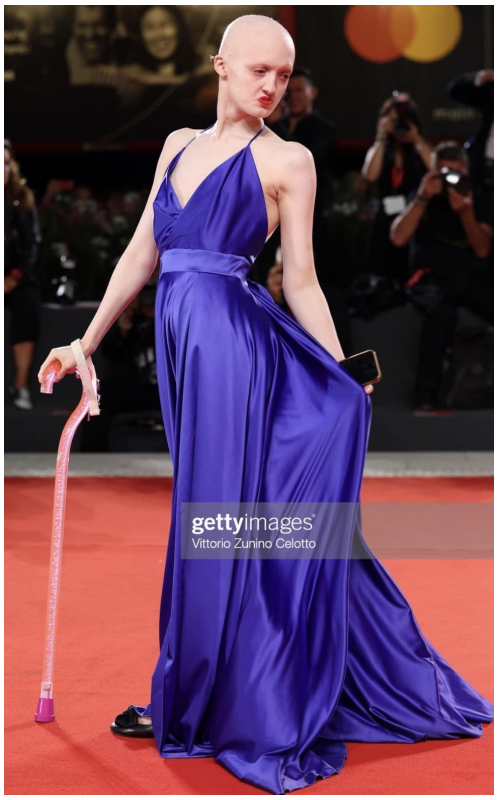
The Yearly ED-Lines

October 2023

Say hello to our new Ambassador



We are thrilled to share some incredible news with you!

The ED Society are excited to announce our new Ambassador, someone whose journey is nothing short of inspiring and whose dedication promises to be a game-changer for our mission.

Our new ambassador is none other than Hannah Harpin, a remarkable girl who has overcome numerous challenges in her life, and is currently making waves in the world of modeling. She boasts a significant presence on social media and in the fashion industry, and we are overjoyed that she has accepted our invitation to advocate for our cause.

What makes this announcement even more special is that we have known Hannah since she was a baby, and we have had the privilege of being her first port of call for support. Over the years, we have built a strong and lasting relationship with her and her family.

"We are absolutely delighted to welcome Hannah to the ED Society team," said Diana Perry, CEO.

"Her story of resilience and her commitment to making the world a better place are truly inspiring. We are confident that her involvement will help us reach new heights and drive positive change in our community."

Hannah has faced adversity with incredible tenacity and strength. She sadly experienced severe bullying during her school years, but refused to let it define her. We stepped in to support her and provided funding for some of her wigs, and it warms our hearts to see how she has not only thrived, but also risen above the challenges posed by bullies. Today, she is a powerful activist for ableism and disability rights, fearlessly championing her cause and empowering others to do the same.

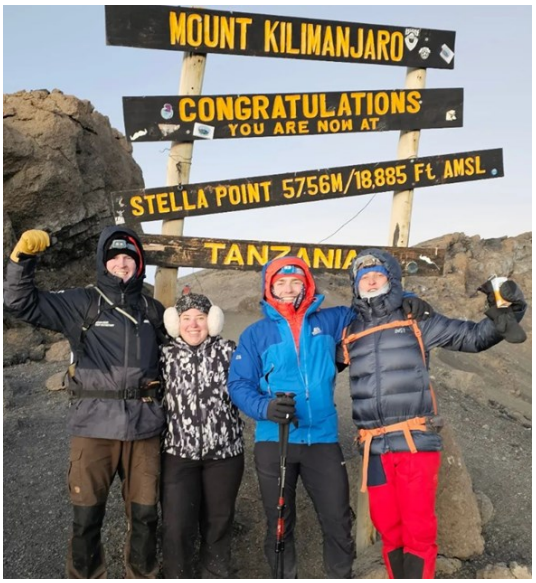
What is truly remarkable about Hannah is that she has turned her experiences into a force for change, and we are honored to have her on board as an ambassador for our charity. With her passion and dedication, we believe she will play a crucial role in helping us bring Ectodermal Dysplasia into the spotlight, advance our mission, and promote our cause to a wider audience.

