

ECTODERMAL DYSPLASIA SOCIETY

England & Wales · Charity number 1089135

Details

Other names EDS

Status Registered

Legal form Other

Registered 2001-10-31

Register [View on the Charity Commission register](#)

Contact

Address Unit 1 Maida Vale Business Centre
Leckhampton
Cheltenham
Glos
GL53 7ER

Phone 01242261332

Email diana@edsociety.co.uk

Website www.edsociety.co.uk

Activities

Objects: THE RELIEF OF SICKNESS AND THE PROTECTION AND PRESERVATION OF THE HEALTH OF PERSONS AFFECTED BY ECTODERMAL DYSPLASIA AND ANY RELATED CONDITION AND THEIR FAMILIES AND CARERS IN PARTICULAR BY BUT NOT RESTRICTED TO A) THE ADVANCEMENT OF THE EDUCATION OF THE MEDICAL PROFESSION AND THE GENERAL PUBLIC INTO ECTODERMAL DYSPLASIA AND ITS IMPLICATIONS FOR THE FAMILY. B) THE PROMOTION OF RESEARCH INTO THE CAUSES, EFFECTS, TREATMENT AND MANAGEMENT OF ECTODERMAL DYSPLASIA AND TO DISSEMINATE THE USEFUL RESULTS THEREOF.

Activities: The relief of sickness and the protection and preservation of the health of persons affected by Ectodermal Dysplasia (ED) and any related condition.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities, The General Public/mankind

Geography

- **Area of benefit:** NOT DEFINED. IN PRACTICE WORLDWIDE
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-12-31	£107,407	£115,098	-	-
2024-12-31	£77,208	£72,613	-	-
2023-12-31	£62,771	£71,229	-	-
2022-12-31	£71,573	£50,984	-	-
2021-12-31	£34,163	£43,857	-	-
2020-12-31	£42,813	£48,201	-	-

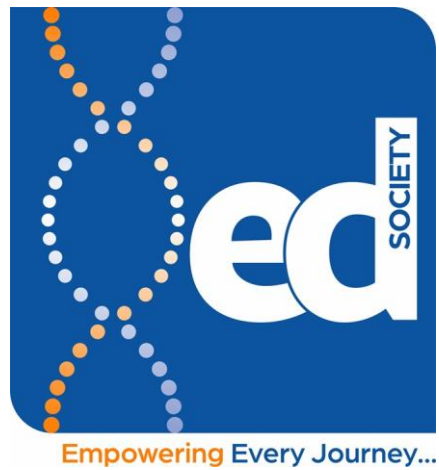
Trustees

Name	Role	Appointed
PAUL COLLACOTT	Chair	
ALAN WALLER		2013-04-24
Alison Smith		2026-01-10
Andy Ponting		2017-05-06
DIANA PERRY		
Elaine Aylward		2025-03-22
Helen Wickins		2025-07-12
Larissa Donna Pelham		2020-04-25
Nick Briggs		2020-04-25
SHARON COOPER		2012-11-26
Sarah James		2026-01-10
Scott Gallacher		2015-05-16
Stuart Atkiss		2016-05-07

ECTODERMAL DYSPLASIA SOCIETY

England & Wales - Charity number 1089135

Accounts



Trustees' Annual Report and Accounts for the period ending

31st December 2025

The Ectodermal Dysplasia Society, Unit 1 Maida Vale Business Centre, Maida Vale Road,
Cheltenham, Glos. GL53 7ER England
Tel: +44 (0) 1242 261332 Mobile: +44 (0) 7774 465712
www.edsociety.co.uk Email: info@edsociety.co.uk

Ectodermal Dysplasia Society

Trustees' Annual Report for the period 1st January – 31st 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 14th 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.

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
9th 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

		2025			2024	
		£	£	£	£	£
		Restricted funds	Unrestricted funds	Total		
INCOME	Notes					
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	
Total incoming resources		61,557.16	45,850.20	107,407.36		77,208.19
EXPENDITURE						
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	
Total resources expended		51,649.13	63,449.05	115,098.18		72,613.57
Net outgoing / incoming resources before losses on revaluation of overseas funds					-7,690.82	4,594.62
Loss/gain on revaluation of overseas funds 3					220.19	-167.90
Net incoming resources / expenditure					-7,470.63	4,426.72
Total funds brought forward					88,316.99	83,890.27
Total funds carried forward					80,846.36	88,316.99

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

	2025		2024	
	£	£	£	£
FIXED ASSETS				
Tangible assets	-		-	
CURRENT ASSETS				
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
CURRENT LIABILITIES				
Creditors	-		-	
Accrued expenses	-		-	
		-		-
		80,846.36		88,316.99
REPRESENTED BY				
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
		80,846.36		88,316.99

These accounts were approved by the Trustees at the Annual General Meeting held on 9th 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 31st 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 31st 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

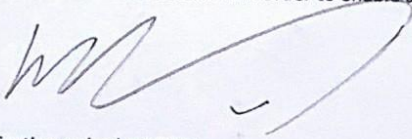
In connection with my examination, no matter has come to my attention:

(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

ECTODERMAL DYSPLASIA SOCIETY

England & Wales - Charity number 1089135

Accounts



Trustees' Annual Report and Accounts for the period ending

31st December 2024

The Ectodermal Dysplasia Society, Unit 1 Maida Vale Business Centre, Maida Vale Road,
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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
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Constitution

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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.
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 - 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

	Notes	2024			2023	
		£ Restricted funds	£ Unrestricted funds	£ Total	£	£
INCOME						
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	-		-	
		-		-
		<u>88,316.99</u>		<u>83,890.27</u>
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
		<u>88,316.99</u>		<u>83,890.27</u>

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:

27/3/25.

