

# ICHTHYOSIS SUPPORT GROUP

England & Wales · Charity number 1142457

## Details

|                |                                                         |
|----------------|---------------------------------------------------------|
| Other names    | ISG                                                     |
| Status         | Registered                                              |
| Legal form     | Charitable company                                      |
| Company number | <a href="#">07609904</a>                                |
| Registered     | 2011-06-17                                              |
| Register       | <a href="#">View on the Charity Commission register</a> |

## Contact

|         |                                                                            |
|---------|----------------------------------------------------------------------------|
| Address | 12 Manor Fields<br>Alrewas<br>Burton-On-Trent<br>Staffordshire<br>DE13 7DA |
| Phone   | 08003689621                                                                |
| Email   | <a href="mailto:isg@ichthyosis.org.uk">isg@ichthyosis.org.uk</a>           |
| Website | <a href="http://www.ichthyosis.org.uk">www.ichthyosis.org.uk</a>           |

## Activities

**Objects:** 3.1 TO PROMOTE AND PROTECT THE PHYSICAL AND MENTAL HEALTH OF SUFFERERS OR ICHTHYOSIS AND ANY ASSOCIATED CONDITION IN THE UNITED KINGDOM AND THE REPUBLIC OF IRELAND THROUGH THE PROVISION OF FINANCIAL ASSISTANCE, SUPPORT, EDUCATION AND PRACTICAL ADVICE; 3.2 TO ADVANCE THE EDUCATION OF THE GENERAL PUBLIC AND MEDICAL PROFESSION IN ALL AREAS RELATING TO ICHTHYOSIS AND ANY ASSOCIATED CONDITION, AND ITS IMPLICATION FOR THE FAMILY; 3.3 TO PROMOTE RESEARCH INTO THE MANAGEMENT OF ICHTHYOSIS AND ANY ASSOCIATED CONDITION AND TO PUBLISH THE USEFUL RESULTS OF THAT RESEARCH, AND TO SUPPORT ORGANISATIONS WORLDWIDE PROMOTING RESEARCH INTO ICHTHYOSIS; AND 3.4 SUCH OTHER PURPOSES AS ARE CHARITABLE ACCORDING TO THE LAWS OF ENGLAND AND WALES FOR THE BENEFIT OF THE PUBLIC.

**Activities:** To provide support for sufferers of ichthyosis and their families. To advance the education of the general public and medical profession in all areas relating to ichthyosis. To promote research into the management and treatment of ichthyosis. Operates throughout the UK and Republic of Ireland.

## Classification

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- **How:** Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Other Charitable Activities
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Charities Or Voluntary Bodies

## Geography

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- Ireland
- Northern Ireland
- Scotland
- Throughout England And Wales

## Finances

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| Period end | Income   | Expenditure | Assets | Employees |
|------------|----------|-------------|--------|-----------|
| 2025-06-30 | £98,494  | £123,221    | -      | -         |
| 2024-06-30 | £91,618  | £124,341    | -      | -         |
| 2023-06-30 | £100,059 | £73,823     | -      | -         |
| 2022-06-30 | £68,948  | £77,921     | -      | -         |
| 2021-06-30 | £393,719 | £42,060     | -      | -         |

## Trustees

| Name                    | Role  | Appointed  |
|-------------------------|-------|------------|
| PAUL WILLIAM WHITEHOUSE | Chair | 2011-05-19 |
| Baljinder Sohi          |       | 2023-06-10 |
| Kay Holby               |       | 2024-03-24 |
| Lee James Lancashire    |       | 2017-02-26 |
| MARGARET ALDWIN         |       | 2011-05-19 |
| Mudassar Ulhaq          |       | 2014-10-28 |
| RAYMOND JAMES ROWLEY    |       | 2011-05-19 |
| Simon Brown             |       | 2025-03-22 |
| Tejvir Sohi             |       | 2024-03-24 |

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# Accounts

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# Ichthyosis Support Group

(a Company Limited by Guarantee)

Trustees' Report and Financial Statements  
for the year ended 30 June 2025

Registered Company number 07609904

Registered Charity number 1142457

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2025

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## Report of the Trustees

The directors of Ichthyosis Group Support Ltd (“the charitable company”) are its Trustees for the purpose of charity law and throughout this report are collectively referred to as its Trustees. The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association, and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (updated 1 January 2019).

The Trustees have pleasure in presenting the charitable company’s report and financial statements for the year ended 30 June 2025.

### OBJECTIVES AND ACTIVITIES

#### **Objects of the Charity as set out in the governing document.**

The objects of the Charity are to:

1. Promote and protect the physical and mental health of people affected by Ichthyosis and any associated condition in the United Kingdom and the Republic of Ireland through the provision of financial assistance, support, education, and practical advice.
2. Advance the education of the general public and medical profession in all areas relating to Ichthyosis and related conditions, including the implications for affected families.
3. Promote research into the management of Ichthyosis and any associated condition, publish the useful results of that research, and support organisations worldwide that promote research into Ichthyosis.
4. Further such other charitable purposes according to the laws of England and Wales for the benefit of the public.

#### **Activities during the Period to Achieve the Charity’s Objects and Obligations of Public Benefit:**

During the period, the Charity undertook a wide range of activities in support of its charitable purposes, including:

- Maintaining a telephone helpline available 24 hours a day, 7 days a week.
- Engaging with new members to understand the support they may require.
- Maintaining the ISG website and social media channels, including Facebook, X/Twitter, Instagram, and LinkedIn, as well as the email helpline.
- Producing regular newsletters for members and supporters.
- Holding regular directors’ meetings at the office, in addition to bi-monthly conference calls.
- Delivering both in-person and online member events, including:
  - 8 August 2024 – Online X-linked Ichthyosis presentation and Q&A.
  - 14 September 2024 – Scottish Information Day at Leonardo Boutique Huntingtower Perth, with a day trip to PGL Dalguise for children and on-site activities for younger members.
  - 29–30 October 2024 – Irish Family Conference at Barretstown, County Kildare, Ireland.

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## Report of the Trustees (continued)

The Charity also:

- Worked closely with its Medical Advisory Board, comprising consultant dermatologists, a dermatology nurse, and an ophthalmologist, who provide expert information and respond to questions from individuals affected by Ichthyosis and members of the public.
- Worked closely with the British Association of Dermatologists on dermatology issues affecting people living with Ichthyosis.
- Encouraged and supported fundraising efforts through promotional materials and by sharing individuals' online fundraising pages through social media and other channels.
- Applied for grants from external funding organisations, including for the Faces of ISG photoshoot project. An application to the British Association of Dermatologists was successful, securing £3,628.
- Continued to raise awareness of Ichthyosis, particularly during Ichthyosis Awareness Month in May.
- Continued filming with a number of families for the Charity's video stories project.
- Ensured directors and members represented ISG at professional conferences, including the British Association of Dermatologists Annual Meeting and the British Dermatological Nursing Group Annual Conference, where they staffed stands to raise awareness of Ichthyosis and the work of ISG.
- Supported presentations delivered by the Medical and Communications Manager at a number of professional events, including:
  - British Association of Dermatologists Conference, Manchester, July 2024 our Medical and Communications Manager, was invited to present in a plenary session with Professor Jemima Mellerio. Together they delivered "Scales of the Unexpected", reflecting both healthcare professional and patient perspectives on the challenges of living with Ichthyosis.
  - European Society for Dermatological Research, Lisbon, 3–4 September 2024 – We co-presented "Challenged by Ichthyosis" with Ichthyosis advocate Karin Veldman and Dr Antoni Gosynski as part of the Patient Symposium.
  - British Dermatological Nursing Group Meeting, Harrogate, 18 September 2024 – We presented "Scales of the Unexpected."
- May and June 2024 –Delivered online teaching sessions for paediatricians, junior dermatologists, and other healthcare professionals on two separate paediatric dermatology courses.
- 12 November 2024 – Presented at the Genomics for Dermatology Course at Hinxton Hall Conference Centre, Cambridgeshire.
- 26 March 2025 – Presented as part of the online course Fundamentals of Dermatology for Nurses and Paramedics.
- Liaised with researchers and companies to share research news and developments, actively recruit prospective participants for studies, and keep members informed of clinical trial developments.
- Continued attending the monthly Ichthyosis clinic at Birmingham Children's Hospital on the first Thursday of each month.
- Commenced attendance at a monthly Ichthyosis clinic at Great Ormond Street Hospital.
- On 18 March 2025, supported wider awareness activity when our Medical and Communications Manager shared her personal journey of living with Netherton Syndrome through filming with Quoin Pharmaceuticals as part of the Netherton NOW campaign.
- Relocated the Charity's office in July 2024 from Denmark Street, Wokingham, to Rubra One, Mulberry Business Park, Wokingham, following a tenancy change and rehousing by Wokingham Council. The PO Box was cancelled and the correspondence address was changed to match this address.

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## **Report of the Trustees (continued)**

### **Grant Making**

Where suitable project applications are received and funds allow, the Charity makes grants for research projects. The amount available is determined from year to year. Applications are welcomed and assessed by the Medical Advisory Board.