Hannah has expressed her enthusiasm for her new role - **“Being an ambassador means the absolute world to me. I first met someone who had the same condition as me, and his name was Fergus. Fergus taught me everything on how to become an ED ambassador and I’m glad to be following in his footsteps. I can now help children with ectodermal dysplasia, to help them reach their goals and give them something which I didn’t have as a child. I’m hoping to help women with ectodermal dysplasia too!”**

We can't wait to see all the incredible things Hannah will accomplish as part of our ED family. Her story is a shining example of triumph over adversity, and we are privileged to have her as a part of our journey.

Please join us in extending a warm welcome to Hannah, and stay tuned for the amazing work we will achieve together.

Reaching new heights for ectodermal dysplasia



On Tuesday 5th September Adam Reid began his journey of climbing Mount Kilimanjaro – all in aid of ectodermal dysplasia and the ED Society.

"We were super nervous for him – what a huge task to take on but wow, what an achievement and to fundraise for us is amazing!" - Danielle, fundraising and marketing officer for the ED Society said.

Adam first got in contact with us back in October 2022 after signing up to take on the Mount Kilimanjaro Trek through 'Choose a Challenge'.

"In September 2023 I will be climbing Mount Kilimanjaro to raise funds for the ED Society." Adam said.

"I have chosen the ED Society as they have been extremely supportive to my friend, and her family in helping with medical referrals and operations from a very young age."

Adam has taken on this huge challenge, and been so proactive in his fundraising all on his own. He has held a couple of coffee mornings and pub quizzes over the last year, raising £850 and £585 alone.

His fundraising target was £4690 – and he has smashed it. He is now over £5000.

"Funds raised will help the ED Society provide support services and hope to families, like my friend, alongside working towards finding treatment for ED. In addition to providing referrals to specialists and promoting awareness to the general public."

Inspired to take on a challenge like Adam?

We are now registered as an open partner with Choose a Challenge. This gives us charity access to all of their public open trips to offer to our supporters.

Get in touch with us today, or you can check out the Choose a Challenge website here.

We made the list

As part of the Newborn Genomes Programme, we are happy to announce that all EDA-related genes (EDA, EDAR, EDARADD) and the NEMO gene associated with Ectodermal Dysplasia are now included in the listing.....Isn't that amazing?

"Information from babies' genomes could help us do more research on how our genes affect our health and provide opportunities and potential benefits to individuals from having their genomic data available to inform future healthcare decisions."

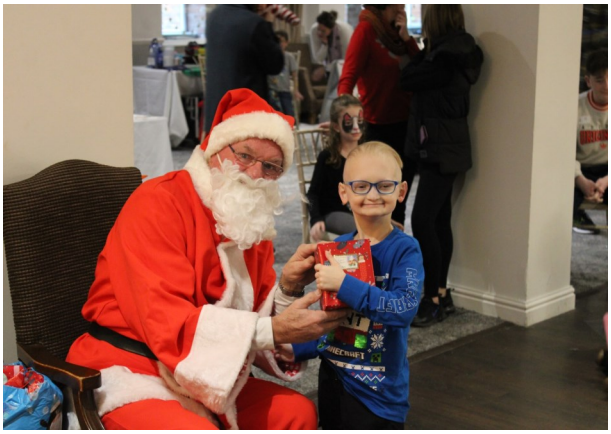
This study will explore the possibilities of genome sequencing in newborn babies, helping to identify a wider range of rare genetic conditions alongside routine heel prick newborn screening.

It will include 100,000 newborns, recruited across approximately 25 NHS sites. The first babies are expected to be enrolled in the study at the end of 2023.

Have you recently had a baby or are you currently pregnant? If so, please get in touch with your GP to discuss being referred. You could also talk with your Midwife or contact us for more information.

Visit the Newborn Genomes Programme website for more information.

