https://tinyurl.com/sponsor-james-stanyer>

Letters



Do you have ideas or experiences you'd like to share, a question you'd like to ask or an important point to make? Can you help answer questions that others have raised?

Our letters pages offer members the chance to share information. Please do get in touch if you'd like to join the conversation.

You can email us at exchange@eczema.org
Or write to: Editor, *Exchange* magazine, National Eczema Society, 11 Murray Street, London NW1 9RE.

The views expressed in the letters pages are not necessarily those of the Society. See our disclaimer on page 3.

Yoga and eczema

I really enjoyed the article about yoga, meditation and eczema in the last issue of *Exchange* (Winter 2023, pages 13–16). It inspired me to join a yoga class and I love it! Although I'm still learning, I've already noticed it helps me be more present and I feel calmer somehow. Stress is a big eczema trigger for me and it's difficult to avoid stressful situations sometimes. Yoga is helping me stay calmer and it's brilliant for my fitness and flexibility too. I so recommend trying.

Amelia



Poetry corner

NES member **Elizabeth Hamilton Pylypiw** shares her poem *Dark night of the soul* about her challenging experiences of living with eczema.

Dark night of the soul

I have visited those dark places
Struggling to stay afloat
Living this 'hell on earth'
Disease

This chronic condition
Touching skin
Fingers working flesh
Self-harm in all its frenzy
Finding outlets through pain...

No comfort in this skin
I present to the world
Meant to protect me
From the elements
It seeks

Depression through hopelessness
Staring back in my face
The dark night
Has no empathy
In this apathetic space
Steroid atrophy
Has no mercy

Have you ever expressed your feelings about eczema through art, poetry or prose? Do send it in – we'd love to see! **Editor**



This body cries through layers
Shedding on itself
Taking me to places
Unvisited by most...

I look beyond those eyes
Of blue
The mirrors to my Soul
Fragmented
But I know I'm in there
Somewhere, someplace
Begging to escape
Searching relief to calm
Conflicting steroids
Coupled with potion
Solo disease
As individual
As life itself
Trapped in this cocoon
I dream to escape...

Imaginary kisses
As real as lips brushing skin
Skimming the outer layer
Senses stirred within...

LEGACIES AND IN MEMORIAM



We are deeply grateful for the thoughtful legacy gifts received from the late Mr Edwin Paul Rogers, Mrs Mary Louise Greaves, Mrs Lynne Sandrock, Mrs Mary Aylen, Mr Denver Griffiths, Mrs Glenda Kemsley and Mrs Jeanette Holland-Jones.

Legacies are such an important source of donations for the Society and a wonderful way for supporters to make a lasting difference for future generations. In particular, legacies enable us to fund research to find new treatments and, ultimately, a cure for eczema.

We also appreciate and value the generous donations made at funerals and at other in-memoriam events and anniversaries in honour of National Eczema Society supporters who have passed away.

Many thanks to the family and friends of the following Society supporters for their generosity: Mrs Harpreet Bangar, Mrs Joan Hall, Mrs Dorothy Little, Mrs Berta Davidson, Mr Roy Brooks, Mrs Maureen Brockhurst, Mr Andrew Bullock, Mr Patrick Black, Mrs Rosemary Astra Phelps and Mrs Mary Dustin.

A GIFT IN YOUR WILL

Leave a gift in your Will and you'll make a significant contribution to improving the lives of people affected by eczema.

Over the years, National Eczema Society (NES) has often been remembered in the Wills of members and supporters – on occasion, very generously. This money is crucial in helping to give us the financial stability we need to continue and to grow the services and support we provide on behalf of the millions of people living with eczema.

We know from talking to our members and supporters that many more of you would like to continue to support NES for future generations, in the form of a legacy. However, without a Will in place, these kind intentions come to nothing.

Your gift – large or small – will bring help to people like Ryan's mum:

'Without the eczema helpline when Ryan was little, I don't know what I would have done.'

Will you consider including NES among those you want to help?

Remembering us in your Will would make a lasting impact, benefiting many people.

How to include a gift in your Will

Including a legacy to the National Eczema Society is straightforward.

- **Simply tell your solicitor** of your wish and our name, address and Charity Registration Number:
National Eczema Society
11 Murray Street, London NW1 9RE
Charity Registration Number
1009671 in England and Wales
- **Anyone can leave a legacy** and every bequest is important, no matter what its value.
- Legacies to charity are also **tax free**.
- If someone leaves **10% of their estate to charity**, any inheritance tax due on the rest of their estate would then be charged at 36% instead of 40%.

24 hour
hydration



Doublebase™ Once

Proven to provide at least **24 hours' hydration**¹
from **1 application**.

Doublebase Once is an effective emollient¹,
for the management of dry skin conditions
such as atopic eczema.

It is also **easy to apply, absorbs well** into the
skin and has a **pleasant consistency**².



[Doublebase.com](https://www.doublebase.com)

Ask for Doublebase™ Once – the yellow pack – at your local pharmacy.

Always read the leaflet. 'Doublebase' is a trademark. Legal category: Class I medical device.

Essential Information about this product, including uses, directions, contraindications, warnings and side effects is available from the manufacturer: Dermal Laboratories Ltd, Tatmore Place, Gosmore, Hitchin, Herts, SG4 7QR, UK.

Date of preparation: March 2022.

Reference 1. Comparison of the skin hydration of Doublebase Once emollient with Epaderm Ointment in a 24-hour, single application study, in subjects with dry skin. Extract report summarising skin hydration results for wiped off sites. Data on file. Dermal Laboratories Ltd, Hitchin, UK. Epaderm® Ointment is a registered trademark of Mölnlycke Health Care. **2.** Evaluation of performance and acceptability of a novel, long acting (24h) emollient gel. Data on file. Dermal Laboratories Ltd, Hitchin, UK.

Adverse events should be reported. Reporting forms and information can be found at yellowcard.mhra.gov.uk. Adverse events should also be reported to Dermal.

 **DERMAL**
TOPICAL INNOVATION
www.dermal.co.uk

DDXPR302/MAR22