2024 - 2025

# The Yearly ED-Lines

## The Power of Community:

### CEO Diana Perry Reflects on an Amazing Year


First of all, a very warm welcome to all our new ED friends - we are so delighted you've joined our community. It means so much to have you with us, and we look forward to walking alongside you and your families every step of the way.

Everything we've achieved together this year has been truly inspiring - from the success of ICED25, to families receiving the support they so desperately needed, to children smiling with confidence after receiving new dentures. None of this would have been possible without the generosity, kindness, and encouragement of our ED community.

ICED25 especially showed us the power of coming together as a community. With the strength, compassion, and determination we share - alongside the dedication of medical professionals - there is no limit to what we can achieve for everyone affected by Ectodermal Dysplasia.

I want to say a huge thank you to our wonderful Board of Trustees and Medical Advisory Board. Their constant support and dedication over the past three years made ICED25 possible, and I'm so deeply grateful for everything they gave to help us bring it to life.

A very special thank you also goes to the families who joined us on the final "Family" day - your presence filled the event with warmth, laughter, and togetherness, For me personally, it was incredibly special to share that day with you, seeing connections made and friendships grow - a reminder of exactly why we do what we do.

I would also like to thank the rest of the incredible ED Team, Danielle, Elly and Kelly for their continued dedication and commitment throughout the year. Whatever your needs have been, they have always been there for you, offering guidance and support.

As Jaye is no longer with the ED Society, we are pleased to share that Kelly has now taken on the role of Family Liaison. This vital role provides families with a first point of contact, offering guidance, reassurance, and practical support whenever it is needed. Kelly's warmth, compassion, and dedication shine through in everything she does. Many of you will already know her as approachable and caring, and we are confident that in this role she will continue to be a steady presence for our families throughout their ED journey - ensuring that no one ever feels alone.

One of the most powerful outcomes of ICED25 was the recognition that women with ED are far more than "just carriers." A preliminary women's survey confirmed what we have always known - women live with real and often severe symptoms that affect both physical health and mental wellbeing. For too long, their voices have been overlooked. Now, we are preparing to carry out a wider global research programme to collect the evidence needed to ensure women with ED are fully recognised, supported, and believed. When the time comes, I would like every female from puberty to old age to take part, so this research is truly representative and powerful enough for the medical world to finally accept that women are not just carriers. This work is about more than data - it is about giving women a voice, showing the reality of their daily struggles, and making sure that future generations grow up being believed, supported, and cared for.


Over the past year, the ED Society has continued to provide vital support to families and individuals navigating the challenges of ED. Our team have helped with Blue Badge appeals; over 20 DLA applications, appeals and tribunals (all of which attended successful); 7 PIP applications and appeals; multiple theme park access passes; motability appeals; genetics referral letters; 2 cases of employee/workplace support; housing issues; dental referral letters and school healthcare plans/EHCP issues. Each of these interventions makes a real difference, ensuring that those affected by ED can access the rights, services, and opportunities they deserve.

**Together, we are stronger - and together, we are building a future where every person affected by Ectodermal Dysplasia feels seen, supported, and never alone - and that future is closer than ever thanks to you.**

# Celebrating a Year of Progress

## New NHS Network for Ectodermal Dysplasia Patients

We're pleased to share that there is now a dedicated NHS Rare Disease Collaborative Network (RDCN) for individuals affected by Ectodermal Dysplasia (ED) and related conditions.

Access to care for ED has often been challenging due to the complexity and fragmentation of specialist services. To address this, an application was made to NHS England to create a dedicated RDCN - and we're delighted that this was approved in February 2025.

The ED RDCN brings together national experts who are committed to improving patient care, advancing research, and increasing understanding of ED.

As part of the RDCN, individuals affected by known or suspected ED can now be discussed virtually by a multi-disciplinary team of specialists. This means expert advice can be shared with your clinician without the need to travel for additional appointments.

**If your doctor or specialist would like to learn more about how to access this support, please ask them to contact us, diana@edsociety.co.uk and we can connect them with the RDCN team.**

## ICED25: A Milestone for the ED Community

In June 2025, we proudly hosted the 9th International Conference on Ectodermal Dysplasia (ICED25) in Birmingham. The conference was filled with engaging, informative sessions led by experts from around the world, who generously shared their time, knowledge, and experience to help strengthen our ED community.

The final day was dedicated to families, and it truly captured the spirit of the ED community. We loved welcoming both familiar faces and new families, sharing stories, and learning together. The atmosphere was one of compassion, connection, and hope.

We've been so touched by all the feedback received:

*"The sessions on both the scientific and family days were fascinating - it was amazing to see both communities come together."*

*"My teenage son also benefited from attending. It was evident a huge amount of planning went into the event, and you all worked so hard to bring it together."*

*"It was an incredible day. The work of the ED Society truly changes lives. You've changed my family's life forever — in the best possible way."*

*"The event was so well organised - I can't stress enough how brilliant it was."*

Feedback like this makes all the hard work worthwhile. ICED25 has left a lasting impact on us all, and we're so proud of what was achieved. We hope every attendee left with new insights, meaningful memories, and stronger connections within our global ED family. Once part of the ED family, always part of the ED family.