Come party with us



As the festive season quickly approaches, we at the ED Society are filled with joy for the support you have shown us throughout the year. Your commitment to our cause has made a tremendous impact, and we cannot wait to celebrate this Christmas with you.

We are thrilled to invite you and your loved ones to our upcoming Christmas party, a celebration of community.

Event Details:

Date: 2nd December 2023

Time: 11am—4pm

Location: The Hatherley Manor Hotel, Cheltenham, GL2 9QA

Dress Code: Your best festive attire.

At our Christmas party, you will have the chance to make new friends, forge meaningful connections, and join our ever-growing ED family.

Not only will our dedicated team be present to chat and offer support and advice, but we are honored to have esteemed medical professionals from our medical advisory board in attendance. They will be available to address any questions or concerns you may have.

Secure Your Tickets Now:

Tickets for this event are available to purchase on our website **here** - or if you could please complete and return the form enclosed with this newsletter.

Due to time running out, we encourage you to act fast and secure your tickets now for an unforgettable day.

We understand the significance of spending time with loved ones during the festive season, so feel free to bring your family and friends along. The more, the merrier!

If you have any questions or require further information about the event, please do not hesitate to get in touch with us. Your enquiries are always welcome, and we are here to provide the answers and support you need.

Can you help get people talking about ED?

Our mission to create awareness and make a meaningful impact for those affected by ED is our driving force. We believe that together, we can raise our voices even louder and reach more people who can benefit from our efforts.

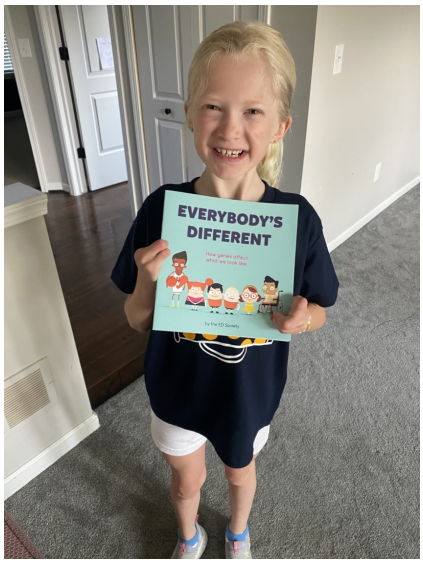
We are reaching out to our vibrant and diverse ED community to ask for your help in spreading the word.

Do you or someone you know work in the field of Public Relations (PR) or Media? Your expertise and connections could play a crucial role in helping us expand our reach and create lasting change.

By partnering with PR and media professionals, we can tell our story more effectively and engage with a wider audience. Sharing stories, experiences, and the incredible work we do will enable us to reach those who need our support and encourage more individuals to join our cause.

If you or someone you know has the skills, passion, or connections, please get in touch and email: **danielle@edsociety.co.uk**

The power of monthly giving



Just over a year ago, we bid farewell to our traditional annual membership and introduced **"Friends of the ED Society".**

Your response has been nothing short of incredible. We cannot thank you enough for embracing this change, especially for those of you who have already set up your monthly donations.

In the words of one of our dedicated supporters, **"No matter how often we chat or seek help, the Charity instantly feels like home."**

Join us today

By choosing to set up a monthly donation, you are doing something truly extraordinary. You are giving a voice to individuals across the UK and around the world who live with Ectodermal Dysplasia.

Your support enables us to advocate for recognition, provide invaluable support, advice, resources, and push for change.

Becoming a "Friend" is easy, and your contribution can start from as little as £2 a month. Setting it up takes less than a minute, but the impact you make is significant.

You can initiate your monthly gift via the donation page on our website, or by completing the form enclosed with this newsletter.

We want you to know that your contributions grant our families the medical attention they rightfully deserve. The growth and prominence of Ectodermal Dysplasia in the spotlight depend on your continuous support, and the awareness you raise through your monthly donations.

As we look to the future, together, we can strive to bring Ectodermal Dysplasia to the forefront and ensure that nobody affected by this condition faces it alone.

