



# Trustees' Annual Report and Accounts for the period ending

31<sup>st</sup> December 2025

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## **Ectodermal Dysplasia Society**

### **Trustees' Annual Report for the period 1<sup>st</sup> January – 31<sup>st</sup> December 2025**

Charity number 1089135

Unit 1, Maida Vale Business Centre, Maida Vale Road, Leckhampton, Cheltenham, GL53 7ER

#### **Trustees**

Stuart Atkiss  
Nick Briggs  
Paul Collacott - Chairman  
Sharon Cooper  
Scott Gallacher  
Larissa Pelham  
Diana Perry - Chief Executive and Secretary  
Andy Ponting  
Alan Waller - Treasurer  
Elaine Aylward (Irish Representative)  
Helen Wickens  
Alison Smith  
Sarah James

#### **Administration**

Elly Lomas - Finance  
Danielle Gue - Marketing & Fundraising  
Kelly Phelan - Administration & Family Liaison

#### **Bankers**

NatWest, 31 The Promenade, Cheltenham, Glos. GL50 1LE  
Scottish Widows Bank, 67, Morrison Street, Edinburgh EH3 8YJ

#### **Constitution**

The Ectodermal Dysplasia Society was formed by a Constitution dated 14<sup>th</sup> July 2001. The Ectodermal Dysplasia Society currently has about 938 contacts. Trustees are appointed at the Annual General Meeting and hold office for a term of up to 3 years. Trustees are able to be re-appointed after their period has ended.

#### **Objectives**

The Ectodermal Dysplasia Society is a charity dedicated to improving the health and wellbeing of people whose lives are affected by the Ectodermal Dysplasias. We work together with people who have Ectodermal Dysplasia, their families, researchers, health and other professionals to develop and share expertise, increase awareness and understanding, and assist with the day-to-day management of Ectodermal Dysplasia.

Although the Ectodermal Dysplasia Society is based in the UK, we support individuals, families and professionals worldwide.

Full details of the Ectodermal Dysplasia Society and current activities can be found on the website at [www.edsociety.co.uk](http://www.edsociety.co.uk).

### **Mission (Why we exist)**

The Ectodermal Dysplasia Society's mission is to increase understanding and awareness of the Ectodermal Dysplasias and to ensure that everyone affected receives the information, support and care they need to live life to the fullest.

We provide trusted guidance, practical advice and compassionate support to individuals and families, as well as to the professionals and organisations who work with them.

The Ectodermal Dysplasia Society aim to:

- Be the leading, trusted point of contact for accurate and accessible information on the Ectodermal Dysplasias.
- Offer personalised support and guidance to individuals and families affected by the condition.
- Equip schools, health professionals and social care teams with the knowledge they need to understand Ectodermal Dysplasia and respond effectively.
- Increase awareness of Ectodermal Dysplasia across the medical and wider professional communities.
- Promote early recognition and diagnosis, particularly in babies and children at risk of serious symptoms such as overheating, breathing difficulties, or feeding problems.

### **Vision (What we want to be)**

The work of the ED Society is guided by six strategic objectives. Together, they shape how we support individuals and families affected by Ectodermal Dysplasia, and how we work with professionals to improve understanding, care and outcomes.

#### **1. Communication**

We provide clear, accessible and reliable information about the Ectodermal Dysplasias. Our resources are written in plain language and include practical guidance to help individuals and families understand the condition and manage its effects in everyday life.

#### **2. Database**

We hold a solid and trusted database that brings together individuals, and families affected by Ectodermal Dysplasia, alongside medical professionals with experience or a specialist interest in the condition. This enables better connection, collaboration and support across our community.

#### **3. Liaison & Support**

We work closely with individuals, families, healthcare professionals and our Medical Advisory Board to offer personalised support, guidance and signposting. Our aim is to ensure that no one affected by Ectodermal Dysplasia feels isolated or unsupported.

#### **4. Contact Network**

We actively foster connections between individuals and families affected by Ectodermal Dysplasia, helping to build a supportive network where people can share experiences, practical advice and emotional support.

## **5. Raising Awareness**

We promote greater awareness and understanding of Ectodermal Dysplasia among healthcare professionals and the wider public, helping to improve recognition, diagnosis and access to appropriate care.