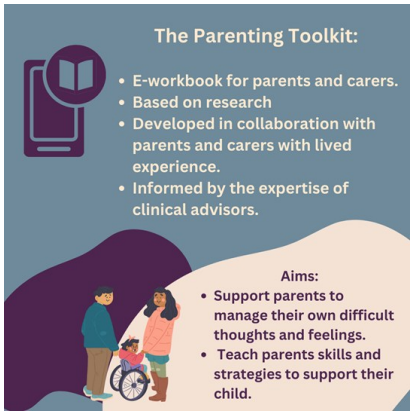


## Recognising the Support of VTCT

The ICED Family Day offered a rare opportunity for professionals to meet face-to-face with individuals and families affected by ED. Thanks to a generous grant from the VTCT, we were able to ease the cost of travel, accommodation, and attendance, making it possible for more families to be part of this invaluable day.

## Helping Families Navigate Life with ED - FREE Parenting Toolkit

We were proud to help shape a fantastic new resource for families in the ED community - the **Visible Difference Parenting Toolkit.**




Developed by the Centre for Appearance Research, with valuable input from parents, carers, and clinicians – including contributions from our own Medical Advisory Board member Dr. Maia Thornton and our CEO Diana Perry - this toolkit offers families practical guidance and interactive support for everyday life. We were delighted to see it showcased at ICED25 in Birmingham earlier this year.

**Inside, you'll find:**

♦Guidance on supporting your child while also caring for yourself.

♦Advice on managing challenges such as teasing, bullying and healthcare appointments.

♦Interactive activities to build resilience, manage emotions and navigate daily situations.

Now that it's available, we're thrilled that families affected by ED can access and benefit from this brilliant resource completely free of charge.

**Find out more and download the toolkit via our website: www.edsociety.co.uk/the-visible-difference-parenting-toolkit**

## Funding Boost to Refresh Our Resources

FUNDED BY

In May 2025, the ED Society was awarded a £1,000 grant from the British Association of Dermatologists (BAD) Patient Support Group Funding.

This support comes at the perfect time after our rebrand, enabling us to update and improve all printed and downloadable materials so they're clearer, more accessible and reflective of the experiences of those living with ectodermal dysplasia.

Work is already underway and we'll be sharing our refreshed guides and resources soon. A huge thank you to BAD for recognising the importance of up-to-date information and supporting the ED community.

## Jeans for Genes Grant Powers Our Mission

Back in April, the ED Society was awarded a £5,000 grant from the Jeans for Genes Grant Programme to help cover our core running costs.

This generous support is already making a real difference to our work and to the families we support across the ED community. We are so grateful to the Jeans for Genes team and the grant panel, who shared that they were ***"impressed by the work we do and keen to help us continue our mission."***

## Our Patron's Journey to the World Top 100

Our Patron Francesca Jones has had a truly inspiring tennis season, reaching a career-high ranking of world No. 72. Fran was born with Ectrodactyly Ectodermal Dysplasia (EEC), which affects the fingers and toes. She has three fingers and a thumb on each hand, three toes on her right foot and four toes on her left, and also started life with webbed fingers. To adapt her game, she uses an extra-lightweight racket with a thinner handle to accommodate her grip – proof of her determination to succeed at the highest level.

This has been a great year for Fran: she reached her second WTA 250 semi-final in São Paulo, broke into the top 100 for the first time, and lifted the biggest title of her career at the WTA 125 in Contrexéville. She also triumphed at the Palermo Ladies Open (WTA 125), secured a W75 title in Prague without dropping a set, and came through qualifying to reach the main draw at the Mutua Madrid Open. Earlier in the year, she opened her season with her eighth career singles title on clay at the W75 Vacaria.

Fran's achievements are proof that barriers can be overcome with resilience, dedication, and passion. She continues to be a powerful role model -and we're so proud to celebrate her achievements with the ED community worldwide and can't wait to see what comes next!

**You can find out more information about Fran and her current stats online - https://www.lta.org.uk/fan-zone/british-tennis-players/francesca-jones/**

# From Hong Kong to the UK - Thriving Through Change

Back in the early pandemic days of summer 2020, our family underwent a major upheaval as we left Hong Kong and moved to the UK. For my wife and for Connor, this represented a new challenge, as although both had visited the UK on several occasions, this would be the first time they had lived there.

Whilst we were sad to leave Hong Kong, the obvious benefit of moving to the UK, would be the cooler weather, which affords Connor more opportunities with regards to outdoor activities.

In Hong Kong, he was limited to playing football in the winter months, or whenever it was so hot that they moved sessions into air conditioned indoor centres. He joined in sports days at school, and we tried to get out and about as much as possible, but in near constant 30c+ heat, that wasn't easy.

## Finding the Right Support

The move offered many challenges, such as finding the right care for Connor. We have been lucky to attend St Thomas Hospital on multiple occasions, where their dental team has been an incredible help, and we always turn it into a fun day out in London.