ECTODERMAL DYSPLASIA SOCIETY

England & Wales - Charity number 1089135

Accounts



Trustees' Annual Report and Accounts
for the period ending

31st December 2023

The Ectodermal Dysplasia Society, Unit 1 Maida Vale Business Centre, Maida Vale Road,
Cheltenham, Glos. GL53 7ER England
Tel: +44 (0) 1242 261332 Mobile: +44 (0) 7774 465712
www.edsociety.co.uk Email: info@edsociety.co.uk

Ectodermal Dysplasia Society

Trustees' Annual Report for the period 1st January – 31st December 2023

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)

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 732 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 work of the Ectodermal Dysplasia Society will be guided by 6 strategic objectives;

- 1) Communication - To make available information that is clearly written and easy to understand on the different Ectodermal Dysplasias, together with practical advice on how to manage their effects.
- 2) Membership Management - To build a solid membership database of both those individuals and families affected by Ectodermal Dysplasia, and of those medical professionals with an interest in or experience of treating such individuals and families.
- 3) Liaison & Support - To liaise with individuals, families, professionals and members of the Medical Advisory Board with the aim of providing personal support and advice to those affected by Ectodermal Dysplasia.
- 4) Contact Network - To build relationships between individuals and families affected by Ectodermal Dysplasia to encourage mutual practical and emotional support.
- 5) Raise Awareness - To promote awareness and understanding of Ectodermal Dysplasia to both the medical profession and general public.
- 6) Fundraising - To raise funds to support the Ectodermal Dysplasia Society in its work to provide services, equipment and grants to individuals and families affected by Ectodermal Dysplasia.

Achievements in 2022

- School - Assisted parents and Schools in creating School Care Plans specific to the day-to-day management of Ectodermal Dysplasia; attended school meetings.
- Disability Living Allowance – assisted families in completing Disability Living Allowance (DLA) and Personal Independent Payment (PIP) application forms; wrote appeal letters, attended zoom meetings to prepare families for their tribunal and attended the telephone tribunal with them.
- Assisted families in obtaining a Blue Badge.
- Assisted families in being re-housed.
- Encouraged and assisted individuals to Fundraise.
- Successfully received a grant from Jeans for Genes, the Foyle Foundation and the British Association of Dermatology.
- Continued working on the International Ectodermal Dysplasia Network (EDIN) website aimed at medical professionals and Ectodermal Dysplasia support organisation leaders around the world.
- Attended virtual Conferences to obtain information and bring awareness.
- Attended the British Association of Dermatology virtual meetings.
- Attended European Reference Networks (ERN) and ePAG virtual meetings.
- Attended EDIN virtual meetings.
- Assisted EspeRare in the progression of the ER004 treatment therapy.
- Gave Presentations to medical organisations.

- Assisted families in finding Dentists who have experience of Ectodermal Dysplasia through the Dental network set up by one of the Medical Advisory Board members.
- Produced Newsletters.
- Began a redesign of our existing website.
- Promoted our published book “A Guide to Ectodermal Dysplasia”.
- Promoted our published children’s book “Everybody’s Different”. We are now having this translated into difference languages.
- Continued working on the temperature regulation research.
- Continued assisting in the creation of a temperature device.
- Applied and received various grants.
- Attended virtual meetings regarding “Appearance Matters”.
- Continued working towards a better system for our Incontinentia Pigmenti community.
- Continued creating a Disability Living Allowance Guide.
- Began work planning the International ED Conference to be held in Birmingham in June 2025; attending meetings with the Scientific and Organisation Committees.
- Worked with the Society’s Trustees regarding our long-term plan.
- Have set up Google Drive, with the aim of moving the Society forward to becoming as paperless as possible.

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 2023 were £62,770.54 (2022: £71,572.78). 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 £3,000
- British Association of Dermatologists £1,000
- The Foyle Foundation £5,000

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 £71,228.68 (2022: £50,983.72). 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.

In 2024, the Ectodermal Dysplasia Society is planning to fund:

- A portion of the Temperature Research programme.
- Family members' applications to the Support Fund.
- An annual event.
- Conferences.
- Presentations.
- Supporting members through the process of DLA/PIP applications, appeals and tribunals, school meetings, Blue Badge applications and appeals, etc.
- Continue the support of individuals, families and medical professionals.
- Completion of the ED Society's website and the international EDIN website.
- Attending training courses for social media, fundraising and benefits.
- Applications for grants.
- Completing the Disability Living Allowance Guide.
- Increasing our marketing and fundraising activities.
- Continue the work planning the International ED Conference to be held in Birmingham in June 2025; attending meetings with the Scientific and Organisation Committees.