### **Volunteers' Contribution**

Unpaid volunteers made a significant and valued contribution to the Charity throughout the year. They supported affected families through peer networking, assisted with fundraising activities, and provided practical help at the national conference and other regional events. Volunteers also offered administrative support to the office, strengthening the day-to-day running of the Charity.

The Charity is fortunate to benefit from a dedicated group of volunteers who play an active role in delivering the annual national conference and children's residential camps, helping to ensure these events are safe, inclusive, and welcoming for all participants.

In addition, the Charity's Ambassadors continue to provide peer support to members, promote awareness of Ichthyosis, and represent ISG within their communities, thereby extending the Charity's reach and impact across the UK and Ireland.

### **ACHIEVEMENTS AND PERFORMANCE**

In exercising their duties to achieve the Charity's objectives, the directors have paid due regard to the Charity Commission's guidance on public benefit when determining the Charity's activities.

The major achievements of the Charity during the reporting period and subsequent period include:

- Membership growth – ISG membership continues to grow, with over 1,400 families in the UK and Ireland and a further 550 affected families worldwide.
- Provision of support and information – The Charity continued to provide an important reference and support service to the general public and to those affected by ichthyosis through its helpline, website, and social media channels, drawing on both lived experience and the expertise of the Medical Advisory Board.
- Raising awareness – ISG continued to increase public awareness of ichthyosis by working with media outlets and affected individuals to highlight the condition, resulting in national media exposure.
- Engagement with industry and research partners – The Charity maintained dialogue with pharmaceutical companies to encourage grant support, greater research activity, and stronger commitment to improving treatments for ichthyosis.
- Clinical and NHS engagement – ISG continued to liaise with hospitals and NHS England to support the development of specialised clinics for ichthyosis and other rare genetic skin conditions. The Charity now attends two paediatric clinics each month: Birmingham Children's Hospital on the first Thursday of the month, and Great Ormond Street Hospital on the fourth Thursday of the month.
- Unity Lottery – Continued participation in Unity Lottery has helped to secure a regular monthly income stream for the Charity.

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## Report of the Trustees (continued)

- Annual national event – Since 1999, ISG has organised a national event bringing together members of all ages and with varying forms and severity of ichthyosis. These events offer information, education, peer support, and opportunities to hear from medical professionals and pharmaceutical companies about developments relevant to life with a rare genetic skin condition.
- ISG children’s camps – Since 2014, ISG has offered children’s camps through PGL for affected children and their siblings. These camps provide opportunities to take part in activities such as zip wire, orienteering, and climbing, while also helping children build confidence, work as a team, and connect with peers who understand the challenges of living with a rare skin condition.
- Fundraising – The Charity benefited from a range of fundraising activities during the year, including:
  - December 2024 – ISG online Visufund Christmas fundraiser, “Light Up the Christmas Tree” (£200).
  - March–June 2024 – Fundraising by member Demi-Lea for her son with X-linked ichthyosis, including a cake sale, 5k walk, and “guess the name of the dinosaur” fundraiser (£593.90).
  - January 2025 – Fundraising by the Kenny family in Ireland (£12,394.58).
  - May 2025 – Dr Ioannis, Dermatology Registrar, and two friends ran the Battersea Half Marathon for Ichthyosis Awareness Month (£1,425).
  - June 2025 – Consultant Dermatologist Gordon Hale ran an ultramarathon (£2,096).
- Grants and sponsorship – The Charity secured support from a number of organisations, including but not limited to:
  - Quoin Pharmaceuticals – £7,500 (Irish event), £25,000 (unrestricted), and £5,000 (Family Conference 2025)
  - Timber Pharmaceuticals / Biocryst – £2,000
  - Alliance – £1,500
  - Dermal – £1,000 and £3,594.40
  - Sponsorship of 13 newsletters (Menarini – £1,211.70)

## FUTURE PLANS

The Charity remains committed to expanding its operational capacity and broadening the support and services it can offer to members, subject to available resources and funding.

Planned activities include:

- Delivering the Family Conference in Duxford in October 2025.
- Continuing to develop the Charity’s operational structure so that projects and initiatives that were previously beyond available capacity can be implemented in future.
- Sustaining and growing support services, awareness activity, education for healthcare professionals, and engagement with research and clinical partners.
- Continuing to seek grant funding, sponsorship, and fundraising support to strengthen long-term sustainability and expand impact.

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## **Report of the Trustees (continued)**

### **FINANCIAL REVIEW**

As shown in the Statement of Financial Activities on page 12, the Charity holds unrestricted funds just below £390,000, largely as a result of a significant legacy received in 2021/22. The directors are carefully considering how to best apply these resources in furtherance of the Charity's objectives. Areas under consideration include:

- Investment.
- Research grants.
- Grants for individuals affected by Ichthyosis.
- Development of an Ichthyosis registry.
- Securing the future of the ISG through support for core costs.

Restricted funds of £13,426 remain to be spent in future years in accordance with their assigned purpose. After designated funds of £20,000 have been set aside for grants for research purposes and £25,000 for salary costs, general funds of £55,496 in addition to the legacy fund of £288,971 are available for ongoing charitable purpose. Depending on future decisions regarding the use of the legacy funds, further amounts may be designated in due course.

Although the Charity has benefited from this generous legacy, once these funds have been committed or invested, ISG will continue to rely on income generated through member and supporter fundraising, together with successful grant applications. This means the Charity may remain vulnerable to fluctuations in income in future years. The directors therefore recognise the importance of continuing to manage resources prudently, while maintaining and strengthening fundraising and grant income wherever possible

### **General Reserve Policy**

In view of the fact that much of the charity's income arises from grants, proceeds of special events, sponsorships and other fundraising efforts on a "one-off" basis, the reoccurrence of which cannot be guaranteed from one year to another, it is considered desirable to maintain a General Reserve Level equal to the core expenditure and other known commitments budgeted to occur in the following accounting year, less anticipated regular income in that year. This would require an amount of around £65,000. As at 30<sup>th</sup> June 2025, un-restricted free reserves were £56,996, which is short of that required by our policy.

### **Review of the Reserve Policy**

The Reserve Policy is reviewed annually after the end of the financial year in the light of the results for that financial year, or earlier if there is any substantial change in the Charity's financial circumstances.

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## **Report of the Trustees (continued)**

### **Risk Assessment**

Trustees endeavor to identify the major risks to which the Charity is exposed and put in place procedures to manage such risks on an on-going basis. Appropriate insurance cover is held or taken out covering employment risks and such other risks that may be identified from time to time.

### **FUNDS HELD AS A CUSTODIAN TRUSTEE**

No such funds are held.

### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

#### **Organisational Structure and Decision Making**

The Board of directors meet a minimum of four times a year in person, or more often as necessary, in addition to numerous conference calls. They administer the Charity and take major and strategic decisions. Day-to-day functions are carried out by the Administrator and by some Board members.

#### **Governing Document**

The governing document is the Articles of Association and subject to the provisions set out in the Companies Act 2006 and the Charities Act 2011, where applicable.

#### **Method of Recruitment and Appointment of Directors**

Directors must be a member of the Charity and not be disqualified as a Director or Trustee by the Articles. No body or individual external to the Charity is permitted to appoint directors. Members are invited to put themselves forward or be nominated by other members as directors by means of newsletters circulated to all members by post or electronically, and invited to do so at General Meetings.

Directors are elected by the members at General Meetings for a term of three years. Directors may offer themselves for re-election at the end of their term of office.

The Board may at any time co-opt any individual who is qualified to be appointed as a director to fill a vacancy in their number or as an additional director. A co-opted director holds office until the next General Meeting at which they must stand for election by the members.

#### **Induction and Training of Directors**

Once appointed, new directors receive appropriate training in their duties and responsibilities by reference to relevant literature including publications issued by the Charity Commissioners and advice and assistance from existing directors. Where possible, directors are encouraged to attend related training courses and seminars.

### **REFERENCE AND ADMINISTRATIVE INFORMATION**

#### **Trustees**

Margaret Aldwin  
Raymond James Rowley  
Paul William Whitehouse  
Mudassar Ulhaq  
Lee James Lancashire

Baljinder Sohi  
Tejvir Sohi  
Kay Holby  
Simon Brown (appointed 22 March 2025)

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## Report of the Trustees (continued)

### Registered Office

Ichthyosis Support Group Also known as "ISG"  
12 Manor Fields  
Alrewas  
Burton on Trent  
DE13 7DA

**Company Registration Number:** 07609904

**Charity Registration Number:** 1142457

### Office and Postal Address

Ichthyosis Support Group  
Rubra One  
Mulberry Business Park  
Wokingham  
RG41 2QL

### Bankers

CAF Bank Limited  
25 Kings Hill Avenue  
Kings Hill  
West Malling  
Kent, ME19 4JQ

HSBC  
16-17 The Broadway  
Thatcham  
Newbury  
Berkshire, RG19 4HX

### Independent Examiner

Karen Hanlan  
Karen Hanlan Independent Examiner Ltd  
1 Saracen Close  
Ettington  
CV37 7SZ

### Solicitors

Blandy and Blandy LLP  
One Friar Street  
Reading  
Berkshire  
RG1 1DA

Approved by the Board and signed on its behalf by:

Lee Lancashire  
*Trustee*

Date: 12/3/2026

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2025

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## **Statement of Trustees' responsibilities**

The Trustees are required to prepare financial statements for each financial year which give a true and fair view of the state of the affairs of the charitable company and of the surplus or deficit incurred by the charitable company for that year. In preparing those financial statements the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue to exist.