We were worried about Connor starting school as he had never seen the school he was enrolled in, but he took too it well, enjoys it and has built up a good group of friends. The next challenge will be when he moves up to senior school in September.

Whilst we are a little nervous about that, we are reassured that through the activities that Connor partakes in, he has built up a network of friends that come from across the area's junior schools and many of those friends will attend the same senior school.

## Thriving in Sports and Community

Soon after we arrived, he joined a local football team, starting in the U7's. He is now at U11 level and enjoys it very much. He has even picked up a couple of medals along the way. Only in one of the all-day summer events, did he ever struggle with the weather. He managed a couple of group games before we had to take the decision to pull him out. The team went on to win the event and stopped by on their way home to pass him his winner's medal. Something he cherishes.

Last summer, he joined the local cricket team. It is something he'd asked about, but being a summer sport, we weren't sure whether to go ahead with this. But then we reasoned that there are only a handful of truly hot days in an English summer and so he signed up. He really enjoys it and his team made the Hampshire cup semi-finals and were invited to the home of Hampshire CCC (The Utilita Bowl), to perform skills tests before a T20 match against Essex. A lovely memory as they were all shown on the big screen! He was also invited for a trial with Hampshire and whilst he wasn't selected this year, he'll keep on trying.


## Embracing Every Opportunity

We don't feel that Connor's condition in anyway holds him back from participating in any activities that any of his peers can do. He is always one of the first to put his hand up for any activity the school offers and before Christmas, he was selected to switch on the town's Christmas lights, which led to him appearing in the local paper and was a lovely memory for him. The activities he does are mostly team based (aside from his karate) and the friends he has made will stand him in good stead. As the teams he plays in get older, they grow as friends and teammates. And although some players will leave and some join, there is always a core that look after each other, which extends into the school and local community.

## Inspiration in Unexpected Places

As a family, we love watching our local non-league football team. At a recent game, we were thrilled to see that the referee had Ectodermal Dysplasia. He officiated the match brilliantly, and we had immense respect for him. Being a referee is a tough job and seeing him take charge with such confidence was truly inspiring. ***(And in a lovely small-world connection, the referee was Jordan – who has also written an article for this very newsletter!)***

Our journey since moving to the UK has been one of growth, new experiences, and community support. Through every challenge, Connor has shown resilience and determination, proving that nothing holds him back from pursuing what he loves.

## Update on Connor

Since this article was first written, Connor's cricket has gone from strength to strength. He was named Club Bowler of the Year for the U11s, having taken the most wickets in the league. He also has another trial for Hampshire coming up this Saturday.

Most recently, Connor's U13 side—where he plays up an age group - enjoyed a lap of honour at the Utilita Bowl ahead of the Ladies Cup Final, after winning their league. It was a fantastic experience for him and a real highlight in his cricket journey so far.

# Pedalling for Awareness: London to Brighton Challenge

Earlier this year, Sarah and I took on the London to Brighton Cycle Challenge with a very personal goal in mind: raising awareness of Ectodermal Dysplasia (ED) within our family, friends, and wider community. Too often, we meet people who have never heard of ED, and we wanted this event to be a way of sharing our story and shining a light on what it means for families like ours.

As a passionate cyclist and professional bicycle mechanic, I had previously completed the London to Brighton ride as a personal achievement. This time, however, the challenge held a far deeper meaning. I wanted to make our son, Gordon James, proud while raising vital funds for the Ectodermal Dysplasia Society. The Society's work is essential in ensuring that children, like Gordon James, grow up in a community where they can meet others with similar experiences and feel a sense of belonging, and support.

Gordon James's early years have not been without challenges. From tongue tie and skin infections to difficulties with body temperature regulation, and interrupted sleep, his first 18 months were overwhelming at times. As parents, we often felt stretched and uncertain, but we have done everything we can to keep him healthy, happy, and safe. Taking on the London to Brighton challenge was our way of reflecting on that journey and celebrating how far we have come as a family.

Crossing the finish line was an emotional moment not just because of the ride itself, but because of the purpose behind it. And while my finishing time of 4 hours and 45 minutes is one I'm proud of, I'm already setting my sights on our next challenge, with hopes of beating it!

Above all, this ride was about raising awareness and showing Gordon James that he has a strong, supportive community around him. We are deeply grateful for everyone who encouraged us, donated, and shared our story.

Together, we can continue to spread awareness and ensure that families affected by ED never feel alone.

# Be Part of the Community That Cares

When you become a Friend of the ED Society, you're joining a community that stands beside families living with ED. Everything we do at the ED Society - from providing free information and advice, to supporting families, carers, professionals and schools - is only possible because of the generosity of our community. It is your donations and fundraising that keep us going.

As a small charity with no government funding, we rely solely on the kindness of our supporters. Recently, we have lost some of our regular donors, and this has reminded us how important regular giving is to our future. Becoming a Friend of the ED Society https://edsociety.co.uk/get-involved/friends-of-the-ed-society/ is one of the most impactful ways you can help secure our work and leave a lasting legacy.

Regular donations mean we can plan ahead, grow our support services, and dedicate more time to the people who need us most.