## **6. Fundraising**

We raise funds to sustain and grow the work of the ED Society, enabling us to provide vital services, specialist equipment and financial grants to individuals and families affected by Ectodermal Dysplasia.

## **Achievements in 2025**

### **Supporting Families & Individuals**

- Assisted parents and schools in developing School Care Plans tailored to the management of Ectodermal Dysplasia and attended school meetings.
- Helped families with Disability Living Allowance (DLA) and Personal Independent Payment (PIP) applications, writing appeal letters, preparing them for tribunals, and attending these when needed.
- Assisted families in obtaining a Blue Badge
- Secured rehousing for members seeking help.
- Supported and encouraged individuals to fundraise, strengthening our community's financial sustainability.
- Held the annual children's Christmas party.
- Commenced work to produce a children's bullying book.

### **Research & Medical Collaboration**

- Continued working closely with global Ectodermal Dysplasia support leaders, attending regular virtual international meetings.
- Supported EspeRare in advancing the ER004 treatment therapy for Ectodermal Dysplasia.
- Obtained PGT licences for additional ED syndromes.
- Continued research into temperature regulation and its impact on Ectodermal Dysplasia.
- Assisted families in finding specialist dentists through our Dental Network, set up by our Medical Advisory Board.
- Commenced a Women's survey in collaboration with the NFED.
- Attended conferences to gain and share knowledge, including:
  - British Association of Dermatology (virtual meetings)
  - European Reference Networks (ERN) & ePAG (virtual meetings)
  - EDIN (virtual meetings)

### **Education, Awareness & Publications**

- Hosted the successful Ectodermal Dysplasia International Network (EDIN25) conference in Birmingham in June 2025.

- Delivered presentations to medical organisations to improve awareness and understanding of Ectodermal Dysplasia.
- Continued work towards improving resources for the Incontinentia Pigmenti (IP) community.

### Organisational Growth & Future Planning

- Successfully received grants, including funding from Jeans for Genes and the British association of Dermatology.
- Applied for and received various additional grants/donations to support our work.
- Worked closely with Trustees on our long-term strategy to ensure sustainability and growth.

These achievements reflect our ongoing commitment to supporting families, advancing research, raising awareness, and strengthening our organisation to make a lasting impact.

### Policy on reserves

- Reserves are maintained at a level which ensures the Ectodermal Dysplasia Society's core activity can continue during a period of unforeseen difficulty.
- A proportion of reserves are to be maintained in a readily realisable form.
- The calculation of the required level of reserves is an integral part of the Ectodermal Dysplasia Society's planning, budget and forecast cycle and takes into account:
  - Risks associated with each stream of income and expenditure being different from that budgeted
  - Planned support and research fund
  - The Ectodermal Dysplasia Society's commitments.

The reserves that we have set aside provide financial stability and the means for the development of our principal activity. We intend to maintain our reserves at a level which is at least equivalent to approximately 75% of our annual expenditure. We intend to use the reserves in the following manner:

- a Support fund for the benefit of our members
- b Annual Event fund
- c Liabilities in the event of closure, redundancy, rent and utility bills. The Trustees annually review the amount of reserves that are required to ensure they are adequate to fulfil our continuing obligations.

No funds were in deficit during the period.

### Income and expenditure

The main source of income is through donations and fundraising. Total receipts in 2025 were £107,407.36 (2024: £77,208.19). We are extremely grateful to our members and others associated with the Ectodermal Dysplasia Society for the generosity of their giving. We are also very grateful to our donors who include:

- Jeans for Genes
- British Association of Dermatologists

- VTCT
- Cheisi Farmaceutici
- An international ED member

The main expenditures are wages and rent, which enable the infrastructure of support provided by the Ectodermal Dysplasia Society. Total outgoing resources in the year were £115,098.18 (2024: £72,613.57). Direct support to individual members is also given and, while allowing the provision of essential equipment such as air-conditioning units, humidifiers, wigs, travel expenses for attending schools and tribunals, etc., represents a lesser proportion of the Ectodermal Dysplasia Society's outgoings than is applied to verbal advice and moral support.