The Trustees have overall responsibility for ensuring that the charitable company has an appropriate system of controls, financial and otherwise.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy, at any time, the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006.

They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities and to provide reasonable assurance that:

- the charitable company is operating efficiently and effectively;
- its assets are safeguarded against un-authorised use or disposition;
- proper records are maintained and financial information used within the charity or for publication is reliable;
- the charitable company complies with relevant laws and regulations.

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## **Independent Examiner's Report to the Trustees of Ichthyosis Support Group ('the Company')**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 June 2025 which are set out on pages 12 to 23.

### **Responsibilities and basis of report**

As the charity trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

### **Independent examiner's statement**

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

- 1) accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- 2) the accounts do not accord with those records; or
- 3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
- 4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102).

I have no concerns and have come across no matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Karen Hanlan,  
Member of Institute of Chartered Accountants England & Wales  
Karen Hanlan Independent Examiner Ltd  
1 Saracen Close  
Ettington  
CV37 7SZ

Date: 12/3/2026

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**Statement of Financial Activities (including an Income & Expenditure Account)**

|                                                                    |             | Un-<br>restricted<br>funds<br>2025 | Restricted<br>funds<br>2025 | Total<br>2025   | Total<br>2024   |
|--------------------------------------------------------------------|-------------|------------------------------------|-----------------------------|-----------------|-----------------|
| <b>Income from:</b>                                                | <b>Note</b> | <b>£</b>                           | <b>£</b>                    | <b>£</b>        | <b>£</b>        |
| Donations and legacies                                             | 1           | 41,690                             | 3,628                       | <b>45,318</b>   | 57,481          |
| Charitable Activities                                              | 2           | 27,187                             | -                           | <b>27,187</b>   | 27,293          |
| Trading Activities                                                 | 3           | 21,303                             | -                           | <b>21,303</b>   | 3,767           |
| Investments                                                        | 4           | 4,686                              | -                           | <b>4,686</b>    | 3,077           |
| <b>Total income</b>                                                |             | <b>94,866</b>                      | <b>3,628</b>                | <b>98,494</b>   | <b>91,618</b>   |
| <b>Expenditure on:</b>                                             |             |                                    |                             |                 |                 |
| Raising funds                                                      | 5           | 6,004                              | -                           | <b>6,004</b>    | 5,238           |
| Charitable activities                                              | 6           | 116,267                            | 950                         | <b>117,217</b>  | 119,103         |
| <b>Total Expenditure</b>                                           |             | <b>122,271</b>                     | <b>950</b>                  | <b>123,221</b>  | <b>124,341</b>  |
| <b>Net (expenditure)/income and net movement in funds for year</b> |             | <b>(27,405)</b>                    | <b>2,678</b>                | <b>(24,727)</b> | <b>(32,723)</b> |
| <b>Reconciliation of funds</b>                                     |             |                                    |                             |                 |                 |
| Total funds brought forward                                        |             | 416,872                            | 10,748                      | 427,620         | 460,343         |
| <b>Total funds carried forward</b>                                 |             | <b>389,467</b>                     | <b>13,426</b>               | <b>402,893</b>  | <b>427,620</b>  |

The statement of financial activities includes all gains and losses recognised in the year.  
All income and expenditure derive from continuing activities.

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## Balance sheet

|                                                |       |                 |          |
|------------------------------------------------|-------|-----------------|----------|
| Company registered number 07609904             | Notes | <b>2025</b>     | 2024     |
|                                                |       | <b>£</b>        | <b>£</b> |
| <b>Fixed Assets</b>                            |       |                 |          |
| Tangible assets                                | 9     | <b>1,099</b>    | 1,088    |
|                                                |       | <b>1,099</b>    | 1,088    |
| <b>Current Assets</b>                          |       |                 |          |
| Debtors                                        | 10    | <b>14,659</b>   | 3,369    |
| Cash at bank and in hand                       |       | <b>403,103</b>  | 429,648  |
|                                                |       | <b>417,762</b>  | 433,017  |
| <b>Current Liabilities</b>                     |       |                 |          |
| Creditors: amounts falling due within one year | 11    | <b>(15,968)</b> | (6,485)  |
|                                                |       |                 |          |
| Net current assets                             |       | <b>401,794</b>  | 426,532  |
| <b>Net assets</b>                              |       | <b>402,893</b>  | 427,620  |
| <b>The funds of the Charity:</b>               |       |                 |          |
| Restricted Funds                               | 12    | <b>13,426</b>   | 10,748   |
| Unrestricted Funds                             |       |                 |          |
| - general                                      |       | <b>55,496</b>   | 64,142   |
| - designated grant fund                        |       | <b>20,000</b>   | 9,953    |
| - designated salary fund                       |       | <b>25,000</b>   | -        |
| - designated legacy fund                       |       | <b>288,971</b>  | 342,777  |
|                                                |       | <b>389,467</b>  | 416,872  |
| <b>Total charity funds</b>                     |       | <b>402,893</b>  | 427,620  |

The accompanying accounting policies and notes form part of these financial statements.

For the year ended 30 June 2025 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Responsibilities of directors/Trustees:

(a) The members have not required the charitable company to obtain an audit of its financial statements for the year in question in accordance with section 476 of the Companies Act 2006 - however, in accordance with section 145 of the Charities Act 2011 the financial statements have been examined by an independent examiner whose report appears on page 11.

(b) The directors/Trustees acknowledge their responsibility for complying with the requirements of the Companies Act with respect to accounting records and the preparation of accounts.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

Approved by the Trustees and signed on their behalf by:  
Lee Lancashire, Trustee

Date: 12/3/2026

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for the year ended 30 June 2025

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## Principal accounting policies

### Status of the company

The charitable company is limited by guarantee and does not have share capital. The liability of members is limited to £10 per member.

### Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (updated 1 January 2019) - (Charities SORP (FRS102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) and the Companies Act 2006.

Ichthyosis Support Group meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

### Going concern statement

The financial statements have been prepared on a going concern basis which assumes that the Charitable Company will continue to operate. The validity of this assumption is dependent upon the continuance of support from the Charitable Company's supporters and donors. The Charitable Company's current business plan shows that the Charitable Company will be able to operate in the foreseeable future. Based on this understanding, the directors believe that it remains appropriate to prepare the financial statements on a going concern basis. The financial statements do not include any adjustments, which would result from the basis of preparation being inappropriate.

### Funds

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations and grants subject to conditions imposed by the provider or by specific terms of the appeal under which the funds were raised. The restrictive conditions are binding upon the Charitable Company.

### Income

Income is recognised when the charitable company has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income relating to future periods, as a result of donor imposed conditions specifying the time period, has been treated as deferred income.

Income dependent on certain conditions, amounting to more than mere administrative requirements, is recognised when the conditions have been fulfilled.

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2025

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## Principal accounting policies (continued)

### Donated services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charitable company of the item is probable and the economic benefit can be measured reliably. In accordance with the Charities SORP FRS102, general volunteer time is not recognised.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charitable company which is the amount the charitable company would have been willing to pay to obtain the services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

### Investment income receivable

Bank interest and dividends are shown on the basis of amounts receivable in the year.

### Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charitable company to the expenditure. All expenditure is accounted for on an accruals basis. Expenditure is classified under the following activity headings:

- Costs of raising funds comprises the costs of staff time, publicity and other costs associated with raising income.
- Expenditure on charitable activities includes the costs of direct charitable activities undertaken to further the purposes of the charity and their associated support & governance costs.

### Tangible fixed assets

Depreciation is provided at a rate calculated to write off the cost on a straight line basis over a period of less than the estimated useful life of the assets as follows:

|                                                  |         |
|--------------------------------------------------|---------|
| Computer equipment, Office equipment & furniture | 4 years |
|--------------------------------------------------|---------|

Fixed asset purchases above £500 are capitalised.

### Cash and cash equivalents

Cash and cash equivalents include cash at bank and in hand and short term deposits repayable within a three month notice period.

### Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

### Creditors

Creditors are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.

### Taxation

As a registered charity with no trading activities, no provision is considered necessary for taxation.

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2025

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## Principal accounting policies (continued)

### Pension costs

The charity contributes into a Group Personal Pension Plan for employees. This pension plan is defined contribution in nature and as required under FRS102 the annual cost is recognised as incurred and included in the Statement of Financial Activities.

### Foreign exchange movements

The charity has a Euro bank account to receive funds raised by members in the Republic of Ireland. The balance is converted to sterling at the year end rate and any exchange movements are taken to the Statement of Financial Activities and treated as 'Other income/Expense'.

### Cash flow

Under Charities SORP FRS102, update bulletin 1, as a small charity there is no requirement to produce a cashflow statement.