**They allow us to:**

* Provide one-to-one advice and guidance for families.
* Advocate with schools, professionals, and health services for better care.
* Run awareness campaigns and events that bring our community together.
* Offer practical support through our Support Fund - helping with costs for air-con units, wigs, travel to medical specialists, and more.

They also enable us to represent the ED community at key medical events across the country - raising awareness, advocating for better understanding, and ensuring ED has a voice on national and international stages. This year, Diana and Danielle attended the British Association of Dermatology Conference in Glasgow, where they engaged with medical professionals from around the world, sharing vital insights about ED and shining a spotlight on the condition.

Becoming a Friend is simple, flexible, and open to everyone - not only those personally affected by ED, but also extended family, friends, colleagues, and anyone who wants to help make a difference.

As a Friend, you'll stay connected with our community through newsletters and updates, have access to our medical specialist network, and know that your regular gift is directly helping families to feel less alone.

**You can set up your regular donation quickly and securely online via www.edsociety.co.uk/donation - or get in touch with us if you'd like a hand getting started.**

# What's Coming Up?

## Our Favourite Event of the Year is Back!

The countdown to Christmas has begun - and we can't wait to celebrate with you at our annual ED Society Christmas Party, on **Saturday 6th December 2025, from 11am - 4pm at The Hatherley Manor Hotel & Spa in Cheltenham.**

Our Christmas Party is always a magical highlight, bringing together families from across the ED community to share laughter, friendship, and festive cheer. It's a chance to reconnect with familiar faces, welcome our new families, and enjoy a day that's all about fun, joy, and togetherness.

**What's new this year?**
We're excited to welcome Non Stop Kids Entertainment, bringing fresh fun and festive energy to the day, including:

* Mini Arrival Disco to kick off the celebrations.
* An award-winning Christmas-themed comedy magic show.
* Party games with a festive twist.
* Disco lights, prizes, and sweets to keep the fun flowing all afternoon.

**Plus:**

* **Catch Up & Connect –** Meet the ED team, and spend time with professionals from our Medical Advisory Board. This is a rare opportunity to ask questions directly, share concerns, and get expert advice about ED and its impact on your family.
* **Festive Fun –** Mad Hattie is back with her face-painting magic (she never wants to leave!) plus a craft table bursting with glitter and creativity.
* **A Feast to Enjoy –** A delicious buffet lunch, tea and coffee - all included with your ticket.
* **Exciting ED Tombola –** Win fantastic prizes, kindly donated by local companies and our generous supporters.
* **A Magical Ending –** No Christmas party would be complete without a visit from Santa! He'll be arriving with gifts for every child, plus cake to round off the day.

This is more than just a party - it's a celebration of our community. A place where children can feel confident and included, and families can relax knowing they're surrounded by people who truly understand.

**Tickets are on sale now at - https://edsociety.co.uk/events/ - and a registration form is included in this mailing.**

The ED Society will not refuse any family who are unable to join the party on financial grounds. If you would like to attend but are having difficulty, please email: danielle@edsociety.co.uk

## Support for Families and Loved Ones

We recently received a heartfelt message from one of our members who attended the ED Society Christmas Party in December last year. Meeting our Ambassador, Hannah Harpin, inspired them to reflect on the emotional and mental health support available not just for those directly affected by ED, but also for the wider family - the grandparents, aunts, uncles, siblings, and others who care so deeply.

**They shared:**
*"I had the honour of attending the ED Society Christmas Party on Saturday 7th December 2024. I met a particular heroine of mine, ED Society Ambassador Hannah Harpin, and she is such an amazing person that it got me thinking..... How many people within the group get all the emotional and mental health support they really need, and does this support only need to apply to the person /child affected?*

*As a grandparent of a child affected by ED, I started to wonder if there is an opportunity for us all to support each other. Help our daughters, sons, nieces, nephews, and grandchildren with a sharing network, geared to us - the onlookers. How often have we had to not share a holiday or special day because our loved ones have to share themselves between their child and their illness?*

*I would love to say to my granddaughter "come on kiddo it's just us" but there are so many deciding factors that need to be addressed before that day that it negates the 'us' time.*

*I also feel that sometimes I don't always understand when my granddaughter is having a particularly bad day and feel that I don't want to burden her mum and dad with what I feel can be inane questions. I wonder if parents feel that they can't always ask for help because they feel like a failure. My thoughts are for perhaps a Facebook group, for us onlookers, where we can share ideas that may help our loved ones without feeling overbearing to them."*

We think this is such a thoughtful idea and could provide real value to many families in our ED community.

Would this kind of support network be of interest to you or your family members? If so, we'd love to hear from you. Please get in touch with us at danielle@edsociety.co.uk and we can explore how best to set this up.

## ED Christmas Card Competition


We're calling on all the budding artists in our ED community to get festive and creative!