Diana Perry
Chief Executive and Secretary
15th March 2024

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

	Notes	2023			2022	
		£ Restricted funds	£ Unrestricted funds	£ Total	£	£
INCOME						
Interest		257.48	146.56		92.82	
Donations	3		18,347.50		17,330.31	
Gift Aid			3,932.51		3,328.27	
Members fees			865.09		1,083.43	
Fundraising			13,820.39		17,407.31	
Christmas Party & Raffle			2,667.60		2,066.61	
Merchandise sales	1		1,042.44		292.47	
Grants			9,000.00		28,388.00	
ICED sponsorship		7,500.00	-		-	
Other income	4		5,190.97		1,583.56	
Total incoming resources		7,757.48	55,013.06	62,770.54		71,572.78
EXPENDITURE						
Wages		3,224.99	42,782.48		32,135.51	
Postage and Stationery			1,553.33		754.66	
Telephone			351.09		366.41	
Computer related costs			3,395.28		1,433.22	
Committee members' expenses			766.14		1,835.17	
Insurance			519.55		451.71	
Christmas Party & Raffle			4,115.10		3,592.96	
Subscriptions			-		150.82	
Support for members	2	1,133.68	-		-	
Rent			7,920.00		7,920.00	
Fund Raising and Marketing Expenses	1		4,978.99		1,944.01	
Other expenditure			488.05		399.25	
Total resources expended		4,358.67	66,870.01	71,228.68		50,983.72
Net incoming resources before losses on revaluation of overseas funds				-8,458.14		20,589.06
Loss/gain on revaluation of overseas funds	3			-124.07		230.76
Net expenditure / incoming resources				-8,582.21		20,819.82
Total funds brought forward				92,472.48		71,652.66
Total funds carried forward				83,890.27		92,472.48

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

	2023		2022	
	£	£	£	£
FIXED ASSETS				
Tangible assets	-		-	
CURRENT ASSETS				
Gift Aid due	2,200.00		1,722.25	
HSBC	3,208.00		31,447.15	
NatWest	8,733.40		-	
Scottish Widows Account	65,331.87		54,806.67	
Irish Funds (see note 3)	4,372.31		4,496.38	
Cash in hand	44.69		0.03	
		83,890.27		92,472.48
CURRENT LIABILITIES				
Creditors	-		-	
Accrued expenses	-		-	
		-		-
		83,890.27		92,472.48
REPRESENTED BY				
General Fund		63,216.18		75,198.40
Restricted funds:				
Support Fund		16,398.08		17,274.08
ICED sponsorship		4,275.01		-
		83,890.27		92,472.48

These accounts were approved by the Trustees at the Annual General Meeting held on 15th March 2024

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 - £3,000
 - b) British Association of Dermatologists - £1,000
 - c) The Foyle Foundation - £5,000
- 3 Amounts paid from the Support Fund comprised £1,133.68 (2022: £nil) 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 (2022: net expenditure of £nil) and the closing balance was £4,372.31 (2022: £4,496.38). Amounts in Euros have been translated at the year-end rate of 1.1597 (2022: 1.1277) Euros to the Pound. The loss on revaluation of funds of £124.07 (2022: gain of £230.76) represents the change in value of the Irish funds resulting in the movement in the Euro exchange rate between the end of 2022 and 2023.
- 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 2023 (2022: nil).
- 7 Movements in reserves

	Restricted Funds	General Fund	Total	Restricted Funds	General Fund	Total
Opening Balance	17,274.28	75,198.20	92,472.48	17,274.02	54,378.64	71,652.66
Incoming resources	7,757.48	55,013.06	62,770.54	0.06	71,572.72	71,572.78
			-		-	
Resources expended	-4,358.67	-66,870.01	71,228.68	-	50,983.72	-50,983.72
Revaluation	-	-124.07	-124.07	-	230.76	230.76
Balance Carried Forward	20,673.09	63,217.18	83,890.27	17,274.08	75,198.40	92,472.48

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 2023, 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: 143 Salisbury Avenue, Cheltenham, Glos. GL51 3DG

Date:

8/3/24

ECTODERMAL DYSPLASIA SOCIETY

England & Wales - Charity number 1089135

Accounts



Trustees' Annual Report and Accounts
for the period ending

31st December 2022

The Ectodermal Dysplasia Society, Unit 1 Maida Vale Business Centre, Maida Vale Road,
Cheltenham, Glos. GL53 7ER England
Tel: +44 (0) 1242 261332 Mobile: +44 (0) 7774 465712
www.edsociety.co.uk Email: info@edsociety.co.uk

Ectodermal Dysplasia Society

Trustees' Annual Report for the period 1st January – 31st December 2022

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)

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
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 732 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 work of the Ectodermal Dysplasia Society will be guided by 6 strategic objectives;

- 1) Communication - To make available information that is clearly written and easy to understand on the different Ectodermal Dysplasias, together with practical advice on how to manage their effects.
- 2) Membership Management - To build a solid membership database of both those individuals and families affected by Ectodermal Dysplasia, and of those medical professionals with an interest in or experience of treating such individuals and families.
- 3) Liaison & Support - To liaise with individuals, families, professionals and members of the Medical Advisory Board with the aim of providing personal support and advice to those affected by Ectodermal Dysplasia.
- 4) Contact Network - To build relationships between individuals and families affected by Ectodermal Dysplasia to encourage mutual practical and emotional support.
- 5) Raise Awareness - To promote awareness and understanding of Ectodermal Dysplasia to both the medical profession and general public.
- 6) Fundraising - To raise funds to support the Ectodermal Dysplasia Society in its work to provide services, equipment and grants to individuals and families affected by Ectodermal Dysplasia.