## **Planned Funding Allocations for 2026**

### **Research & Medical Advancements**

- Continue the Temperature Regulation Research Programme to improve understanding and treatment options for Ectodermal Dysplasia.
- Continue working on the Women's survey with a view to publication on completion.

### **Direct Support for Families & Individuals**

- Provide financial assistance through the Support Fund, helping families with essential ED related needs.
- Support DLA/PIP applications, appeals, and tribunal representation, as well as Blue Badge applications and appeals.
- Assist families with school meetings, ensuring that School Care Plans are properly implemented.

### **Awareness, Education & Advocacy**

- Host an annual event to bring together families, professionals, and researchers.
- Organise and participate in conferences and presentations to spread awareness and educate key stakeholders.
- Continue providing guidance and resources to individuals, families, and medical professionals.

### **Digital & Organisational Growth**

- Continue to assist with the international EDIN website.
- Attend training courses to enhance expertise in social media, fundraising, finance and benefits assistance.
- Increase marketing and fundraising activities to strengthen financial sustainability.

### **International Ectodermal Dysplasia Conference 2028 (ICED28)**

- Assist the Italian ED organisation as they begin to plan for the ICED28 conference.
- Attend the International ED leaders meeting in Denmark in September 2026

These funding priorities align with our mission to support, educate, and advocate for those affected by Ectodermal Dysplasia while ensuring the sustainability of our organisation.

The ED Society planned and delivered the 9th International Conference for Ectodermal Dysplasia (ICED25), held in Birmingham in June 2025. As a result, the accounts show activity relating to donations and sponsorship received specifically for this event. This funding was provided by both UK-based and overseas individuals and organisations and was restricted to conference delivery.

Diana Perry  
Chief Executive and Secretary  
9<sup>th</sup> May 2026

## **Ectodermal Dysplasia Society**

### **Financial Statements**

#### **Accounting policies**

- 1 The basis of preparation is receipts and payments, with the exception of gift aid, which is recognised as due at the time of the related donation.
- 2 Fixed tangible assets with an initial value greater than £1,000 are capitalised.
- 3 The General Fund represents funds not subject to any restrictions regarding their use and are available for the general purposes of the charity. The Support Fund represents funds which must be used in accordance with specific restrictions imposed by donors or which have been reserved for particular purposes.



**ECTODERMAL DYSPLASIA SOCIETY**  
**INCOME AND EXPENDITURE ACCOUNT**  
**For the year ended 31 December**

		<b>2025</b>			<b>2024</b>	
		£	£	£	£	£
INCOME	Notes	Restricted funds	Unrestricted funds	Total		
Interest		8.72	748.54		1,003.85	
Donations	3		10,900.07		15,139.46	
Gift Aid			9,249.18		5,875.41	
Members fees			1,407.81		493.02	
Fundraising			12,017.33		33,224.27	
Christmas Party & Raffle			2,923.67		2,167.48	
Merchandise sales	1		133.24		256.94	
Grants		11,000.00	7,062.00		13,750.00	
ICED income		50,548.44	-		5,013.84	
Other income	4		1,408.36		283.92	
<b>Total incoming resources</b>		<b>61,557.16</b>	<b>45,850.20</b>	<b>107,407.36</b>		77,208.19
<b>EXPENDITURE</b>						
Wages		3,693.39	41,412.52		48,206.89	
Postage and Stationery			1,125.68		941.79	
Telephone			346.81		173.25	
Computer related costs			1,391.08		2,023.68	
Committee members' expenses			1,755.01		2,276.37	
Insurance			594.87		566.64	
Christmas Party & Raffle			2,967.11		4,651.98	
Subscriptions			230.15		-	
Support for members	2	860.74	-		334.98	
Rent			7,920.00		7,920.00	
Fund Raising and Marketing Expenses	1		5,232.40		4,757.18	
Other expenditure		47,095.00	473.42		760.81	
<b>Total resources expended</b>		<b>51,649.13</b>	<b>63,449.05</b>	<b>115,098.18</b>		72,613.57
Net outgoing / incoming resources before losses on revaluation of overseas funds				<b>-7,690.82</b>		4,594.62
Loss/gain on revaluation of overseas funds	3			220.19		-167.90
Net incoming resources / expenditure				<b>-7,470.63</b>		4,426.72
Total funds brought forward				<b>88,316.99</b>		<b>83,890.27</b>
Total funds carried forward				<b>80,846.36</b>		<b>88,316.99</b>