For just £2.50 per entry, children are invited to design the official ED Society Christmas cards. Two winners will be chosen:

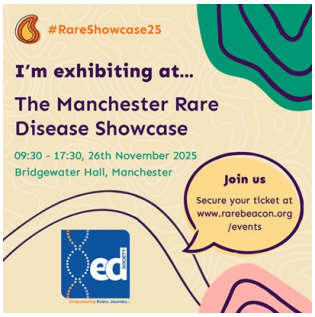
* **Ages 3–8**
* **Ages 9–15**

The winning designs will be printed as our Christmas cards and sold in the ED online shop, helping to raise vital funds to continue our work.

To take part, simply email a scan or clear photo of your child's artwork, along with their name and age, to danielle@edsociety.co.uk.

**Help us spread the word - and best of luck to all our festive little creators!**

## Beacon Rare Disease Showcase




In November, Diana and Danielle will be representing the ED Society at the Beacon Rare Disease Showcase in Manchester.

These events are vital for small charities like ours - they bring together patients, families, researchers, healthcare professionals, and industry experts for a full day of collaboration, and innovation. By being present, we can ensure that Ectodermal Dysplasia has a voice and a platform among the wider rare disease community.

For us, it's about more than simply attending. These showcases allow us to share lived experiences, raise awareness of ED, and build valuable connections that can lead to new research, advocacy opportunities, and greater recognition of ED on a national scale. We're proud to be part of this important conversation and will share updates with you after the event.

## #TeamED Marathon News 2026

The ED Society has been lucky enough to secure three charity places for the 2026 Brighton Marathon - and we're so pleased to say that all three were snapped up within just one week!

In addition, we also have a runner in the 2026 London Marathon, thanks to a place gained through the charity ballot.

Opportunities like these don't come easily for small charities like ours, so we're especially excited to cheer on our runners as they take on these incredible challenges in support of Ectodermal Dysplasia and the community.

We'll be sharing more about our runners and their fundraising pages soon - giving you the chance to follow their journeys and show your support with a donation. Every step they take will help us continue our mission.

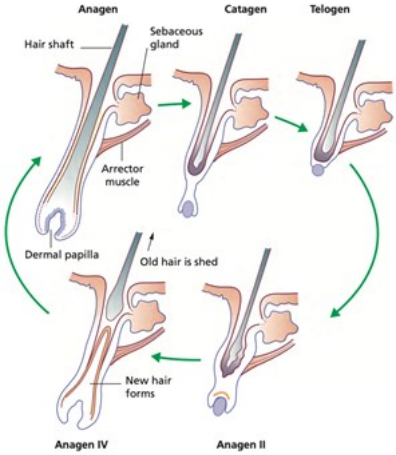
# Did You Know?

Ectodermal Dysplasia can sometimes cause a lack of fingerprints, known as adermatoglyphia. This happens when the tiny ridges and furrows in the skin don't form, leaving fingerprints absent. It can affect not only the fingertips, but also other areas of the body.

Do you find holding a pen difficult, or swiping on your phone frustrating? You're not alone - many people with ED face the same challenges.

# Hair in Ectodermal Dysplasia

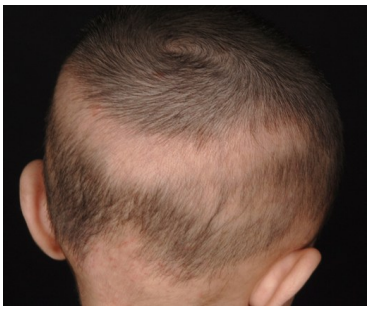
*Presented by Andrew Messenger, University of Sheffield, at ICED25*




Hair is produced by structures in the skin called hair follicles. In humans, hair follicles form and hair starts to grow during fetal life and it is generally thought that we have a full complement of hair follicles at birth. The process of embryonic development of hair follicles involves a cascade of chemical signals passing between cells of the fetal epidermis – the outer ectodermal layer of the skin – and the underlying cells in the dermis – the connective tissue layer which is largely mesodermal in origin.

Ectodermal dysplasias involving hair growth are due to alterations (variants or mutation) in genes that control these signals, resulting in poor or absent hair follicle development. In most cases these gene variants result in a reduction or absence of the signal it codes for but there are a small number of genetic hair disorders where a variant in the gene causing the disorder actually increases its function. Hair growth is not a continuous process.

Each hair follicle undergoes repeated episodes where it is actively making a hair - known as anagen – followed by a period of rest when hair growth has stopped – known as telogen. This is known as the hair cycle, and it occurs repeatedly in all hair follicles throughout life. The length to which a hair will grow is largely determined by the duration of anagen. On the scalp anagen may last for several years, though it gets shorter as we get older, whereas on the eyebrows anagen lasts only a few weeks. On the scalp, telogen lasts around three months, the old hair is then shed and the follicle goes back into anagen and starts the process once again. The process that occurs as the hair follicle moves from telogen into anagen during the hair cycle is very similar to embryonic hair follicle development in the fetus and involves similar chemical signals, hence gene variants that impair hair follicle development can also have ongoing effects on hair growth throughout life.