## Notes to the financial statements

### 1. Income from donations and legacies

|                                                 | 2025<br>£     | 2024<br>£     |
|-------------------------------------------------|---------------|---------------|
| <b>Un-restricted:</b>                           |               |               |
| Donations                                       | 11,690        | 24,981        |
| Grants                                          | 25,000        | 25,000        |
| Gifts in kind                                   | 5,000         | 7,500         |
| Total un-restricted grants & donations          | 41,690        | 57,481        |
| <b>Restricted grants &amp; donations:</b>       |               |               |
| British Association of Dermatologists           | 3,628         | -             |
| Total restricted grants                         | 3,628         | -             |
| <b>Total income from donations and legacies</b> | <b>45,318</b> | <b>57,481</b> |

Gifts in kind relates to subsidised office & meetings space provided.

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2025

## Notes to the financial statements (continued)

### 2. Income from charitable activities

|                                                | 2025          | 2024          |
|------------------------------------------------|---------------|---------------|
|                                                | £             | £             |
| Corporate sponsorship                          | 26,085        | 26,904        |
| Other charitable services provided             | 1,102         | 389           |
| <b>Total income from charitable activities</b> | <b>27,187</b> | <b>27,293</b> |

### 3. Income from trading activities

|                                             | 2025          | 2024         |
|---------------------------------------------|---------------|--------------|
|                                             | £             | £            |
| Promotional material                        | 5,374         | 2,721        |
| Unity Lottery                               | 1,104         | 1,046        |
| Fundraising events                          | 14,825        | -            |
| <b>Total income from trading activities</b> | <b>21,303</b> | <b>3,767</b> |

### 4. Income from investments

|               | 2025  | 2024  |
|---------------|-------|-------|
|               | £     | £     |
| Bank interest | 4,686 | 3,077 |

### 5. Analysis of expenditure on raising funds

|                                    | 2025         | 2024         |
|------------------------------------|--------------|--------------|
|                                    | £            | £            |
| Staff costs                        | 5,000        | 5,012        |
| Other fundraising costs            | 1,004        | 226          |
| <b>Total cost of raising funds</b> | <b>6,004</b> | <b>5,238</b> |

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2025

## Notes to the financial statements (continued)

### 6. Analysis of expenditure on charitable activities

| 2025                                              | Un-<br>restricted<br>£ | Designated<br>£ | Restricted<br>£ | Total<br>£     |
|---------------------------------------------------|------------------------|-----------------|-----------------|----------------|
| Staff costs                                       | 34,241                 | 8,806           | -               | 43,047         |
| Family day/Conference/Youth Camp inc. merchandise | 20,011                 | -               | 950             | 20,961         |
| Research grant                                    | 9,918                  | 9,953           | -               | 19,871         |
| Training costs                                    | 955                    | -               | -               | 955            |
| Office overheads & administration                 | 4,030                  | -               | -               | 4,030          |
| Rent – in kind                                    | 5,000                  | -               | -               | 5,000          |
| Insurance                                         | 583                    | -               | -               | 583            |
| Website costs                                     | 4,563                  | -               | -               | 4,563          |
| Newsletter production & postage                   | 4,354                  | -               | -               | 4,354          |
| Telephone, postage & IT costs                     | 2,977                  | -               | -               | 2,977          |
| Travel & accommodation                            | 3,468                  | -               | -               | 3,468          |
| CRM                                               | 1,809                  | -               | -               | 1,809          |
| Membership fees                                   | 360                    | -               | -               | 360            |
| Trustee expenses                                  | 3,393                  | -               | -               | 3,393          |
| Independent examiner fees                         | 1,100                  | -               | -               | 1,100          |
| Bank charges                                      | 258                    | -               | -               | 258            |
| Depreciation                                      | 488                    | -               | -               | 488            |
| <b>Total expenditure on charitable activities</b> | <b>97,508</b>          | <b>18,759</b>   | <b>950</b>      | <b>117,217</b> |

| 2024                                              | Un-<br>restricted<br>£ | Designated<br>£ | Restricted<br>£ | Total<br>£     |
|---------------------------------------------------|------------------------|-----------------|-----------------|----------------|
| Staff costs                                       | 20,047                 | -               | -               | 20,047         |
| Family day/Conference/Youth Camp                  | 41,204                 | -               | -               | 41,204         |
| Research grant                                    | -                      | 1,000           | -               | 1,000          |
| Video project                                     | -                      | -               | 5,405           | 5,405          |
| Office overheads & administration                 | 13,581                 | -               | -               | 13,581         |
| Rent – in kind                                    | 7,500                  | -               | -               | 7,500          |
| Insurance                                         | 564                    | -               | -               | 564            |
| Website costs                                     | 4,145                  | -               | -               | 4,145          |
| Newsletter production & postage                   | 6,203                  | -               | -               | 6,203          |
| Telephone, postage & IT costs                     | 1,447                  | -               | -               | 1,447          |
| Travel & accommodation                            | 3,979                  | -               | -               | 3,979          |
| CRM                                               | 1,086                  | -               | -               | 1,086          |
| Membership fees                                   | 449                    | -               | -               | 449            |
| Trustee expenses                                  | 8,117                  | -               | -               | 8,117          |
| Independent examiner fees                         | 1,100                  | -               | -               | 1,100          |
| Legal/professional fees                           | 1,272                  | -               | -               | 1,272          |
| Bank charges                                      | 269                    | -               | -               | 269            |
| Depreciation                                      | 1,735                  | -               | -               | 1,735          |
| <b>Total expenditure on charitable activities</b> | <b>112,698</b>         | <b>1,000</b>    | <b>5,405</b>    | <b>119,103</b> |

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2025

## Notes to the financial statements (continued)

### 7. Net expenditure for the year

|                                                        | 2025 | 2024  |
|--------------------------------------------------------|------|-------|
|                                                        | £    | £     |
| Net expenditure for the year is stated after charging: |      |       |
| Depreciation                                           | 488  | 1,735 |
| Independent examiners fees -                           |      |       |
| Independent examination                                | 940  | 940   |
| Accountancy services                                   | 160  | 160   |

### 8. Analysis of staff costs, trustee remuneration and expenses

|                    | 2025          | 2024          |
|--------------------|---------------|---------------|
|                    | £             | £             |
| Salaries           | 47,011        | 24,511        |
| National Insurance | -             | -             |
| Pension            | 1,036         | 548           |
| Total              | <u>48,047</u> | <u>25,059</u> |

### Staff Numbers

|                                                           | Number   | Number      |
|-----------------------------------------------------------|----------|-------------|
| Average number of full-time equivalent excluding Trustees | <u>1</u> | <u>0.67</u> |

No employees had employee benefits in excess of £60,000 (2024: nil).

The charitable company's trustees were not paid or received any other benefits from employment with the charity in the year. Trustee expenses of £5,104 for travel, subsistence and family day costs were reimbursed to 7 Trustees during the year (2024: £6,988, 9 Trustees).

The key management personnel of the charity comprise the trustees and the part time Operations Manager, Trustees receive no remuneration or other benefits from the charity. The remuneration of key management personnel (including pension contributions) for the year was £24,485 (2024: £25,059).

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2025

## Notes to the financial statements (continued)

### 9. Tangible fixed assets

|                       | 2025<br>Fixture,<br>fittings &<br>equipment<br>£ | 2024<br>Fixtures,<br>fittings &<br>equipment<br>£ |
|-----------------------|--------------------------------------------------|---------------------------------------------------|
| <b>Cost</b>           |                                                  |                                                   |
| At beginning of year  | 9,133                                            | 7,682                                             |
| Additions             | 499                                              | 1,451                                             |
| At end of year        | <u>9,632</u>                                     | <u>9,133</u>                                      |
| <b>Depreciation</b>   |                                                  |                                                   |
| At beginning of year  | 8,045                                            | 6,310                                             |
| Charge for the year   | 488                                              | 1,735                                             |
| At end of year        | <u>8,533</u>                                     | <u>8,045</u>                                      |
| <b>Net Book Value</b> |                                                  |                                                   |
| At end of year        | <u>1,099</u>                                     | <u>1,088</u>                                      |

### 10. Debtors

|               | 2025<br>£     | 2024<br>£    |
|---------------|---------------|--------------|
| Trade debtors | 6,380         | -            |
| Prepayments   | 8,279         | 3,369        |
|               | <u>14,659</u> | <u>3,369</u> |

### 11. Creditors: amounts falling due within one year

|                              | 2025<br>£     | 2024<br>£    |
|------------------------------|---------------|--------------|
| Trade Creditors              | 1             | 1,564        |
| Taxation and social security | 1,867         | 1,121        |
| Accruals                     | 1,100         | 2,300        |
| Deferred income              | 13,000        | 1,500        |
|                              | <u>15,968</u> | <u>6,485</u> |