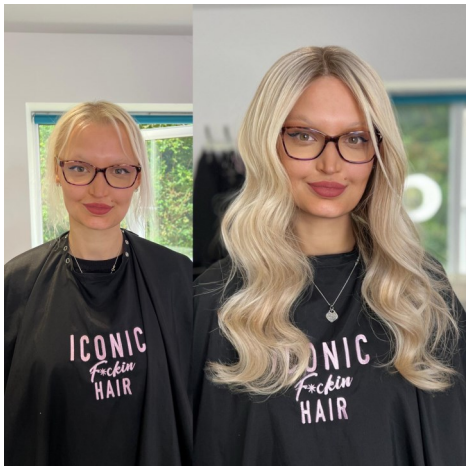
We achieve great things because of you

Your generosity has made an incredible impact this year, allowing us to grow our support fund, which was established in response to the unique needs of the families and individuals we are privileged to support.

The funds raised have been instrumental in providing small grants for essential equipment, treatment, and care to enhance the well-being of our community affected by ED.

This year, thanks to your contributions, we have achieved remarkable milestones;

- We fulfilled our Family Liaison, Jaye's, dream by supporting her in getting the long hair she always desired
- We extended our assistance to a man who, at 56 years old, finally received a diagnosis after years of struggling with overheating, equipping him with a cooling vest
- When two of our office computers unexpectedly crashed, your support allowed us to swiftly replace them, ensuring uninterrupted assistance to our community
- We also expanded the reach of our award-winning children's book, "Everybody's Different", by printing more copies, having it translated into German and French and are currently working on translating it into Spanish
- Most recently, we designed and printed our new ED emergency cards, a vital resource for our ED community.



Throughout this year, we've penned countless letters of support and appeals for various benefits, such as DLA and PIP, along with letters for schools and housing needs. We've been there every step of the way, attending tribunals to ensure that our families receive the assistance they deserve.

We are happy to share the incredible strides we've made:

- DLA Applications—10
- DLA Appeals and tribunals—7
- PIP applications and tribunals - 4
- Housing needs and air con grants - 8
- School needs/issues - 5
- Access passes - 5

The demands on our resources have grown, and the level of support we've been providing has never been higher.

It's essential to recognise that none of this would be possible without your generous donations. The enthusiasm and support from our community has been our driving force. Your contributions enable us to continue offering the vital support our families depend on.

Thank you for being part of the ED Society family, and here's to another year of making a positive impact!

We are winners

We were in shock to have been selected to receive £1,000 as part of Benefact Group's Movement for Good Awards this month, thanks to all the nominations from our ED community.

"For a small, non-profit charity like us, this £1,000 will go a long way." - Diana Perry, CEO, says.

Back in July, members of the public were invited to nominate good causes and winners were drawn at random.

"I want to send my heartfelt thanks to each and every one of you who rallied behind us in the recent Movement for Good £1,000 draw."

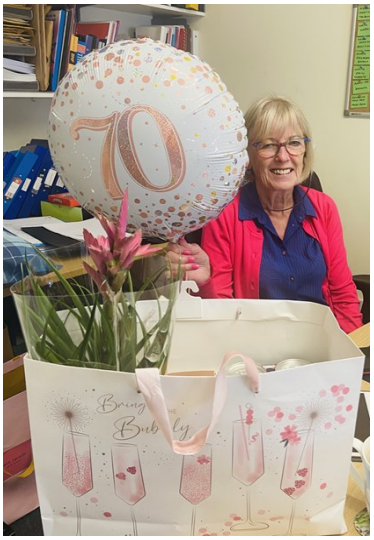
We had the privilege of welcoming a representative from the awarding organisation into our office at the beginning of October. She took the time to learn about the vital work we do in raising awareness and providing support to families living with ED.

"Last week I had the privilege to visit one of our £1,000 Movement for Good award winners. This is a small charity near to our office where £1,000 can go a long way and they have great plans for the money to allow them to help more families."- Caroline said.