Achievements in 2022

- School - Assisted parents and Schools in creating School Care Plans specific to the day-to-day management of Ectodermal Dysplasia; attended school meetings.
- Disability Living Allowance – assisted families in completing Disability Living Allowance (DLA) and Personal Independent Payment (PIP) application forms; wrote appeal letters, attended zoom meetings to prepare families for their tribunal and attended the telephone tribunal with them.
- Assisted families in obtaining a Blue Badge.
- Assisted families in being re-housed.
- Encouraged and assisted individuals to Fundraise.
- Successfully received a grant from Jeans for Genes and the British Association of Dermatology.
- Continued working on the International Ectodermal Dysplasia Network website aimed at medical professionals and Ectodermal Dysplasia support organisation leaders around the world.
- Attended virtual Conferences to obtain information and bring awareness.
- Attended the British Association of Dermatology virtual meetings.
- Attended ERN and ePAG virtual meetings.
- Attended EDIN virtual meetings.
- Assisted EspeRare in the progression of the ER004 treatment therapy.
- Gave Presentations to medical organisations.

- Assisted families in finding Dentists who have experience of Ectodermal Dysplasia through the Dental network set up by one of the Medical Advisory Board members.
- Produced Newsletters.
- Continued working on creating a new up to date website.
- Promoted our published book “A Guide to Ectodermal Dysplasia”.
- Promoted our published children’s book “Everybody’s Different”. We are now having this translated into difference languages
- Continued working on the temperature regulation research.
- Continued assisting in the creation of a temperature device.
- Applied and received various grants.
- Attended virtual meetings regarding “Appearance Matters”.
- Continued working towards a better system for our Incontinentia Pigmenti community.
- Continued creating a Disability Living Allowance Guide.
- Began work planning the International ED Conference to be held in Birmingham in June 2025; attending meetings with the Scientific and Organisation Committees.
- Worked with the Society’s Trustees regarding our long-term plan attending meetings with the sub-groups in operations, website, vision, marketing and fundraising and finance.
- Have set up Google Drive, with the aim of moving the Society forward to becoming as paperless as possible.

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 2022 were £71,572.78 (2021: £34,163.40). 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:

- Next £12,000
- VTCT £10,000
- The Foyles Foundation £5,000
- British Association of Dermatologists £598
- Stone King Foundation £450

The main expenditures are wages and rent, which enable the infrastructure of support and counselling provided by the Ectodermal Dysplasia Society. Total outgoing resources in the year were £50,983.72 (2021: £43,857.12). 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.

In 2023, the Ectodermal Dysplasia Society is planning to fund:

- A portion of the Temperature Research programme.
- Family members' applications to the Support Fund.
- An annual event.
- Conferences.
- Presentations.
- Supporting members through the process of DLA/PIP applications, appeals and tribunals, school meetings, Blue Badge applications and appeals, etc.
- Continue the support of individuals, families and medical professionals.
- Completion of the ED Society's website and the international EDIN website.
- Attending training courses for social media, fundraising and benefits.
- Applications for grants.
- Completing the Disability Living Allowance Guide.
- Increasing our marketing and fundraising activities.
- Continue the work planning the International ED Conference to be held in Birmingham in June 2025; attending meetings with the Scientific and Organisation Committees.

Diana Perry
Chief Executive and Secretary
22nd April 2023

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

	Notes	2022		2021	
		£	£	£	£
INCOME					
Interest		92.82		62.25	
Donations	3	17,330.31		12,968.11	
Gift Aid		3,328.27		2,611.42	
Members fees		1,083.43		1,388.08	
Fundraising		17,407.31		7,482.09	
Christmas Party & Raffle		2,066.61		1,458.00	
Merchandise sales	1	292.47		93.45	
Grants		28,388.00		8,100.00	
Other income	4	1,583.56		-	
Total incoming resources			71,572.78		34,163.40
EXPENDITURE					
Wages		32,135.51		31,614.85	
Postage and Stationery		754.66		787.30	
Telephone		366.41		918.69	
Computer related costs		1,433.22		1,278.58	
Committee members' expenses		1,835.17		0.00	
Insurance		451.71		431.28	
Christmas Party & Raffle		3,592.96		50.00	
Subscriptions		150.82		-	
Support for members	2	-		-	
Rent		7,920.00		7,660.00	
Fund Raising and Marketing Expenses	1	1,944.01		590.35	
Other expenditure		399.25		526.07	
Total resources expended			50,983.72		43,857.12
Net incoming resources before losses on revaluation of overseas funds			20,589.06		-9,693.72
Gain on revaluation of overseas funds	3		230.76		-269.75
Net expenditure / incoming resources			20,819.82		-9,963.47
Total funds brought forward			71,652.66		81,616.13
Total funds carried forward			92,472.48		71,652.66

