



Trustees' Annual Report and Accounts for the period ending

31st December 2024

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Ectodermal Dysplasia Society

Trustees' Annual Report for the period 1st January – 31st December 2024

Charity number 1089135

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

Trustees

Stuart Atkiss
Stephen Ayland
Nick Briggs
Paul Collacott - Chairman
Sharon Cooper
Scott Gallacher
Simon Lee-Jones
Larissa Pelham
Diana Perry - Chief Executive and Secretary
Andy Ponting
Alan Waller - Treasurer
Martin Williams
Elaine Aylward (Irish Representative)
Chantelle Epton

Administration

Elly Lomas – Accounts
Jaye Dix – Family Liaison
Danielle Gue – Social Media/Benefits/Website/Marketing & Fundraising
Kelly Phelan - Administration

Bankers

HSBC Bank, 2, The Promenade, Cheltenham, Gloucestershire, GL50 1LR
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 14th July 2001. The Ectodermal Dysplasia Society currently has about 879 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.

Mission (Why we exist)

The Ectodermal Dysplasia Society aims to promote awareness and understanding of the Ectodermal Dysplasias by providing detailed information and practical advice to those individuals and families affected by Ectodermal Dysplasia and to the medical professionals, local authorities and those who support them in living life to the full.

The Ectodermal Dysplasia Society aim to:

- be the first port of call for all those seeking information on the Ectodermal Dysplasias
- provide immediate support to individuals and families who have received an initial diagnosis or who suspect Ectodermal Dysplasia may be the cause of the symptoms
- provide personalised support to individuals and families affected by Ectodermal Dysplasia and provide personalised guidance to authorities in the UK (e.g. schools, Social Services) seeking to understand how to manage the effects of Ectodermal Dysplasia on individuals and families in their community
- raise the awareness of Ectodermal Dysplasia within the medical profession and other community officials in the UK (e.g., health visitors, social workers) in order to promote early diagnosis of babies and children with life-threatening symptoms of Ectodermal Dysplasia (e.g. overheating, breathing difficulties, feeding difficulties).

We have an established Medical Advisory Board of professionals who have the relevant skills to assist us in these aims.

Vision (What we want to be)

Our vision is that every individual and family affected by Ectodermal Dysplasia is equipped with the knowledge needed to manage Ectodermal Dysplasia effectively and live life to the full; and that medical professionals have the information and understanding they need to support those affected.

The Ectodermal Dysplasia Society seeks to raise funds to provide support services, equipment and grants to families affected by Ectodermal Dysplasia in the UK.

Strategy: How We Will Make This Happen

The Ectodermal Dysplasia Society is committed to improving the lives of those affected by Ectodermal Dysplasia. Our work is guided by six key strategic objectives:

1. **Clear Communication** – Providing easily accessible, well-structured information on the different forms of Ectodermal Dysplasia, along with practical guidance on managing symptoms effectively.
2. **Membership & Database Management** – Building and maintaining a comprehensive membership database, including individuals and families affected by Ectodermal Dysplasia, as well as medical professionals with relevant experience and interest in treating the condition.

3. **Liaison & Personal Support** – Working closely with individuals, families, professionals, and our Medical Advisory Board to offer tailored advice, support, and advocacy.
4. **Community & Contact Network** – Strengthening connections between families affected by Ectodermal Dysplasia, encouraging a supportive environment for practical and emotional assistance.
5. **Awareness & Education** – Promoting awareness and understanding of Ectodermal Dysplasia within both the medical community and the general public, ensuring better recognition and earlier diagnosis.
6. **Sustainable Fundraising** – Generating financial support to enable the Society to continue providing services, equipment, and grants, ensuring ongoing assistance to those in need.

Through these strategic objectives, we aim to enhance the support, treatment, and quality of life for individuals with Ectodermal Dysplasia, while driving awareness and collaboration within the medical community and beyond.

Achievements in 2024

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.

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.
- 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.
- Attended conferences to gain and share knowledge, including:
 - British Association of Dermatology (virtual meetings)
 - European Reference Networks (ERN) & ePAG (virtual meetings)
 - EDIN (virtual meetings)
 - Appearance Matters (virtual meetings)
 -

Education, Awareness & Publications

- Delivered presentations to medical organisations to improve awareness and understanding of Ectodermal Dysplasia.
- Published and promoted:
 - “A Guide to Ectodermal Dysplasia”
 - Children’s book: “Everybody’s Different” (translated into multiple languages).
 - Began working on a bullying awareness book.
- Academic Recognition – Co-authored an article on Ectodermal Dysplasia and climate change, published in *The Lancet*.
- Continued work towards improving resources for the Incontinentia Pigmenti (IP) community.

Organisational Growth & Future Planning

- Successfully received grants, including funding from Jeans for Genes.
- Applied for and received various additional grants/donations to support our work.
- Created a new logo and strapline.
- Finalised the redesign of our website for better accessibility and engagement.
- Continued planning for the International Ectodermal Dysplasia Conference (Birmingham, June 2025), attending meetings with the Scientific and Organisation Committees.
- 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 2024 were £77,208.19 (2023: £62,770.54). 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
- Next plc

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 £72,613.57 (2023: £71,228.68). 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 2025

Research & Medical Advancements

- Contribute funding towards the Temperature Regulation Research Programme to improve understanding and treatment options for Ectodermal Dysplasia.