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2025

## Notes to the financial statements (continued)

### 12. Funds

| 2025                       | Balance at<br>beginning of<br>year<br>£ | Income<br>£   | Expenditure<br>£ | Transfers<br>£  | Balance<br>at end of<br>year<br>£ |
|----------------------------|-----------------------------------------|---------------|------------------|-----------------|-----------------------------------|
| <b>Restricted funds</b>    |                                         |               |                  |                 |                                   |
| BAD Video project          | 1,528                                   | -             | -                | -               | <b>1,528</b>                      |
| Boehringer Video project   | 8,270                                   | -             | -                | -               | <b>8,270</b>                      |
| BAD – Faces of ISG project | -                                       | 3,628         | -                | -               | <b>3,628</b>                      |
| Goldsmiths My Story        | 433                                     | -             | (433)            | -               | -                                 |
| Scottish Event             | 517                                     | -             | (517)            | -               | -                                 |
|                            | <u>10,748</u>                           | <u>3,628</u>  | <u>(950)</u>     | <u>-</u>        | <u><b>13,426</b></u>              |
| <b>Unrestricted funds</b>  |                                         |               |                  |                 |                                   |
| Designated grant fund      | 9,953                                   | -             | (9,953)          | <b>20,000</b>   | <b>20,000</b>                     |
| Designated legacy fund     | 342,777                                 | -             | (8,806)          | <b>(45,000)</b> | <b>288,971</b>                    |
| Designated salary fund     | -                                       | -             | -                | <b>25,000</b>   | <b>25,000</b>                     |
| General fund               | 64,142                                  | 94,866        | (103,512)        | -               | <b>55,496</b>                     |
|                            | <u>416,872</u>                          | <u>94,866</u> | <u>(122,271)</u> | <u>-</u>        | <u><b>389,467</b></u>             |
| <b>Total Funds</b>         | <u>427,620</u>                          | <u>98,494</u> | <u>(123,221)</u> | <u>-</u>        | <u><b>402,893</b></u>             |

| 2024                      | Balance at<br>beginning of<br>year<br>£ | Income<br>£   | Expenditure<br>£ | Balance<br>at end of<br>year<br>£ |
|---------------------------|-----------------------------------------|---------------|------------------|-----------------------------------|
| <b>Restricted funds</b>   |                                         |               |                  |                                   |
| BAD Video project         | 6,933                                   | -             | (5,405)          | <b>1,528</b>                      |
| Boehringer Video project  | 8,270                                   | -             | -                | <b>8,270</b>                      |
| Goldsmiths My Story       | 433                                     | -             | -                | <b>433</b>                        |
| Scottish Event            | 517                                     | -             | -                | <b>517</b>                        |
|                           | <u>16,153</u>                           | <u>-</u>      | <u>(5,405)</u>   | <u><b>10,748</b></u>              |
| <b>Unrestricted funds</b> |                                         |               |                  |                                   |
| Designated grant fund     | 10,953                                  | -             | (1,000)          | <b>9,953</b>                      |
| Designated legacy fund    | 342,777                                 | -             | -                | <b>342,777</b>                    |
| General fund              | 90,460                                  | 91,618        | (117,936)        | <b>64,142</b>                     |
|                           | <u>444,190</u>                          | <u>91,618</u> | <u>(118,936)</u> | <u><b>416,872</b></u>             |
| <b>Total Funds</b>        | <u>460,343</u>                          | <u>91,618</u> | <u>(124,341)</u> | <u><b>427,620</b></u>             |

**Restricted funds are for the following purposes:**

Video Project – funded by BAD & Boehringer Ingelheim to produce a range of videos giving insight into the lives of people/families affected by Ichthyosis, sharing the experiences & challenges they face.

BAD (British Association of Dermatologists) – grant towards a project highlighting the work of ISG

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2025

## Notes to the financial statements (continued)

Goldsmiths My Story – Grant from the Goldsmiths charity to cover the cost of writing and creating the ISG My story booklet.

### Designated funds are for the following purposes:

Designated Grant fund – grants for research purposes

Designated salary fund – funds for one years salary costs for the Medical & Communications manager

Legacy fund – legacy money set aside whilst review conducted to agree its use

### 13. Analysis of net assets between funds

| <b>2025</b>              | <b>Un-<br/>restricted<br/>£</b> | <b>Designated<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|--------------------------|---------------------------------|-------------------------|-------------------------|--------------------|
| Fixed assets             | 1,099                           | -                       | -                       | 1,099              |
| Debtors                  | 14,659                          | -                       | -                       | 14,659             |
| Cash at bank and in hand | 55,706                          | 333,971                 | 13,426                  | 403,103            |
| Creditors                | (15,968)                        | -                       | -                       | (15,968)           |
| <b>Funds</b>             | <b>55,496</b>                   | <b>333,971</b>          | <b>13,426</b>           | <b>402,893</b>     |

| <b>2024</b>              | <b>Un-<br/>restricted<br/>£</b> | <b>Designated<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|--------------------------|---------------------------------|-------------------------|-------------------------|--------------------|
| Fixed assets             | 1,088                           | -                       | -                       | 1,088              |
| Debtors                  | 3,369                           | -                       | -                       | 3,369              |
| Cash at bank and in hand | 66,170                          | 352,730                 | 10,748                  | 429,648            |
| Creditors                | (6,485)                         | -                       | -                       | (6,485)            |
| <b>Funds</b>             | <b>64,142</b>                   | <b>352,730</b>          | <b>10,748</b>           | <b>427,620</b>     |

### 15. Related party transactions

Mandy Aldwin-Easton, the daughter of Margaret Aldwin, was paid £25,563, including pension contributions for employment as Medical and Marketing manager during the year. A fair and open recruitment campaign was carried out for the position and neither Mrs Aldwin-Easton or Mrs M Aldwin were part of the decision making process. Remuneration was set by the other trustees & at a level applicable to the role in the marketplace.

There were no further transactions with related parties during the year.

### 16. Controlling Interests

The charity is controlled by the Trustees.

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2025

## Notes to the financial statements (continued)

### 17. Prior year comparative Statement of Financial Activities

|                                                               | Un-<br>restricted<br>funds<br>2024 | Restricted<br>funds<br>2024 | Total<br>2024  |
|---------------------------------------------------------------|------------------------------------|-----------------------------|----------------|
| <b>Income from:</b>                                           | <b>£</b>                           | <b>£</b>                    | <b>£</b>       |
| Donations and legacies                                        | 57,481                             | -                           | 57,481         |
| Charitable Activities                                         | 27,293                             | -                           | 27,293         |
| Trading Activities                                            | 3,767                              | -                           | 3,767          |
| Investments                                                   | 3,077                              | -                           | 3,077          |
| <b>Total income</b>                                           | 91,618                             | -                           | 91,618         |
| <b>Expenditure on:</b>                                        |                                    |                             |                |
| Raising funds                                                 | 5,238                              | -                           | 5,238          |
| Charitable activities                                         | 113,698                            | 5,405                       | 119,103        |
| <b>Total Expenditure</b>                                      | 118,936                            | 5,405                       | 124,341        |
| <b>Net expenditure and net movement<br/>in funds for year</b> | (27,318)                           | (5,405)                     | (32,723)       |
| <b>Reconciliation of funds</b>                                |                                    |                             |                |
| Total funds brought forward                                   | 444,190                            | 16,153                      | 460,343        |
| <b>Total funds carried forward</b>                            | <b>416,872</b>                     | <b>10,748</b>               | <b>427,620</b> |

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# Accounts

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# Ichthyosis Support Group

(a Company Limited by Guarantee)

Trustees' Report and Financial Statements  
for the year ended 30 June 2024

Registered Company number 07609904

Registered Charity number 1142457

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2024

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## Report of the Trustees

The directors of Ichthyosis Group Support Ltd (“the charitable company”) are its Trustees for the purpose of charity law and throughout this report are collectively referred to as its Trustees. The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association, and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (updated 1 January 2019).

The Trustees have pleasure in presenting the charitable company’s report and financial statements for the year ended 30 June 2024.

### OBJECTIVES AND ACTIVITIES

#### Objects of the Charity as set out in the governing document:

1. Promote and protect the physical and mental health of sufferers of ichthyosis and any associated condition in the United Kingdom and the Republic of Ireland through the provision of financial assistance, support, education and practical advice;
2. Advance the education of the general public and medical profession in all areas relating to ichthyosis and any related condition, and its implication for the family;
3. Promote research into the management of ichthyosis and any associated condition and to publish the useful results of that research, and to support organisations worldwide promoting research into ichthyosis, and
4. Such other purposes as are charitable according to the laws of England and Wales for the benefit of the public.