**In infants, coordinated hair cycling can create a halo-like pattern and cause a patch of hair loss on the back of the scalp, often mistaken for pillow rubbing.**

**In many mammals, hair cycles are seasonally coordinated, causing moulting. In humans, this coordination is briefly seen in infants but soon disappears, and each hair follicle cycles on its own.**

Most disorders termed ectodermal dysplasia show reduced hair growth on the scalp (hypotrichosis), typically referred to as ‘sparse hair’. This may vary from mild thinning to almost complete absence of hair growth. Hair density appears low and hairs do not grow very long, due to a short anagen phase. Hair growth in other sites may also be sparse including eyebrows, eyelashes and body hair. The texture of the hair is variable. In HED forms hair fibers are variously described as fine in calibre, soft and silky, wiry and light in colour. The hair in AEC and EEC syndromes may be more brittle and wiry and with some patchy loss of hair, and fine and brittle in Clouston syndrome. Hair loss in incontinentia pigmenti (IP) follows the linear streaky pattern where skin was inflamed in the neonatal period and may represent loss of hair follicles in these sites. It typically affects the crown region in adults. The hair in IP may also be coarse and wiry.

The clinical diagnosis of ectodermal dysplasia in those presenting with hypotrichosis rests on signs of abnormalities in other ectoderm-derived tissues (teeth, nails). With the possible exception of IP, the hair abnormalities in ectodermal dysplasias are not specific and there are other genetic hair and acquired hair disorders that present with sparse hair. A complication is that ‘minor’ forms of ectodermal dysplasias may not show a full range of features. For example, a recent study has found that ‘short anagen syndrome’, an uncommon condition where scalp hair cannot grow long, but without other features of ectodermal dysplasia, may be associated with variant regions in the ***WNT10A gene. Variants in WNT10A can cause severe forms of ectodermal dysplasia and, intriguingly, some variants are associated with male balding***.

There are no treatments that will correct the underlying cause of impaired hair growth in ectodermal dysplasias. Treatment with minoxidil may help to improve hair growth to some extent although the response is variable and treatment must be continued indefinitely to maintain it. Minoxidil was originally marketed as a tablet for the treatment of high blood pressure and increased hair growth in those taking it was an unexpected side effect. For treating hair loss, minoxidil is available over-the-counter for adults as a topical lotion or foam (it is not licensed for use in children under 18 though is sometimes prescribed in children). Increasingly, minoxidil is being used as an oral tablet for treating hair loss but this does need to be prescribed and usually initiated by a dermatologist.

Hair transplantation, where hair follicles are moved surgically from one site on the scalp to another, can be helpful in cases where hair loss is localised and there is normal hair growth elsewhere on the scalp, such as may occur in IP. However, hair transplantation is not suitable for the majority of people with ectodermal dysplasias where hair growth is generally sparse. The appearance of hair may be improved by simple measures that improve hair texture and reduce hair breakage.

Hair care should be gentle, with the regular use of a conditioner and the avoidance of physical or chemical treatments that damage hair structure such as vigorous brushing, permanent dyes and waves. The use of too much heat, particularly if the hair is wet, can also cause hair breakage as can hair styles that cause trauma to the hair. Some people find aids such as wigs or weaves helpful. A good hairdresser or trichologist should be able to advise on these aspects if needed.

Hair can be an emotive feature of our self-identity, and some people struggle to cope with the psychosocial aspects of a lack of hair. Support can come from a number of sources – family, GP, school nurse, psychological services and peer groups. Alopecia UK (**https://www.alopecia.org.uk**) is a charity devoted to helping those with hair loss from any cause, and can be an invaluable source of information and help on coping with the physical and emotional consequences.

# Ground-breaking Clinical Trial in Cardiff


*Cardiff's University Hospital of Wales, the sole UK site for the EDELIFE clinical trial, recently shared an update on its website. We are pleased to reproduce much of that update here, with our thanks and acknowledgement:*

"Cardiff and Vale University Health Board is proud to be the only UK site taking part in Edelife — an international clinical trial that could transform treatment options for X-Linked Hypohidrotic Ectodermal Dysplasia (XLHED).

XLHED is a rare genetic condition which causes missing or abnormal teeth, sparse or thin hair, and a lack of sweat glands. For young children, being unable to sweat can be life-threatening as the body cannot regulate heat. Currently, there are no curative treatments.

The Edelife study is researching a pioneering approach: treating affected baby boys before birth. The missing protein is administered during pregnancy at key stages of development, with the hope of preventing or reducing the effects of the condition. This trial will follow the baby boy 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.

Professor Angus Clarke, Clinical Geneticist and Principal Investigator in Cardiff, has worked with ED families for many years. He explained: *"XLHED is rare, but its impact on daily life can be huge. Learning more about potential treatments that could improve the quality of life for patients is exciting."*

One Cardiff mother taking part in the trial, who grew up with brothers affected by XLHED, shared her motivation: *"I want my son to have equal opportunities and not be limited. Research is so important because it can change lives - sometimes in ways we can't even imagine."*

The study brings together a dedicated team of specialists in fetal medicine, genetics, paediatrics and midwifery, and reflects Wales's ambition to be a leader in genomic research.

To date: 13 patients have been recruited and 11 babies have been born with positive outcomes, such that they can sweat and increased teeth is promising. Edelife are continuing to recruit as they would like around 20 in total. If successful, this trial could change the future for children born with XLHED, offering families new hope where currently there are few options."