Movements in Reserves	Support Fund	General Fund	Total	Support Fund	General Fund	Total
Opening Balance	17,274.02	54,378.64	71,652.66	17,273.78	64,342.35	81,616.13
Incoming resources	0.06	71,572.72	71,572.78	0.24	34,163.16	34,163.40
Resources expended	-	-50,983.72	-50,983.72	-	-43,857.12	-43,857.12
Revaluation	-	230.76	230.76	-	-269.75	-269.75
Balance Carried Forward	17,274.08	75,198.40	92,472.48	17,274.02	54,378.64	71,652.66

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

	2022		2021	
	£	£	£	£
FIXED ASSETS				
Tangible assets	-		-	
CURRENT ASSETS				
Gift Aid due	1,722.25		1,006.37	
HSBC Current Account	31,447.15		11,166.73	
Scottish Widows Account	54,806.67		55,213.91	
Irish Funds (see note 3)	4,496.38		4,265.62	
Cash in hand	0.03		0.03	
		92,472.48		71,652.66
CURRENT LIABILITIES				
Creditors	-		-	
Accrued expenses	-		-	
		-		-
		<u>92,472.48</u>		<u>71,652.66</u>
REPRESENTED BY				
General Fund		75,198.40		54,378.64
Support Fund		<u>17,274.08</u>		<u>17,274.02</u>
		<u>92,472.48</u>		<u>71,652.66</u>

These accounts were approved by the Trustees at the Annual General Meeting held on 22nd April 2023

Trustee

Trustee

Notes to the accounts

- 1 Merchandise sales represent funds raised through the sale of goods promoting the Society.
- 2 Grants received included:
 - a) Next - £12,000
 - b) VTCT - £10,000
 - c) The Foyles Foundation - £5,000
 - d) British Association of Dermatologists - £598
 - e) Stone King Foundation - £450
- 3 Amounts paid from the Support Fund comprised £nil (2021: £402.96) 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 (2021: net expenditure of £12.62) and the closing balance was £4,496.38 (2021: £4,265.62). Amounts in Euros have been translated at the year-end rate of 1.1277 (2021: 1.1887) Euros to the Pound. The gain on revaluation of funds of £230.76 (2021: loss of £269.75) represents the change in value of the Irish funds resulting in the movement in the Euro exchange rate between the end of 2021 and 2022.
- 5 Other income in 2022 included a refund of Statutory Maternity Pay of £1,028.62.
- 6 There were no outstanding debts or guarantees made by the Ectodermal Dysplasia Society as at 31st December 2022 (2021: nil).

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 2022, 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: 143 Salisbury Avenue, Cheltenham, Glos. GL51 3DG

Date:

4/4/23.

ECTODERMAL DYSPLASIA SOCIETY

England & Wales - Charity number 1089135

Accounts



Trustees' Annual Report and Accounts
for the period ending

31st December 2021

The Ectodermal Dysplasia Society, Unit 1 Maida Vale Business Centre, Maida Vale Road,
Cheltenham, Glos. GL53 7ER England
Tel: +44 (0) 1242 261332 Mobile: +44 (0) 7774 465712
www.edsociety.co.uk Email: info@edsociety.co.uk

Ectodermal Dysplasia Society

Trustees' Annual Report for the period 1st January – 31st December 2021

Charity number 1089135

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

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Larissa Pelham
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- 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 work of the Ectodermal Dysplasia Society will be guided by 6 strategic objectives;

- 1) Communication - To make available information that is clearly written and easy to understand on the different Ectodermal Dysplasias, together with practical advice on how to manage their effects.
- 2) Membership Management - To build a solid membership database of both those individuals and families affected by Ectodermal Dysplasia, and of those medical professionals with an interest in or experience of treating such individuals and families.
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- 6) Fundraising - To raise funds to support the Ectodermal Dysplasia Society in its work to provide services, equipment and grants to individuals and families affected by Ectodermal Dysplasia.

Achievements in 2021

- School - Assisted parents and Schools in creating School Care Plans specific to the day to day management of Ectodermal Dysplasia; attended school meetings.
- Disability Living Allowance – assisted families in completing Disability Living Allowance (DLA) and Personal Independent Payment (PIP) application forms; wrote appeal letters, attended zoom meetings to prepare families for their tribunal and attended the tribunal with them.
- Assisted families in obtaining a Blue Badge.
- Assisted families in being re-housed.
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- Successfully received a grant from Jeans for Genes and the British Association of Dermatology.
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- Attended virtual Conferences to obtain information and bring awareness.
- Attended the British Association of Dermatology virtual meetings.
- Attended ERN and ePAG virtual meetings.
- Attended EDIN virtual meetings.
- Assisted EspeRare in the progression of the ER004 treatment therapy.
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- Produced Newsletters.
- Continued working on creating a new up to date website.
- Promoted our published book “A Guide to Ectodermal Dysplasia”.
- Promoted our published children’s book “Everybody’s Different”.
- Continued working on the temperature regulation research.
- Continued assisting in the creation of a temperature device.
- Applied and received various grants
- Attended virtual meetings regarding “Appearance Matters”.
- Began creating a new system to help our Incontinentia Pigmenti community.
- Continued creating a Disability Living Allowance Guide.
- Worked with other Patient Support Groups to create a survey for patients, nurses and consultants in dermatology.
- Continually updated our website regarding Covid-19 Government guidelines and information
- Worked continually from home and the office to support all our ED community during the Covid-19 pandemic and lock-downs
- Worked with the Society’s Trustees creating sub-groups in operations, website, vision, marketing and fundraising and finance, attending meetings, setting up Google Drive, with the aim of moving the Society forward.

