



## **FOR IMMEDIATE RELEASE**

### **Contact:**

**Diana Perry, Chief Executive and Founder**

**The ED Society**

**Email: [diana@edsociety.co.uk](mailto:diana@edsociety.co.uk)**

**Phone: +44 (0)1242 261332**

## **"ED Society Calls for Support Amid Financial Struggles to Secure Sponsorship for Key Conference"**

**Cheltenham, UK – 11th February 2025** – Smaller charities in the UK, including the ED Society, are facing immense challenges in securing vital funding due to the ongoing financial crisis. The ED Society, a non-profit organisation dedicated to supporting individuals and families living with Ectodermal Dysplasia (ED), is experiencing a notable decline in donations and fundraising revenue compared to the previous year.

"As a small charity, we have always relied on the generosity of our supporters, but this year, the funds simply aren't coming in at the levels we need to continue providing our vital services," **said Diana Perry, Chief Executive and Founder of the ED Society.** "We've seen a decline in donations, and our fundraising events are no longer yielding the results they once did. It's an extremely difficult time for everyone, and unfortunately, the people we support are feeling it the most."

The ED Society's most pressing concern is the lack of sponsorship for their upcoming 9th International Conference for Ectodermal Dysplasia (ICED25), which will take place from June 10th to 12th, 2025, at Austin Court in Birmingham, UK. This conference, an essential gathering for medical professionals, researchers, and affected families, is a key opportunity for sharing knowledge, discussing medical advancements, and strengthening support networks for the global ED community.

"Sponsorship for ICED25 is vital for the success of this conference and for the ongoing work of the ED Society. Without the necessary financial backing, we risk not being able to host this event, which would be a huge blow to the entire community," **Perry added.** "ICED25 represents a unique opportunity for

people affected by ED to connect, share their experiences, and access crucial information and resources, so it is imperative we continue to offer this platform."

The ED Society is reaching out to the public, businesses, and potential sponsors to provide the support needed to ensure the success of ICED25. Every contribution, no matter how small, can make a significant impact on the lives of those living with ED.



The poster for the 9th International Conference for Ectodermal Dysplasia (ICED25) features a dark blue background. At the top left is the 'iced 2025' logo. To its right is a QR code. Below the logo, the text reads 'Join us at the 9th International Conference for Ectodermal Dysplasia'. A bulleted list of topics includes: Genetics, Taxonomy and 'Other Types' of ED; Children's Dentistry and Implants; Thermoregulation throughout the lifespan; Dermatology; Psychology and Social Science; Clinical Services / MDTs; and Trials, Treatments and Databases. At the bottom left are three photographs: two of young children and one of two men. On the right side, a vertical banner states '10th - 12th June 2025 Austin Court, Birmingham, UK' next to three circular images showing a conference room, a canal scene, and a building.

"We are facing an uphill battle, but we are confident that our community will rise to the challenge. By supporting the ED Society or sponsoring ICED25, you are making a difference in the lives of those affected by this rare and often misunderstood condition. We ask that you consider supporting our mission during these trying times – together, we can continue to empower the journeys of those living with Ectodermal Dysplasia," **said Diana.**

**For more information on how to support the ED Society or sponsor the ICED25 conference, please visit [www.edsociety.co.uk](http://www.edsociety.co.uk) or contact us directly.**

### **About the ED Society**

Founded in 1996 by Diana Perry, the ED Society is a UK-based charity that provides support and resources for individuals and families affected by Ectodermal Dysplasia (ED). The ED Society offers educational materials, a support network, and a variety of services to help improve the lives of those living with this rare genetic condition.