#### Activities during the Period to Achieve its Objects and Obligations of Public Benefit:

- a) Maintain the telephone helpline available 24 hours per day, 7 days a week.
- b) Engage with new members to understand the support they may need.
- c) Maintain the ISG website, Facebook, Twitter, Instagram, LinkedIn and email helpline.
- d) Produce regular newsletters.
- e) Regular directors’ meetings at the office in addition to bi-monthly conference calls.
- f) Stage in person and online member events- for example:
  - June 2024 Family Day, Beaulieu Motor Museum
  - August 2023 Children’s activity camp – PGL Osmington Bay, Dorset
  - September 2023 Family Conference, Shrewsbury
  - October 2023 Children’s activity camp – PGL Caythorpe Court, Lincolnshire

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## Report of the Trustees (continued)

- a) Worked closely with a team of consultant dermatologists, dermatology nurse and an ophthalmologist known as the Medical Advisory Board, who provide appropriate information and answer questions posed by individuals affected by ichthyosis and the public.
- b) Worked closely with the Dermatology Council for England on dermatology issues affecting ichthyosis patients.
- c) Encourage and support all fund-raising efforts by way of promotional materials and sharing individuals' online fundraising pages via social media and other outlets.
- d) Applied for grants from other funding organisations.
- e) Continually raise awareness of ichthyosis particularly during the month of May, Ichthyosis Awareness Month.
- f) Filming commenced with a number of families for our video stories project.
- g) Directors and members representing ISG attended conferences, such as the British Association of Dermatologists (BAD) Annual meeting, and the British Dermatological Nursing Group (BDNG) Annual Conference in person, manning a stand advocating ichthyosis and the Ichthyosis Support Group.
- h) At the BDNG meeting, a director recorded a podcast with an ISG member. We also participated in a pharmaceutical industry meeting during the same event.
- i) A director presented online educating pediatricians, junior dermatologists and other healthcare professionals in May and June on 2 different pediatric dermatology courses.
- j) Liaised with researchers to share research news and developments including actively recruiting prospective participants.
- k) Continued attending the monthly ichthyosis clinic at Birmingham Children's hospital on the 1<sup>st</sup> Thursday of each month.
- l) Represented the Ichthyosis Support Group at international dermatology meetings including the 2<sup>nd</sup> World Congress on Rare Skin Diseases in Paris, the European Academy of Dermatology and Venereology (EADV) meeting in Berlin and the ERN-Skin Board Meeting in Paris.
- m) Input, feedback and subsequent sharing of various survey and research projects related to physical and/or mental health from other organisations relevant to our members.

### Grant Making

Should we receive suitable project applications and if funds allow, the Charity makes a grant for an amount to be decided from year to year and to be available for research projects. Applications are welcomed and assessed by the Medical Advisory Board.

Awarded grants of £20,116 to the Epidemiological Study of People Living with Ichthyoses in England, which will be paid in the next financial year and £1000 to the Genetic Skin Disease Database in Scotland.

### Volunteer's Contribution

Unpaid volunteers made valuable contributions to the efforts of the Charity during the year by networking with affected families, by raising funds and providing help at our national and other events, and to our Office Manager in the ISG office. We also have a number of dedicated volunteers that participate and are actively involved during our annual national event and children's camps. The dedicated team of 'Ambassadors' continue to support ISG members and activities.

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## Report of the Trustees (continued)

### ACHIEVEMENTS AND PERFORMANCE

In exercising their duties to achieve the objectives of the Charity as set out above, the directors have paid due regard to the Charity Commissioners' guidance on public benefit in deciding what the activities should be.

The following are the major achievements of the Charity during the reporting and subsequent period in fulfilling its objects and duty of public benefit:

- **ISG membership** continues to grow with over 1400 families from the UK and Ireland and a further 550 affected families worldwide;
- **The on-going reference service** to the general public on questions arising in relation to ichthyosis, through our help line, website and social networking, providing information from personal experiences and the professional knowledge of our Medical Advisory Board;
- **Increasing awareness** of ichthyosis amongst the general public by liaising with the media and known affected individuals to highlight the condition, resulting in nationwide media exposure;
- **Liaison with a number of pharmaceutical companies** to encourage grant provision, more research and commitment into better treatments for ichthyosis;
- **Liaison with hospitals** and NHS England to assist and advise their development of specialised clinics for ichthyosis and other rare genetic skin conditions;
- **Unity Lottery.** Maintain involvement to secure a regular monthly income for the charity;
- **Annual national event.** Since 1999, the ISG has organised and run a national event, welcoming members of all ages and severity of ichthyosis, to come together for either an informative and educational conference, or a relaxed Family Day at a suitable venue. These events are key in bringing individuals and families affected by ichthyosis together to gain and share knowledge about living with and managing ichthyosis. These events include medical professionals and pharmaceutical companies who bring their knowledge to help inform members on how better to live with ichthyosis, and to provide relevant updates on subjects related to managing life with a rare genetic skin condition;
- **ISG Youth Camps.** The ISG has since 2014 used PGL organised Youth Camps for young, affected individuals and their siblings. Organised activities include zip wire, orienteering, climbing etc. which helps the children meet with other affected children where they would not usually due to the rarity of the condition, increase their confidence, work as a team, and participate in ISG led discussions on social/psychological issues;
- **Fundraising.** Fundraising events were held including: Jeff Keen Virtual Golf Challenge (£6,160), Shane Kennedy, ISG Member ran the Cork Marathon (£2,300), Thames Bridges Trek 2023 (£632.40) Members IAM fundraising (£573.60), Member Barkwood House Christmas fundraiser (£829.43 online plus offline donations), Dan Butler, ISG Member 'Thresholds Race to the Stones' (£847).
- **Grants and Sponsorship.** We obtained support from but not limited to Quoin Pharmaceuticals (£25,000), Timber Pharmaceuticals (£2,000), Almirall (£7,500); Alliance (£2,972) and CeraVe & La Roche-Posay (£3,103.88), and Dermal (£3,328.18) in sponsorship of 3 newsletters.
- **Website.** The ISG's website continues to be maintained and developed.

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## **Report of the Trustees (continued)**

### **FUTURE PLANS**

We have organised an Ichthyosis Information Day in Perth, Scotland in September 2024 and an Ichthyosis Event at Barretstown, Ireland in October 2024. To make plans to expand the ISG's operational structure and activities and implement projects that resources and funds had not previously allowed.

### **FINANCIAL REVIEW**

As can be seen from the Statement of Financial Activities on page 11, largely due to a sizeable legacy received in 2021/22, there are unrestricted funds in excess of £416,000. To utilize our resource we are considering the following:

- Investment.
- Research grants.
- Grants for individuals affected by ichthyosis.
- Ichthyosis registry.
- Securing the future of the ISG via core costs.

Restricted funds of £10,748 remain to be spent in future years. After designated funds of £9,953 set aside for grants for research purposes, general funds of £64,142 in addition to the legacy fund of £342,777 are available for ongoing charitable purpose. Depending on decisions to be made with the legacy monies, additional funds may be allocated accordingly in the future.

Even though we received a generous legacy amount, once this is invested, we remain reliant on individual members and others carrying out fundraising efforts on the Charity's behalf, and our success at winning grants. In the future this could leave us vulnerable to substantial fluctuations of income and therefore we need to rigorously continue our efforts to keep them in good shape.

### **General Reserve Policy**

In view of the fact that much of the charity's income arises from grants, proceeds of special events, sponsorships and other fundraising efforts on a "one-off" basis, the reoccurrence of which cannot be guaranteed from one year to another, it is considered desirable to maintain a General Reserve Level equal to the core expenditure and other known commitments budgeted to occur in the following accounting year, less anticipated regular income in that year. This would require an amount of around £65,000. As at 30<sup>th</sup> June 2024, un-restricted free reserves were £63,054, which is just short of that required by our policy.

### **Review of the Reserve Policy**

The Reserve Policy is reviewed annually after the end of the financial year in the light of the results for that financial year, or earlier if there is any substantial change in the Charity's financial circumstances.

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## Report of the Trustees (continued)

### Risk Assessment

Trustees endeavour to identify the major risks to which the Charity is exposed and put in place procedures to manage such risks on an on-going basis. Appropriate insurance cover is held or taken out covering employment risks and such other risks that may be identified from time to time.

### FUNDS HELD AS A CUSTODIAN TRUSTEE

No such funds are held.

## STRUCTURE, GOVERNANCE AND MANAGEMENT

### Organisational Structure and Decision Making

The Board of directors meet a minimum of four times a year in person, or more often as necessary, in addition to numerous conference calls. They administer the Charity and take major and strategic decisions. Day-to-day functions are carried out by the Administrator and by some Board members.

### Governing Document

The governing document is the Articles of Association and subject to the provisions set out in the Companies Act 2006 and the Charities Act 2011, where applicable.

### Method of Recruitment and Appointment of Directors

Directors must be a member of the Charity and not be disqualified as a Director or Trustee by the Articles. No body or individual external to the Charity is permitted to appoint directors. Members are invited to put themselves forward or be nominated by other members as directors by means of newsletters circulated to all members by post or electronically, and invited to do so at General Meetings.

Directors are elected by the members at General Meetings for a term of three years. Directors may offer themselves for re-election at the end of their term of office.

The Board may at any time co-opt any individual who is qualified to be appointed as a director to fill a vacancy in their number or as an additional director. A co-opted director holds office until the next General Meeting at which they must stand for election by the members.

### Induction and Training of Directors

Once appointed, new directors receive appropriate training in their duties and responsibilities by reference to relevant literature including publications issued by the Charity Commissioners and advice and assistance from existing directors. Where possible, directors are encouraged to attend related training courses and seminars.