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 2021 were £34,163.40 (2020: £42,812.55). We are extremely grateful to our members and others associated with the Ectodermal Dysplasia Society for the generosity of their giving.

The main expenditures are wages and rent, which enable the infrastructure of support and counselling provided by the Ectodermal Dysplasia Society. Total outgoing resources in the year were £43,857.12 (2020: £48,201.23). 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.

In 2022, the Ectodermal Dysplasia Society is planning to fund:

- A portion of the Temperature Research programme.
- Family members' applications to the Support Fund.
- An annual event.
- Conferences.
- Presentations.
- Supporting members through the process of DLA/PIP applications, appeals and tribunals, school meetings, Blue Badge applications and appeals, etc.
- Continue the support of individuals, families and medical professionals.
- Completion of the ED Society's website and the international EDIN website.
- Attending training courses for social media, fundraising and benefits.
- Applications for grants.
- Completing the Personal Independent Payment Guide.
- Increasing our marketing and fundraising activities.

Diana Perry
Chief Executive and Secretary
7th May 2022

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

		2021		2020	
	Notes	£	£	£	£
INCOME					
Interest		62.25		66.31	
Donations	3	12,968.11		13,927.92	
Gift Aid		2,611.42		3,216.26	
Members fees		1,388.08		1,569.52	
Fundraising		7,482.09		11,145.87	
Christmas Party & Raffle		1,458.00		993.00	
Merchandise sales	1	93.45		317.47	
Grants		8,100.00		10,643.00	
Other income	4	-		933.20	
	Total incoming resources		34,163.40		42,812.55
EXPENDITURE					
Wages		31,614.85		31,204.19	
Postage and Stationery		787.30		1,256.44	
Telephone		918.69		746.46	
Computer related costs		1,278.58		2,989.01	
Committee members' expenses		0.00		200.00	
Insurance		431.28		399.76	
Christmas Party & Raffle		50.00		96.00	
Sponsorship		-		1,800.00	
Support for members	2	-		402.96	
Rent		7,660.00		7,200.00	
Fund Raising Expenses	1	590.35		787.00	
Advertising		-		500.00	
Other expenditure		526.07		619.41	
	Total resources expended		43,857.12		48,201.23
Net incoming resources before losses on revaluation of overseas funds					
			-9,693.72		-5,388.68
Gain on revaluation of overseas funds	3		-269.75		246.16
Net expenditure / incoming resources			-9,963.47		-5,142.52
Total funds brought forward			81,616.13		86,758.65
Total funds carried forward			71,652.66		81,616.13

Movements in Reserves	Support Fund	General Fund	Total	Support Fund	General Fund	Total
Opening Balance	17,273.78	64,342.35	81,616.13	17,675.36	69,083.29	86,758.65
Incoming resources	0.24	34,163.16	34,163.40	1.38	42,811.17	42,812.55
Resources expended	-	-43,857.12	-43,857.12	-402.96	-47,798.27	-48,201.23
Revaluation	-	-269.75	-269.75		246.16	246.16
Balance Carried Forward	17,274.02	54,378.64	71,652.66	17,273.78	64,342.35	81,616.13

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

	2021		2020	
	£	£	£	£
FIXED ASSETS				
Tangible assets	-		-	
CURRENT ASSETS				
Gift Aid due	1,006.37		2,564.93	
HSBC Current Account	11,166.73		9,351.28	
Scottish Widows Account	55,213.91		65,151.90	
Irish Funds (see note 3)	4,265.62		4,547.99	
Cash in hand	0.03		0.03	
		71,652.66		81,616.13
CURRENT LIABILITIES				
Creditors	-		-	
Accrued expenses	-		-	
		-		-
		<u>71,652.66</u>		<u>81,616.13</u>
REPRESENTED BY				
General Fund		54,378.64		64,342.35
Support Fund		<u>17,274.02</u>		<u>17,273.78</u>
		<u>71,652.66</u>		<u>81,616.13</u>

These accounts were approved by the Trustees at the Annual General Meeting held on 7th May 2022

Trustee

Trustee

Notes to the accounts

1. Merchandise sales represent funds raised through the sale of goods promoting the Society. Fund raising expenses include £nil (2020: £198.00) relating to the cost of these goods.
2. Amounts paid from the Support Fund comprised £nil (2019: £402.96) in direct support of Members
3. 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 £12.62 (2020: net expenditure of £53.66) and the closing balance was £4,265.62 (2020: £4,547.99). Amounts in Euros have been translated at the year-end rate of 1.1887 (2020: 1.1182) Euros to the Pound. The loss on revaluation of funds of £269.75 (2020: gain of £246.16) represents the change in value of the Irish funds resulting in the movement in the Euro exchange rate between the end of 2020 and 2021.
4. Other income in 2020 included £479.00 refund in respect of a faulty computer.
5. There were no outstanding debts or guarantees made by the Ectodermal Dysplasia Society at 31st December 2021 (2020: nil).

