



Trustees' Annual Report and Accounts  
for the period ending

31<sup>st</sup> December 2022

## **Ectodermal Dysplasia Society**

### **Trustees' Annual Report for the period 1<sup>st</sup> January – 31<sup>st</sup> 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 14<sup>th</sup> 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](http://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  
22<sup>nd</sup> 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

		2022		2021	
	Notes	£	£	£	£
<b>INCOME</b>					
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		<b>71,572.78</b>		<b>34,163.40</b>
<b>EXPENDITURE</b>					
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		<b>50,983.72</b>		<b>43,857.12</b>
Net incoming resources before losses on revaluation of overseas funds			<b>20,589.06</b>		<b>-9,693.72</b>
Gain on revaluation of overseas funds	3		230.76		-269.75
Net expenditure / incoming resources			<b>20,819.82</b>		<b>-9,963.47</b>
Total funds brought forward			71,652.66		81,616.13
Total funds carried forward			<b>92,472.48</b>		<b>71,652.66</b>

<b>Movements in Reserves</b>	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**

	<b>2022</b>		<b>2021</b>	
	£	£	£	£
<b>FIXED ASSETS</b>				
Tangible assets	-		-	
<b>CURRENT ASSETS</b>				
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
<b>CURRENT LIABILITIES</b>				
Creditors	-		-	
Accrued expenses	-		-	
		-		-
		<u>92,472.48</u>		<u>71,652.66</u>
<b>REPRESENTED BY</b>				
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 22<sup>nd</sup> 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 31<sup>st</sup> 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 31<sup>st</sup> 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.