"Thank you for letting me spend some time with you and Congratulations on being selected"

For more details about this award and our plans for the grant, we invite you to read the full press release.

What a heartwarming celebration



We have been deeply touched by the outpouring of support for our CEO, Diana Perry, on her 70th birthday.

As a mother of two children with ED, her dedication and empathy are truly inspiring. The fact that she established the Society in 1996 and has been tirelessly supporting the ED community on a voluntary basis speaks volumes about her commitment and compassion.

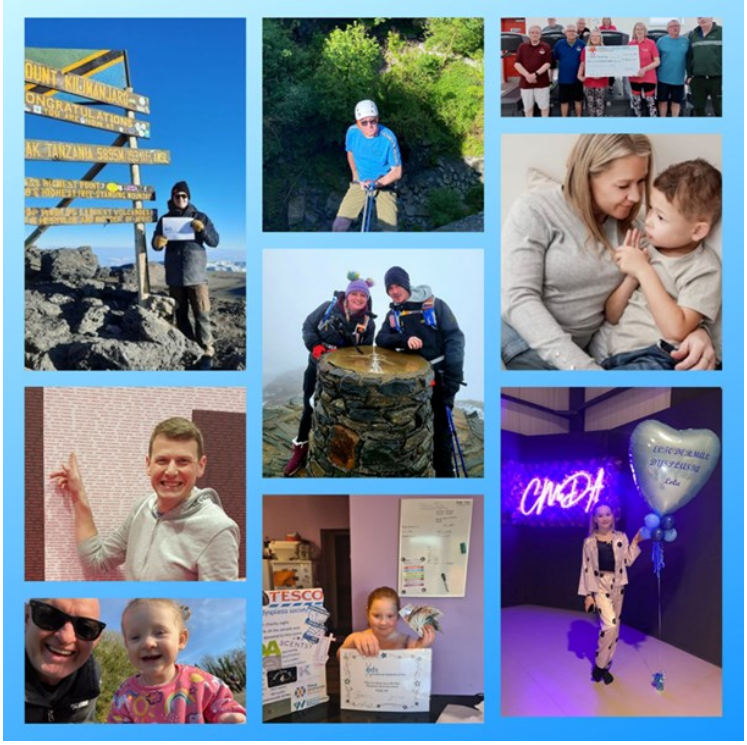
The generosity of those who contributed to the Facebook birthday fundraiser, raising over £800, is a testament to the love and appreciation felt for her and the vital work she does with the Society. We celebrate her milestone birthday and give thanks for her invaluable contributions to the ED community. Here's to many more years of making a difference!

Our superstar fundraisers

WOW—What a year for fundraising!

We want to extend our gratitude to our incredible supporters who have fundraised for us this year.

Your dedication and enthusiasm in fundraising for us has not gone unnoticed. The effort you have poured into your activities, and the incredible funds you have raised, have played a pivotal role in our journey. It's through your invaluable contributions that we find ourselves in a position to make a lasting impact, and one that brings hope to those affected by Ectodermal Dysplasia.



We would like to thank;

- **Adam Reid** climbed Mount Kilimanjaro in September and raised over £5000
- **Simon Downs** ran in the London Marathon in April in aid of ED and raised £1500
- **Lola Vickers** and her Dance School friends hosted a "Movie Night" during ED awareness month in February and raised £500
- **Kevin O'Reilly** ran the Brighton half marathon in February for ED and raised £2500
- **Holmer Lake Primary School** took part in a non uniform day for ED awareness month back in February and raised £235
- **Kayleigh Cockerill-Wright** organised an Easter Egg Raffle in the spa she works at in Australia and raised £195
- **Natasha Keeling and her daughter** hosted a Fundraising Night in their local area, raising £500
- **Barnsley Healthy Hearts** £500
- **Emma Browne and her husband** climbed Mount Snowdon, raising £120
- **Harbour Energy** held a cake sale (thank you Jamie and Joe Carnaby) and raised £531
- **John Banks** abseiled and raised £172
- **Diana's** 70th Birthday Fundraiser on Facebook just over £800
- **EVERYONE** who voted for us in the Movement for Good awards, we won £1000

It is with deep sadness that we received the news of Russell Gilbert's passing. Russell was a dedicated monthly donor to the ED Society for many years. Our thoughts and prayers are with his family and friends during this difficult time.