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 2021, 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

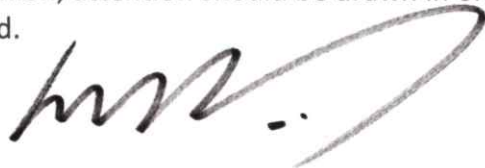
In connection with my examination, no matter has come to my attention:

(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: 143 Salisbury Avenue, Cheltenham, Glos. GL51 3DG

Date:

25/4/22

ECTODERMAL DYSPLASIA SOCIETY

England & Wales - Charity number 1089135

Accounts



Trustees' Annual Report and Accounts
for the period ending

31st December 2020

The Ectodermal Dysplasia Society, Unit 1 Maida Vale Business Centre, Maida Vale Road,
Cheltenham, Glos. GL53 7ER England
Tel: +44 (0) 1242 261332 Mobile: +44 (0) 7774 465712
www.edsociety.co.uk Email: info@edsociety.co.uk

Ectodermal Dysplasia Society

Trustees' Annual Report for the period 1st January – 31st December 2020

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
Mandy White
Martin Williams

Irish Representative

Elaine Aylward

Administration

Sue Beard – Accounts and Website Management
Jaye Dix – Family Liaison
Danielle Gue – Social Media/Benefits

Bankers

HSBC Bank, 2, The Promenade, Cheltenham, Gloucestershire, GL50 1LR
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 662 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 work of the Ectodermal Dysplasia Society will be guided by 6 strategic objectives;

- 1) Communication - To make available information that is clearly written and easy to understand on the different Ectodermal Dysplasias, together with practical advice on how to manage their effects.
- 2) Membership Management - To build a solid membership database of both those individuals and families affected by Ectodermal Dysplasia, and of those medical professionals with an interest in or experience of treating such individuals and families.
- 3) Liaison & Support - To liaise with individuals, families, professionals and members of the Medical Advisory Board with the aim of providing personal support and advice to those affected by Ectodermal Dysplasia.
- 4) Contact Network - To build relationships between individuals and families affected by Ectodermal Dysplasia to encourage mutual practical and emotional support.
- 5) Raise Awareness - To promote awareness and understanding of Ectodermal Dysplasia to both the medical profession and general public.
- 6) Fundraising - To raise funds to support the Ectodermal Dysplasia Society in its work to provide services, equipment and grants to individuals and families affected by Ectodermal Dysplasia.

Achievements in 2020

- School - Assisted parents and Schools in creating School Care Plans specific to the day to day management of Ectodermal Dysplasia; attended school meetings
- Disability Living Allowance – assisted families in completing Disability Living Allowance (DLA) and Personal Independent Payment (PIP) application forms; wrote appeal letters, accompanied and prepared families for and attended tribunals
- Assisted families in obtaining a Blue Badge
- Assisted families in being re-housed
- Encouraged and assisted individuals to Fundraise
- Successfully raised money for new computers following our “computer crisis” appeal
- Successfully received a grant from the National Lottery
- Continued working on the International Ectodermal Dysplasia Network website aimed at medical professionals and support organisation leaders around the world
- Assisted countries to create their own support organisation
- Attended virtual Conferences to obtain information and bring awareness
- Attended the British Association of Dermatology virtual meetings
- Attended ERN and ePAG virtual meetings
- Attended EDIN virtual meetings
- Assisted families through our Support Fund
- Assisted EspeRare in the progression of the ER004 treatment therapy

- Gave Presentations to medical organisations
- Assisted families in finding Dentists who have experience of Ectodermal Dysplasia through the Dental network set up by one of the Medical Advisory Board members
- Produced Newsletters
- Continued working on creating a new up to date website
- Continued working on creating a web app for our youth with a graphics designer
- Promoted our published book “A Guide to Ectodermal Dysplasia”
- Promoted our published children’s book “Everybody’s Different”
- Continued working on the temperature regulation research
- Continue assisting in the creation of a temperature device
- Applied and received various grants
- Attended virtual meetings regarding “Appearance Matters”
- Assisted virtually in the creation of a “Distance Aware” badge rolled out to shops/supermarkets
- Began creating a new system to help our Incontinentia Pigmenti community
- Began creating a Disability Living Allowance Guide
- Worked with other Patient Support Groups towards giving a presentation at the BAD Annual Conference in 2021
- Worked with National Voices creating a heads of policy document
- Created a Personal Independent Living Allowance guide
- Began creating anti-bullying leaflets and guide
- Continually updated our website regarding Covid-19 Government guidelines and information
- Worked continually from home and the office to support all our ED community during the Covid-19 pandemic and lock-downs

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 2020 were £42,812.55 (2019: £65,289.98). We are extremely grateful to our members and others associated with the Ectodermal Dysplasia Society for the generosity of their giving.