## REFERENCE AND ADMINISTRATIVE INFORMATION

### Trustees

Mandy Helen Aldwin-Easton (resigned 1 April 2024)

Margaret Aldwin

Raymond James Rowley

Paul William Whitehouse

Mudassar Ulhaq

Lee James Lancashire

Baljinder Sohi

Sarah Griffiths-Little (resigned 19 March 2024)

Tejvir Sohi (appointed 31 March 2024)

Kay Holby (appointed 31 March 2024)

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## Report of the Trustees (continued)

### Registered Office

Ichthyosis Support Group Also known as "ISG"  
562 Wokingham Road  
Earley  
Reading  
Berkshire  
RG6 7JB

**Company Registration Number:** 07609904

**Charity Registration Number:** 1142457

### Postal Address

Ichthyosis Support Group  
PO Box 1242  
Yateley  
GU47 7FL

### Office Address (storage only)

Ichthyosis Support Group  
Unit 7 Beacontree Plaza  
Gillette Way  
Reading  
RG2 0BS

### Office Address

1st Floor Left  
3 The Court Yard  
Denmark Street  
Wokingham  
RG40 2AZ

### Bankers

CAF Bank Limited  
25 Kings Hill Avenue  
Kings Hill  
West Malling  
Kent, ME19 4JQ

HSBC  
16-17 The Broadway  
Thatcham  
Newbury  
Berkshire, RG19 4HX

### Independent Examiner

Karen Hanlan  
Karen Hanlan Independent Examiner Ltd  
1 Saracen Close  
Ettington  
CV37 7SZ

### Solicitors

Blandy and Blandy LLP  
One Friar Street  
Reading  
Berkshire  
RG1 1DA

Approved by the Board and signed on its behalf by:

Lee Lancashire  
*Trustee*

Date: 24/3/25

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## **Statement of Trustees' responsibilities**

The Trustees are required to prepare financial statements for each financial year which give a true and fair view of the state of the affairs of the charitable company and of the surplus or deficit incurred by the charitable company for that year. In preparing those financial statements the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue to exist.

The Trustees have overall responsibility for ensuring that the charitable company has an appropriate system of controls, financial and otherwise.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy, at any time, the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006.

They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities and to provide reasonable assurance that:

- the charitable company is operating efficiently and effectively;
- its assets are safeguarded against un-authorised use or disposition;
- proper records are maintained and financial information used within the charity or for publication is reliable;
- the charitable company complies with relevant laws and regulations.

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## **Independent Examiner's Report to the Trustees of Ichthyosis Support Group ('the Company')**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 June 2024 which are set out on pages 11 to 23.

### **Responsibilities and basis of report**

As the charity trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

### **Independent examiner's statement**

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

- 1) accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- 2) the accounts do not accord with those records; or
- 3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
- 4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102).

I have no concerns and have come across no matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Karen Hanlan,  
Member of Institute of Chartered Accountants England & Wales  
Karen Hanlan Independent Examiner Ltd  
1 Saracen Close  
Ettington  
CV37 7SZ

Date: 24/3/25

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**Statement of Financial Activities (including an Income & Expenditure Account)**

|                                                                    |             | Un-<br>restricted<br>funds<br>2024 | Restricted<br>funds<br>2024 | Total<br>2024   | Total<br>2023 |
|--------------------------------------------------------------------|-------------|------------------------------------|-----------------------------|-----------------|---------------|
| <b>Income from:</b>                                                | <b>Note</b> | <b>£</b>                           | <b>£</b>                    | <b>£</b>        | <b>£</b>      |
| Donations and legacies                                             | 1           | 57,481                             | -                           | <b>57,481</b>   | 55,063        |
| Charitable Activities                                              | 2           | 27,293                             | -                           | <b>27,293</b>   | 42,500        |
| Trading Activities                                                 | 3           | 3,767                              | -                           | <b>3,767</b>    | 1,534         |
| Investments                                                        | 4           | 3,077                              | -                           | <b>3,077</b>    | 962           |
| <b>Total income</b>                                                |             | <b>91,618</b>                      | <b>-</b>                    | <b>91,618</b>   | 100,059       |
| <b>Expenditure on:</b>                                             |             |                                    |                             |                 |               |
| Raising funds                                                      | 5           | 5,238                              | -                           | <b>5,238</b>    | 5,770         |
| Charitable activities                                              | 6           | 113,698                            | 5,405                       | <b>119,103</b>  | 68,053        |
| <b>Total Expenditure</b>                                           |             | <b>118,936</b>                     | <b>5,405</b>                | <b>124,341</b>  | 73,823        |
| <b>Net (expenditure)/income and net movement in funds for year</b> |             | <b>(27,318)</b>                    | <b>(5,405)</b>              | <b>(32,723)</b> | 26,236        |
| <b>Reconciliation of funds</b>                                     |             |                                    |                             |                 |               |
| Total funds brought forward                                        |             | 444,190                            | 16,153                      | 460,343         | 434,107       |
| <b>Total funds carried forward</b>                                 |             | <b>416,872</b>                     | <b>10,748</b>               | <b>427,620</b>  | 460,343       |

The statement of financial activities includes all gains and losses recognised in the year.  
All income and expenditure derive from continuing activities.

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## Balance sheet

|                                                |       |                |          |
|------------------------------------------------|-------|----------------|----------|
| Company registered number 07609904             | Notes | <b>2024</b>    | 2023     |
|                                                |       | <b>£</b>       | <b>£</b> |
| <b>Fixed Assets</b>                            |       |                |          |
| Tangible assets                                | 9     | <b>1,088</b>   | 1,372    |
|                                                |       | <b>1,088</b>   | 1,372    |
| <b>Current Assets</b>                          |       |                |          |
| Debtors                                        | 10    | <b>3,369</b>   | 5,409    |
| Cash at bank and in hand                       |       | <b>429,648</b> | 468,488  |
|                                                |       | <b>433,017</b> | 473,897  |
| <b>Current Liabilities</b>                     |       |                |          |
| Creditors: amounts falling due within one year | 11    | <b>(6,485)</b> | (14,926) |
|                                                |       |                |          |
| Net current assets                             |       | <b>426,532</b> | 458,971  |
| <b>Net assets</b>                              |       | <b>427,620</b> | 460,343  |
| <b>The funds of the Charity:</b>               |       |                |          |
| Restricted Funds                               | 12    | <b>10,748</b>  | 16,153   |
| Unrestricted Funds                             |       |                |          |
| - general                                      |       | <b>64,142</b>  | 90,460   |
| - designated grant fund                        |       | <b>9,953</b>   | 10,953   |
| - designated legacy fund                       |       | <b>342,777</b> | 342,777  |
|                                                |       | <b>416,872</b> | 444,190  |
| <b>Total charity funds</b>                     |       | <b>427,620</b> | 460,343  |

The accompanying accounting policies and notes form part of these financial statements.

For the year ended 30 June 2024 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Responsibilities of directors/Trustees:

(a) The members have not required the charitable company to obtain an audit of its financial statements for the year in question in accordance with section 476 of the Companies Act 2006 - however, in accordance with section 145 of the Charities Act 2011 the financial statements have been examined by an independent examiner whose report appears on page 10.

(b) The directors/Trustees acknowledge their responsibility for complying with the requirements of the Companies Act with respect to accounting records and the preparation of accounts.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

Approved by the Trustees and signed on their behalf by:  
Lee Lancashire, Trustee

Date: 24/3/25

Ichthyosis Support Group  
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## Principal accounting policies

### Status of the company

The charitable company is limited by guarantee and does not have share capital. The liability of members is limited to £10 per member.

### Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (updated 1 January 2019) - (Charities SORP (FRS102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) and the Companies Act 2006.

Ichthyosis Support Group meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

### Going concern statement

The financial statements have been prepared on a going concern basis which assumes that the Charitable Company will continue to operate. The validity of this assumption is dependent upon the continuance of support from the Charitable Company's supporters and donors. The Charitable Company's current business plan shows that the Charitable Company will be able to operate in the foreseeable future. Based on this understanding, the directors believe that it remains appropriate to prepare the financial statements on a going concern basis. The financial statements do not include any adjustments, which would result from the basis of preparation being inappropriate.

### Funds

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations and grants subject to conditions imposed by the provider or by specific terms of the appeal under which the funds were raised. The restrictive conditions are binding upon the Charitable Company.

### Income

Income is recognised when the charitable company has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income relating to future periods, as a result of donor imposed conditions specifying the time period, has been treated as deferred income.

Income dependent on certain conditions, amounting to more than mere administrative requirements, is recognised when the conditions have been fulfilled.

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## Principal accounting policies (continued)

### Donated services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charitable company of the item is probable and the economic benefit can be measured reliably. In accordance with the Charities SORP FRS102, general volunteer time is not recognised.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charitable company which is the amount the charitable company would have been willing to pay to obtain the services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

### Investment income receivable

Bank interest and dividends are shown on the basis of amounts receivable in the year.

### Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charitable company to the expenditure. All expenditure is accounted for on an accruals basis. Expenditure is classified under the following activity headings:

- Costs of raising funds comprises the costs of staff time, publicity and other costs associated with raising income.
- Expenditure on charitable activities includes the costs of direct charitable activities undertaken to further the purposes of the charity and their associated support & governance costs.

### Tangible fixed assets

Depreciation is provided at a rate calculated to write off the cost on a straight line basis over a period of less than the estimated useful life of the assets as follows:

|                                                  |               |
|--------------------------------------------------|---------------|
| Computer equipment, Office equipment & furniture | 20% per annum |
|--------------------------------------------------|---------------|

Fixed asset purchases above £500 are capitalised.