**For more information, please visit: https://cavuhb.nhs.wales/news/latest-news/cardiff-and-vale-uhb-lead-uk-arm-of-global-trial-for-treatment-of-rare-genetic-condition-in-the-womb/**

**https://edelifeclinicaltrial.com/about-edelife/**

# Update from the ED Society Ambassador, Hannah Harpin

This year has been amazing regarding my life and career - I passed my GCSEs and I'm able to start my nursing course soon.

I have met three people with ED this year, including a friend from America. I have travelled around the world for various jobs and had an amazing opportunity to go on holiday to Florida with a friend. I have also had a new set of dentures made at the Leeds Dental Hospital where I underwent a year long treatment, which included a tooth being taken out. It appears I have a mystery extra tooth.

I'm also hoping to be able to get some special contact lenses which will help me see clearly for the first time .

I will be attending this years ED Christmas party. I am looking forward to catching up with everyone in our community, and hope to make some more new ED friends.

# Celebrating our Supporters


What a year it has been! Between October 2024 and September 2025, our community has come together in so many creative and generous ways, raising an incredible £29,504.37 across 33 different fundraisers. Each effort - whether big or small - has helped us continue our mission to support families living with Ectodermal Dysplasia.

This year's fundraising has shown just how much can be achieved when people pull together. On Facebook, multiple birthday fundraisers showed that thoughtful acts can add up to something powerful.

Sporting challenges were another highlight. Rebecca Nelson and Paddy O'Reilly completed the Brighton Marathon, Not to be outdone, Ross Murray and friends cycled from London to Brighton. Susan Currie and her family took part in the KiltWalk, and Raman Nevile with colleagues at Comex 2000 conquered the Three Peaks Challenge.

Team spirit shone brightly too. Rhondos Football Academy match-funded sponsorship for their Barcelona Tournament. Across the water in Belgium, Rhian Reffell and the British Community serving NATO joined in with our #SweatItOut campaign and hosted various ED Awareness Month events.

Sarah Jones also supported #SweatItOut during ED Awareness Month, and Liz Jones gave in a different way - by donating in lieu of Christmas cards, a thoughtful and lasting gift.

At Trelleborg Sealing Solutions, staff chose the ED Society as one of their quarterly charity beneficiaries - a wonderful example of how workplace giving can make a real difference.

**From marathon miles to mountain climbs, birthday pledges to community events, your support this year has made an extraordinary difference. Every pound raised helps us provide expert advice, raise awareness, and work with schools, health services, and local authorities to ensure families living with ED get the care they deserve.**

**Thank you for every single step, pedal, climb, and donation.**

**Together, you've made 2024–25 a year to remember.**

# No Sweat for the ED Society

*Susan Currie*

This year, I took on the Edinburgh Kiltwalk to raise funds and awareness for The ED Society - a cause that's very close to my heart, as I have ED myself. Being born with missing digits and having bladder issues, amongst other symptoms have meant that dealing with ED became a daily part of my life.

Together with my mum, brother, and fiancé, we (attempted to) train to prepare for the big day, building up to the full 21 miles on 14 September 2025.

On the day of the Kiltwalk, the atmosphere was amazing - so full of energy, encouragement, and kindness. There were people supporting along the way and some great entertainment. There were definitely moments when the miles felt long (especially when the Scottish weather hit for the last mile), but completing the challenge alongside my family made every step worthwhile.

Crossing the finish line was an incredible feeling - a mix of exhaustion, pride, and happiness knowing we'd achieved something special together. In total, we raised £1,214 for The ED Society, and I couldn't be more grateful for everyone's support. Taking part in the Kiltwalk shows how much we can achieve when we come together and shows that amazing things can still be achieved with ED.

Safe to say the blisters and muscle pain were worth it, so much so that there has been chat about the 23-mile one next year!

# Believe in Yourself—My Story by Jordan White

My name is Jordan. I am 26 years old, live in Bournemouth and I have Anhidrotic Ectodermal Dysplasia (AED.) I love all sport, particularly football so much that I am now an FA qualified football referee.

This is my story against the odds. A story that, I hope, will encourage all enthusiastic young footballers and parents reading this, wondering what the future may hold, and that with support and determination, you can succeed.

Growing up with AED, I always knew it was not going to be easy. I would have to overcome many obstacles to lead as normal life as possible with trying to control my body temperature. Adding to this, I also had an passion for all sports, in particular football, kicking a football whenever I could became the norm for me. As soon as I could, I joined a local youth football team.

My parents were always told that I would not be able to play any type of sport and would have to stay indoors in a cool room, but they refused to accept this and were determined that with the necessary precautions, I would live a near normal life as possible, as well as having a very determined and sports minded son who they could not keep still.

Every Sunday, I would be found playing for my local football team as well as the school football team in the week, and playing in every position. During those years my parents would be pitch side with bottles of water to cool me down, and drinks when I knew I needed it, which was usually as I was running past them up the field. In the colder weather they made sure I had base layers on along with hats, gloves and handwarmers.