The main expenditures are wages and rent, which enable the infrastructure of support and counselling provided by the Ectodermal Dysplasia Society. Total outgoing resources in the year were £48,201.23 (2019: £49,926.21). 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.

In 2021, the Ectodermal Dysplasia Society is planning to fund:

- A portion of the Temperature Research programme
- Family members' applications to the Support Fund
- An annual event
- Conferences
- Presentations
- Supporting members through the process of DLA/PIP applications, appeals and tribunals, school meetings, Blue Badge applications and appeals, etc.
- Continued support of individuals, families and medical professionals
- Completion of the ED Society's website and the international EDIN website
- New age-appropriate web app specifically aimed at children
- Attending training courses for social media, fundraising and benefits
- Applications for grants
- Create Best Practice Leaflets with the assistance of the MAB
- Create a fundraising team
- Completing the Disability Living Allowance Guide

Diana Perry
Chief Executive and Secretary
1st May 2021

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

	Notes	2020		2019			
		£	£	£	£		
INCOME							
Interest		66.31		74.97			
Donations	3	13,927.92		16,054.16			
Gift Aid		3,216.26		4,280.18			
Members fees		1,569.52		1,381.70			
Fundraising		11,145.87		18,297.68			
Christmas Party & Raffle		993.00		2,329.35			
Merchandise sales	1	317.47		488.37			
Grants		10,643.00		21,000.00			
Other income	4	933.20		1,383.57			
Total incoming resources			42,812.55		65,289.98		
EXPENDITURE							
Wages		31,204.19		29,321.96			
Postage and Stationery		1,256.44		991.12			
Telephone		746.46		877.18			
Computer related costs		2,989.01		2,166.41			
Committee members' expenses		200.00		3,543.21			
Insurance		399.76		381.81			
Christmas Party & Raffle		96.00		2,186.25			
Sponsorship		1,800.00		-			
Support for members	2	402.96		2,309.15			
Rent		7,200.00		7,200.00			
Fund Raising Expenses	1	787.00		333.00			
Advertising		500.00		109.40			
Other expenditure		619.41		506.72			
Total resources expended			48,201.23		49,926.21		
Net incoming resources before losses on revaluation of overseas funds			-5,388.68		15,363.77		
Gain on revaluation of overseas funds	3		246.16		-292.33		
Net expenditure / incoming resources			-5,142.52		15,071.44		
Total funds brought forward			86,758.65		71,687.21		
Total funds carried forward			81,616.13		86,758.65		
Movements in Reserves							
		Support Fund	General Fund	Total	Support Fund	General Fund	Total
Opening Balance		17,675.36	69,083.29	86,758.65	19,955.68	51,731.53	71,687.21
Incoming resources		1.38	42,811.17	42,812.55	28.83	65,261.15	65,289.98
Resources expended		-402.96	-47,798.27	-48,201.23	-2,309.15	-47,617.06	-49,926.21
Revaluation			246.16	246.16		-292.33	-292.33
Balance Carried Forward		17,273.78	64,342.35	81,616.13	17,675.36	69,083.29	86,758.65

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

	2020		2019	
	£	£	£	£
FIXED ASSETS				
Tangible assets	-		-	
CURRENT ASSETS				
Gift Aid due	2,564.93		3,621.04	
HSBC Current Account	9,351.28		8,695.12	
Scottish Widows Account	65,151.90		70,086.97	
Irish Funds (see note 3)	4,547.99		4,355.49	
Cash in hand	0.03		0.03	
		81,616.13		86,758.65
CURRENT LIABILITIES				
Creditors	-		-	
Accrued expenses	-		-	
		-		-
		<u>81,616.13</u>		<u>86,758.65</u>
REPRESENTED BY				
General Fund		64,342.35		69,083.29
Support Fund		<u>17,273.78</u>		<u>17,675.36</u>
		<u>81,616.13</u>		<u>86,758.65</u>

These accounts were approved by the Trustees at the Annual General Meeting held on 1st May 2021

Trustee

Trustee

Notes to the accounts

1. Merchandise sales represent funds raised through the sale of goods promoting the Society. Fund raising expenses include £198.00 (2019: £333.00) relating to the cost of these goods.
2. Amounts paid from the Support Fund comprise £402.96 (2019: £988.86) in direct support of Members. Additionally, in 2019 a subsidy of £1,320.29 was given for the running expenses of the Christmas party in 2019.
3. 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 £53.66 (2019: net expenditure of £50.78) and the closing balance was £4,547.99 (2019: £4,355.49). Amounts in Euros have been translated at the year-end rate of 1.1182 (2019: 1.1814) Euros to the Pound. The gain on revaluation of funds of £246.16 (2019: loss of £292.33) represents the change in value of the Irish funds resulting in the movement in the Euro exchange rate between the end of 2019 and 2020.
4. Other income in 2020 includes £479.00 refund in respect of a faulty computer. In 2019 other income included £1,126.76 reimbursement of Committee member's expenses principally by the British Association of Dermatologists and Findacure.
5. There were no outstanding debts or guarantees made by the Ectodermal Dysplasia Society at 31st December 2020 (2019: nil).

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 2020, 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: 143 Salisbury Avenue, Cheltenham, Glos. GL51 3DG

Date:

22/3/21