How can I help?

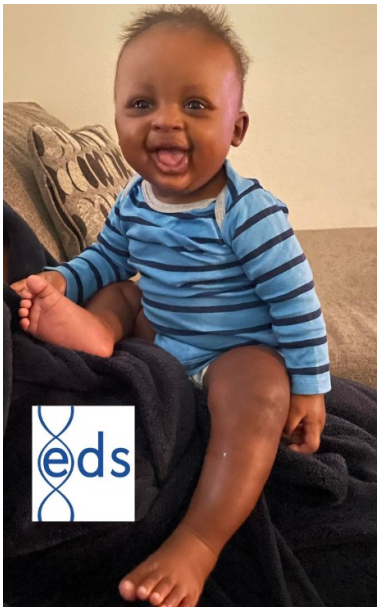
Fundraising doesn't always have to be grand. It is the small gestures that often resonate the most.

We have a cherished memory of a young boy, affected by ED, who grew plants from seed and wanted to sell them outside his home. He donated £15 to the Society, and that £15 means as much to us as £1000, for it represents not just a monetary gift, but helps show your dedication and support.

At the ED Society, we are driven by a shared commitment to creating a better, more informed, and more compassionate world for those living with ED. It is because of supporters like you that we are able to continue our vital work, day after day.

Baby treated with potential recombinant protein therapy

Back in May, a baby boy was born and is the first to receive a recombinant protein therapy in the United States that may correct the symptoms of Ectodermal Dysplasia.



He received the new, potential treatment as part of the XLHED clinical trial that could change his life, and those of future generations affected by x-linked hypohidrotic ectodermal dysplasia.

This clinical trial aims to confirm early studies, which showed this treatment restored sweat gland function and improved other symptoms in several babies. Two other babies in the U.S. received the treatment in Germany prior to a site opening in the States.

Babies born with XLHED have many symptoms, including sparse, fine hair; decreased saliva and mucous production; and missing and/or conical-shaped teeth. The most life-threatening symptom they experience is the inability to sweat. Sweating is a natural way the body cools itself to prevent overheating. Individuals affected by XLHED are at risk for overheating, which can be especially dangerous for babies who cannot communicate that they are too hot.

What is the EDELIFE clinical trial?

It is studying a synthetic protein replacement therapy, called ER004, to treat individuals affected by XLHED. The treatment is given to affected baby boys at key developmental stages before birth via intra-amniotic injections. The mother receives three injections during the second and third trimester of pregnancy, and the baby ingests the protein from the amniotic fluid in the womb.

If approved, this treatment would be the first commercially available treatment for XLHED and the first prenatal therapy to alter a genetic, developmental disorder successfully.

While studies have previously taken place in Germany and France, the first trial site studying this potential treatment in the U.S. opened at Washington University in St. Louis in July of 2022. In March and April of 2023, the first participant at the Washington University site received the potential treatment, and the baby was born in early May.

"I am very excited to be a part of this important clinical trial that has the potential to improve the lives of boys with XLHED," said Dr. Kathy Grange, primary investigator in the EDELIFE clinical trial at Washington University.

This trial will follow the baby for the first five years of his life. While results from the current trial will be published at a future date, prior studies that administered ER004 to fetuses in utero have shown improvements to XLHED symptoms, including restoration of the ability to sweat.