They taught me early on when to recognise the dangers signs, I would wet my feet first followed by my shirt and then my head. My coaches all knew as well and supported me in cooling down or warming up. If I got tired and could not run any more, I was subbed and would sit under an umbrella, or in the shade which did happen a bit at the summer tournaments. Not once did I refuse to play due to my ED, nor did my coaches refuse to play me because of it. My parents made sure of that.

When I reached my teenage years, I decided that I wanted to turn my passion of football into a career. Like all school boys dreams to become a professional footballer, mine was to become a professional football referee, to get to the top and referee at Wembley for my beloved team SPURS, who I follow all around the country. An impossible dream I know, and one that my teachers at school thought I was mad about, when all they encouraged us to do was sit exams and to get a proper job.

At age 15 I took and passed the football refereeing course within the Dorset FA, and becoming a level 7 referee. So, I began the dream. The first step of a long road ahead, I refereed all types of youth football, football academies and ladies football in Dorset, and progressing into Hampshire once I gained enough experience.

On leaving college I dedicated all my time to my refereeing. I was determined to prove to those who doubted that I would never make a career out of being a referee due to my ED, and that only the best make it to the top. I continued to referee all over Dorset and Hampshire, by now my achievements included the Dorset and Hampshire Premier leagues, local football and community teams AFC Bournemouth and Southampton Football Academies, County Police Football Teams and University teams. By now I was getting full up with appointments.

3 years after qualifying, I was promoted straight to level 5, missing out level 6, becoming the first referee in Dorset to have a straight double promotion in one go. By this time I started refereeing various cup finals, the Dorset/ Hampshire Cup Finals as well as School Cup Finals, and of course my old school football teams.

My biggest achievement then came when I was asked to referee in the World Youth International Tournament in Portugal, only one of three referees appointed by Hampshire FA to do so, and in the middle of June in hotter weather. But I did it, with lots of water, a fan, and a fair few ice creams to help keep me cool.

I was on a wave and heading for promotion to level 4, the first step on the pyramid to being managed by the FA themselves, and heading for the National Leagues—only 5 years into my career. 2020 was the year I set out to achieve this, and along came the Covid pandemic, when all sports came to a standstill, so did my promotion hopes.

2021 - when football was beginning to resume came the news from the FA. It was decided for the first time there would be a mid-season promotion for some referees who had achieved good scores from the matches they had officiated at when the pandemic hit us. Only 5 were promoted in Hampshire by my county FA, and I was one of them.

Level 4 promotion, and I was now a semi-professional referee. This brought even bigger appointments, stadiums, crowds and much more running around. I was now referee on the Wessex League, and assistant referee on the Southern and Isham League, travelling all over the South West of England.


This now included Premier League academies and development teams, but my biggest achievement overall came refereeing in the FA Cup 4th round, and the FA Vase Cup in only my second full season at this level.

Shortly after being promoted to level 4 I was diagnosed with ADHD, but I refused to let this stop me from enjoying my passion. In fact, it helps me get my energy levels out. Yes, I get hot or cold on the pitch, more so now with the higher intensity of the games, but with the right precautions in place I can cope well. I am known as the ref who lets teams have plenty of water breaks.

2 years ago, and with my parents support, we realised that the demand for me was getting great, so with the help of a local disabled charity who specialises in helping disabled people become self employed, I started up my own football referee business - **REFJORDAN.**

With my mum as my manager, she takes all my appointments, manages my diary and social media outlets, and makes sure I have everything I need for the match, such as enough water and the correct clothes for the weather. I am now the only disabled referee in Dorset with their own refereeing business.

Along the way, I have been so lucky to have met some football legends. Recently I refereed a local fundraising match, where they had Harry Redknapp as manager, ex QPR Player Charlie Austin, Wes Browning, and some ex Man United players, it was the ultimate dream.

I'm now aiming for my Level 3 promotion, which I narrowly missed out on last season. My goal is to reach the Conference and National League, and to referee in the first round of the FA Cup—and I'm determined to get there. What started as a part-time hobby has now grown into a full-time business. Being part of the first pyramid of the FA National Leagues, I've never been in such high demand—and I never imagined I'd one day be managed directly by the FA themselves.

I will say to any sporting enthusiasts, there is nothing with ED you cannot do. When I am not refereeing, I still play football and golf. You just need to make sure you are well prepared with lots of water, wet cloths, shade and make sure you are cool in the car before your game. When I get hot, I start by putting my feet in water, then on my body and head. I make sure there are lots of water breaks throughout the match. In the colder weather, I have hats and gloves on with a couple of extra pairs of socks and warm under garments.

I am also lucky that my parents are such a huge support to me. Especially my mum, being such a positive influence in helping me fulfil my dream, and help manage my business. She also makes sure that I have all I need in controlling my temperature.

I want to end by saying, **NEVER LET ED BEAT YOU.** Follow your dreams and always believe in yourself!

**You can follow Jordan and his refereeing journey via Ref Jordan on Facebook, @Refjordan on X, and @ref_jordan on Instagram.**


## Contact Us

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