Direct Support for Families & Individuals

- Provide financial assistance through the Support Fund, helping families with essential 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

- Finalise and launch the new ED Society website and contribute to the international EDIN website.

- Attend training courses to enhance expertise in social media, fundraising, and benefits assistance.
- Increase marketing and fundraising activities to strengthen financial sustainability.

International Ectodermal Dysplasia Conference 2025 (ICED25)

- Continue planning for ICED25 (Birmingham, June 2025), attending Scientific and Organisation Committee meetings to ensure a successful event.

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.

Diana Perry
Chief Executive and Secretary
22nd March 2025

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

		2024			2023	
		£	£	£	£	£
INCOME	Notes	Restricted funds	Unrestricted funds	Total		
Interest		4.58	999.27		404.04	
Donations	3		15,139.46		18,347.50	
Gift Aid			5,875.41		3,932.51	
Members fees			493.02		865.09	
Fundraising			33,224.27		13,820.39	
Christmas Party & Raffle			2,167.48		2,667.60	
Merchandise sales	1		256.94		1,042.44	
Grants			13,750.00		9,000.00	
ICED sponsorship		5,013.84	-		7,500.00	
Other income	4		283.92		5,190.97	
Total incoming resources		5,018.42	72,189.77	77,208.19		62,770.54
EXPENDITURE						
Wages		3,528.90	44,677.99		46,007.47	
Postage and Stationery			941.79		1,553.33	
Telephone			173.25		351.09	
Computer related costs			2,023.68		3,395.28	
Committee members' expenses			2,276.37		766.14	
Insurance			566.64		519.55	
Christmas Party & Raffle			4,651.98		4,115.10	
Subscriptions			-		-	
Support for members	2	334.98	-		1,133.68	
Rent			7,920.00		7,920.00	
Fund Raising and Marketing Expenses	1		4,757.18		4,978.99	
Other expenditure			760.81		488.05	
Total resources expended		3,863.88	68,749.69	72,613.57		71,228.68
Net incoming resources before losses on revaluation of overseas funds				4,594.62		-8,458.14
Loss/gain on revaluation of overseas funds 3				-167.90		-124.07
Net incoming resources / expenditure				4,426.72		-8,582.21
Total funds brought forward				83,890.27		92,472.48
Total funds carried forward				88,316.99		83,890.27

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

	2024		2023	
	£	£	£	£
FIXED ASSETS				
Tangible assets	-		-	
CURRENT ASSETS				
Gift Aid due	3,159.00		2,200.00	
ICED	5,724.02		3,208.00	
NatWest	18,867.35		8,733.40	
Scottish Widows Account	56,331.14		65,331.87	
Irish Funds (see note 3)	4,204.41		4,372.31	
Cash in hand	31.07		44.69	
		88,316.99		83,890.27
CURRENT LIABILITIES				
Creditors	-		-	
Accrued expenses	-		-	
		-		-
		88,316.99		83,890.27
REPRESENTED BY				
General Fund		66,489.36		63,217.18
Restricted funds:				
Support Fund		16,067.68		16,398.08
ICED sponsorship		5,759.95		4,275.01
		88,316.99		83,890.27

These accounts were approved by the Trustees at the Annual General Meeting held on 22nd March 2025

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 totalled £13,500 (2023: £9,000) and included £750 from Jeans for Genes.
- 3 Amounts paid from the Support Fund comprised £334.98 (2023: £1,133.68) 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 (2023: net expenditure of £nil) and the closing balance was £4,204.41 (2023: £4,372.31). Amounts in Euros have been translated at the year-end rate of 1.2060 (2023: 1.1597) Euros to the Pound. The loss on revaluation of funds of £167.89 (2023: loss of £124.07) represents the change in value of the Irish funds resulting in the movement in the Euro exchange rate between the end of 2023 and 2024.
- 5 Other income in 2023 included a refund from HMRC of £4,895.26.
- 6 There were no outstanding debts or guarantees made by the Ectodermal Dysplasia Society as at 31st December 2024 (2023: nil).
- 7 Movements in reserves

	Restricted Funds 2024	General Fund 2024	Total 2024	Restricted Funds 2023	General Fund 2023	Total 2023
Opening Balance	20,673.09	63,217.18	83,890.27	17,274.28	75,198.20	92,472.48
Incoming resources	5,018.42	72,189.77	77,208.19	7,757.48	55,013.06	62,770.54
Resources expended	-3,863.88	-68,749.69	-72,613.57	-4358.67	-66,870.01	-72,228.68
Revaluation	-	-167.90	-167.90	-	-124.07	124.07
Balance Carried Forward	21,827.63	66,489.36	88,316.99	20,673.09	63,217.18	83,890.27

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 31st December 2024, 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:

27/8/25.