**ECTODERMAL DYSPLASIA SOCIETY**  
**STATEMENT OF ASSETS AND LIABILITIES**  
**As at 31 December**

	<b>2025</b>		<b>2024</b>	
	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
<b>FIXED ASSETS</b>				
Tangible assets	-		-	
<b>CURRENT ASSETS</b>				
Gift Aid due	7,995.22		3,159.00	
ICED	1,520.00		5,724.02	
NatWest	9,791.59		18,867.35	
Scottish Widows Account	57,079.68		56,331.14	
Irish Funds (see note 3)	4,424.60		4,204.41	
Cash in hand	35.27		31.07	
		80,806.36		88,316.99
<b>CURRENT LIABILITIES</b>				
Creditors	-		-	
Accrued expenses	-		-	
		-		-
		<b>80,846.36</b>		<b>88,316.99</b>
<b>REPRESENTED BY</b>				
General Fund		64,110.70		66,489.36
Restricted funds:				
Support Fund		15,215.66		16,067.68
ICED sponsorship		1,520.00		5,759.95
		<b>80,846.36</b>		<b>88,316.99</b>

These accounts were approved by the Trustees at the Annual General Meeting held on 9<sup>th</sup> May 2026

Trustee

Trustee

## ECTODERMAL DYSPLASIA SOCIETY

### Notes to the accounts

- 1 Merchandise sales represent funds raised through the sale of goods promoting the Society.
- 2 Grants received included:
  - a) Jeans for Genes - £5,000
  - b) British Association of Dermatologists - £2,062
  - c) VTCT - £10,000 (for ICED)
  - d) Cheisi Farmaceutici - £1,000 (for ICED)
- 3 Amounts paid from the Support Fund comprised £860.74 (2024: £334.98) in direct support of Members.
- 4 The Irish Funds comprise funds held in the Republic of Ireland for the benefit of Members there, but are formally part of the Society's funds. Net expenditure for the Irish Funds in the current year amounted to £nil (2024: net expenditure of £nil) and the closing balance was £4,424.60 (2024 £4,204.41). Amounts in Euros have been translated at the year-end rate of 1.1460 (2024: 1.2060) Euros to the Pound. The gain on revaluation of funds of £220.19 (2024: loss of £167.89) represents the change in value of the Irish funds resulting in the movement in the Euro exchange rate between the end of 2024 and 2025.
- 5 Other income in 2025 included refunds on purchases made of £364.19.
- 6 There were no outstanding debts or guarantees made by the Ectodermal Dysplasia Society as at 31<sup>st</sup> December 2025 (2024: nil).
- 7 Movements in reserves

	Restricted Funds 2025	General Fund 2025	Total 2025	Restricted Funds 2024	General Fund 2024	Total 2024
Opening Balance	21,827.63	66,489.36	88,316.99	20,673.09	63,217.18	83,890.27
Incoming resources	61,557.16	45,850.20	107,407.36	5,018.42	72,189.77	77,208.19
Resources expended	-51,649.13	-63,449.05	-115,098.18	-3,863.88	-68,749.69	-72,613.57
Transfer of funds	-15,000.00	15,000.00	-	-	-	-
Revaluation	-	220.19	220.19	-	-167.90	-167.90
Balance Carried Forward	16,735.66	64,110.70	80,846.36	21,827.63	66,489.36	88,316.99

## EXAMINER'S UNQUALIFIED REPORT (FOR A NON-COMPANY CHARITY)

**Independent examiner's report to the trustees of the Ectodermal Dysplasia Society Reg. No. 1089135**

I report on the accounts of the Trust for the year ended 31<sup>st</sup> December 2025, which are set out on the attached pages.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act;
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

### Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

### Independent examiner's statement

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 130 of the 2011 Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Name: William Perry

Relevant professional qualification or body: ACIMA

Address: 7 Larch Rise, Cheltenham, Gloucestershire, GL53 0PY

Date:

26/3/26