We are pleased to report that mum has told us her baby boy has began to sweat! **"Since we started this journey with the NFED community, I've seen how hard it's been for our children to deal with the symptoms of ectodermal dysplasia. Once I heard about the trials, I knew I wanted to make a difference and to help my unborn son. Seeing the complications that his older brothers endure, I'm sure he would thank me once he gets older. This research study has been an amazing experience, and to see all the benefits that have came from it. My son sweats so much, he has a lot of hair coming in, he is active and is passing all his tests with flying colors! We have another appointment in a couple of weeks and I cannot wait for them to see how big he has got! Science has come so far, and I would really like other moms to come forward, and to be a part of something great!"**

How can I get involved?

The EDELIFE clinical trial is sponsored by the Pierre Fabre Group and EspeRare. They are currently seeking volunteer participants at trial sites in the United States, France, Germany, Italy, Spain, and the United Kingdom. Women who are 18 – 40 years old, who have a known or suspected diagnosis of XLHED, and who are currently pregnant or expecting to become pregnant may be eligible to participate. Travel and all expenses associated with participating in the trial are paid by the sponsors.

Those in the U.K. who are interested in learning more can contact Diana Perry, at diana@edsociety.co.uk Outside of the U.K., individuals can find contact information for the trial site nearest them on the EDELIFE website.

9th International Conference For ED — Birmingham June 2025

In 2004 the UK hosted ECTO4, one of the first International Conferences on Ectodermal Dysplasia. We are now honoured to be hosting its successor **"ICED25"** and want to tell you well in advance of this event, which we think will be of interest to our ED community.

International Conference for Ectodermal Dysplasia

We will once again bring together researchers, doctors, dentists, implant surgeons, dermatologists, ophthalmologists, ENT specialists, geneticists, physiologists, psychologists, and representatives of national patient support groups with an international presence of some 150 delegates.

There will be renowned speakers from around the world covering the following themes:

- Genetics, taxonomy and "other types"
- Children's dentistry and dental implants
- Thermoregulation throughout the lifespan, dermatology, hair and nails
- Psychology and social science perspectives: the impact of ED on patients & families and supportive interventions
- Clinical services, ENT, transition from paediatric to adult clinics
- Trials, treatments and databases.

The third day of the conference, 12th June, is tailored exclusively for individuals and parents (sorry, there are no facilities to bring your children to this conference), providing a unique chance to delve deeper into the world ED with the medical professionals in attendance. This day offers a valuable platform to have your burning questions addressed, equipping you with a deeper understanding and insight.

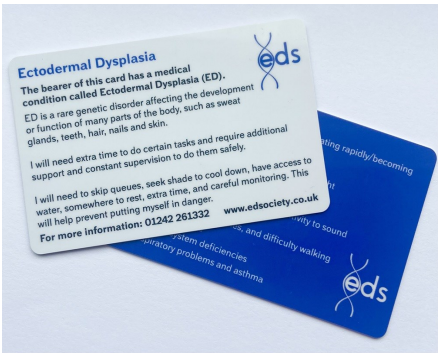
Beyond the educational aspect, it's also a wonderful opportunity to connect and build meaningful friendships with others who share your journey. Join us on this day of learning, growth, and building a supportive community.

It would be incredibly helpful to have any questions you may have in advance. This way, we can ensure you get the most out of the talks available.

Planning is well underway, if you would like to come you can register your place here.

Emergency alert cards

We are excited to introduce our new emergency alert cards, which have been designed with our ED community's well-being in mind. These cards are essential for ensuring individuals receive the correct support when they are away from familiar surroundings, and the people who know them and their condition. We're pleased to let you know that these cards are now available for purchase on our website through our recently launched fully functional online shop, and they have been in high demand since their release.



Our alert cards are a lifeline, providing vital information about you and your medical condition, which is crucial for ensuring prompt and accurate medical attention. The front of the card contains a clear description, while the back lists relevant issues and symptoms associated with ED. These cards are conveniently designed to fit perfectly in your wallet, ensuring that you always have them readily accessible when needed.

Act now and pre-order yours in our online shop.