### Fixed asset investments

Fixed asset investments comprise listed investments and are included at market value. Listed investments are included at closing mid-market value at the balance sheet date. Any gain or loss on revaluation is taken to the Statement of Financial Activities.

### Cash and cash equivalents

Cash and cash equivalents include cash at bank and in hand and short term deposits repayable within a three month notice period.

### Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

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## Principal accounting policies (continued)

### Creditors

Creditors are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.

### Taxation

As a registered charity with no trading activities, no provision is considered necessary for taxation.

### Pension costs

The charity contributes into a Group Personal Pension Plan for employees. This pension plan is defined contribution in nature and as required under FRS102 the annual cost is recognised as incurred and included in the Statement of Financial Activities.

### Foreign exchange movements

The charity has a Euro bank account to receive funds raised by members in the Republic of Ireland. The balance is converted to sterling at the year end rate and any exchange movements are taken to the Statement of Financial Activities and treated as 'Other income/Expense'.

### Cash flow

Under Charities SORP FRS102, update bulletin 1, as a small charity there is no requirement to produce a cashflow statement.

## Notes to the financial statements

### 1. Income from donations and legacies

|                                                 | 2024          | 2023          |
|-------------------------------------------------|---------------|---------------|
|                                                 | £             | £             |
| <b>Un-restricted:</b>                           |               |               |
| Donations                                       | 49,981        | 29,498        |
| Grants                                          | -             | 2,862         |
| Gifts in kind                                   | 7,500         | 7,500         |
| Total un-restricted grants & donations          | 57,481        | 39,860        |
| <b>Restricted grants &amp; donations:</b>       |               |               |
| British Association of Dermatologists ('BAD')   | -             | 6,933         |
| Boehringer Ingelheim International GmbH         | -             | 8,270         |
| Total restricted grants                         | -             | 15,203        |
| <b>Total income from donations and legacies</b> | <b>57,481</b> | <b>55,063</b> |

Gifts in kind relate to office & meetings space provided free of charge.

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## Notes to the financial statements (continued)

### 2. Income from charitable activities

|                                                | 2024          | 2023          |
|------------------------------------------------|---------------|---------------|
|                                                | £             | £             |
| Corporate sponsorship                          | 26,904        | 42,500        |
| Other charitable services provided             | 389           | -             |
| <b>Total income from charitable activities</b> | <b>27,293</b> | <b>42,500</b> |

### 3. Income from trading activities

|                                             | 2024         | 2023         |
|---------------------------------------------|--------------|--------------|
|                                             | £            | £            |
| Promotional material                        | 2,721        | 436          |
| Unity Lottery                               | 1,046        | 1,098        |
| <b>Total income from trading activities</b> | <b>3,767</b> | <b>1,534</b> |

### 4. Income from investments

|                                      | 2024         | 2023       |
|--------------------------------------|--------------|------------|
|                                      | £            | £          |
| Bank interest                        | 3,077        | 334        |
| Dividends                            | -            | 628        |
| <b>Total income from investments</b> | <b>3,077</b> | <b>962</b> |

### 5. Analysis of expenditure on raising funds

|                                    | 2024         | 2023         |
|------------------------------------|--------------|--------------|
|                                    | £            | £            |
| Staff costs                        | 5,012        | 5,239        |
| Other fundraising costs            | 226          | 531          |
| <b>Total cost of raising funds</b> | <b>5,238</b> | <b>5,770</b> |

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## Notes to the financial statements (continued)

### 6. Analysis of expenditure on charitable activities

| <b>2024</b>                                       | <b>Un-<br/>restricted</b> | <b>Designated</b> | <b>Restricted</b> | <b>Total</b>   |
|---------------------------------------------------|---------------------------|-------------------|-------------------|----------------|
|                                                   | <b>£</b>                  | <b>£</b>          | <b>£</b>          | <b>£</b>       |
| Staff costs                                       | 20,047                    | -                 | -                 | <b>20,047</b>  |
| Family day/Conference/Youth Camp                  | 41,204                    | -                 | -                 | <b>41,204</b>  |
| Research grant                                    | -                         | 1,000             | -                 | <b>1,000</b>   |
| Video project                                     | -                         | -                 | 5,405             | <b>5,405</b>   |
| Printing, office and administration costs         | 13,581                    | -                 | -                 | <b>13,581</b>  |
| Rent – in kind                                    | 7,500                     | -                 | -                 | <b>7,500</b>   |
| Insurance                                         | 564                       | -                 | -                 | <b>564</b>     |
| Newsletter production & postage                   | 6,203                     | -                 | -                 | <b>6,203</b>   |
| Telephone, postage & IT costs                     | 5,593                     | -                 | -                 | <b>5,593</b>   |
| Travel & accommodation                            | 3,979                     | -                 | -                 | <b>3,979</b>   |
| CRM                                               | 1,086                     | -                 | -                 | <b>1,086</b>   |
| Membership fees                                   | 449                       | -                 | -                 | <b>449</b>     |
| Trustee expenses                                  | 8,117                     | -                 | -                 | <b>8,117</b>   |
| Independent examiner fees                         | 1,100                     | -                 | -                 | <b>1,100</b>   |
| Legal/professional fees                           | 1,272                     | -                 | -                 | <b>1,272</b>   |
| Bank charges                                      | 268                       | -                 | -                 | <b>268</b>     |
| Depreciation                                      | 1,735                     | -                 | -                 | <b>1,735</b>   |
| <b>Total expenditure on charitable activities</b> | <b>112,698</b>            | <b>1,000</b>      | <b>5,405</b>      | <b>119,103</b> |

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## Notes to the financial statements (continued)

| <b>2023</b>                                       | <b>Un-<br/>restricted<br/>£</b> | <b>Designated<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|---------------------------------------------------|---------------------------------|-------------------------|-------------------------|--------------------|
| Staff costs                                       | 20,957                          |                         | -                       | <b>20,957</b>      |
| Family day/Conference/Youth Camp                  | 7,349                           |                         | -                       | <b>7,349</b>       |
| Training                                          | 300                             |                         | -                       | <b>300</b>         |
| Research grant                                    | -                               | 1,200                   | -                       | <b>1,200</b>       |
| Printing, office and administration costs         | 5,768                           |                         | 520                     | <b>6,288</b>       |
| Rent – in kind                                    | 7,500                           |                         | -                       | <b>7,500</b>       |
| Insurance                                         | 573                             |                         | -                       | <b>573</b>         |
| Newsletter production & postage                   | 9,632                           |                         | -                       | <b>9,632</b>       |
| Telephone, postage & IT costs                     | 3,063                           |                         | 57                      | <b>3,120</b>       |
| Travel & accommodation                            | 180                             |                         | -                       | <b>180</b>         |
| CRM                                               | 417                             |                         | -                       | <b>417</b>         |
| Membership fees                                   | 212                             |                         | -                       | <b>212</b>         |
| Trustee expenses                                  | 5,730                           |                         | -                       | <b>5,730</b>       |
| Independent examiner fees                         | 1,100                           |                         | -                       | <b>1,100</b>       |
| Legal/professional fees                           | 1,835                           |                         | -                       | <b>1,835</b>       |
| Bank charges                                      | 287                             |                         | -                       | <b>287</b>         |
| Depreciation                                      | 1,373                           |                         | -                       | <b>1,373</b>       |
| <b>Total expenditure on charitable activities</b> | <b>66,276</b>                   | <b>1,200</b>            | <b>577</b>              | <b>68,053</b>      |

### 7. Net expenditure for the year

|                                                        | <b>2024<br/>£</b> | <b>2023<br/>£</b> |
|--------------------------------------------------------|-------------------|-------------------|
| Net expenditure for the year is stated after charging: |                   |                   |
| Depreciation                                           | <b>1,735</b>      | 1,373             |
| Independent examiners fees -                           |                   |                   |
| Independent examination                                | <b>940</b>        | 940               |
| Accountancy services                                   | <b>160</b>        | 160               |

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2024

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## Notes to the financial statements (continued)

### 8. Analysis of staff costs, trustee remuneration and expenses

|                                    | 2024          | 2023          |
|------------------------------------|---------------|---------------|
|                                    | £             | £             |
| Salaries                           | 24,511        | 23,965        |
| National Insurance                 | -             | 1,601         |
| Pension                            | 548           | 532           |
| Payments in respect of prior years | -             | 98            |
| Total                              | <u>25,059</u> | <u>26,196</u> |

### Staff Numbers

|                                                           | Number      | Number      |
|-----------------------------------------------------------|-------------|-------------|
| Average number of full-time equivalent excluding Trustees | <u>0.67</u> | <u>0.67</u> |

No employees had employee benefits in excess of £60,000 (2023: nil).

The charitable company's trustees were not paid or received any other benefits from employment with the charity in the year. Trustee expenses of £6,988 for travel, subsistence and family day costs were reimbursed to 9 Trustees during the year (2023: £5,590, 9 Trustees).

The key management personnel of the charity comprise the trustees and the part time Office Manager, Trustees receive no remuneration or other benefits from the charity. The remuneration of key management personnel (including pension contributions) for the year was £25,059 (2023: £26,098).

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2024

## Notes to the financial statements (continued)

### 9. Tangible fixed assets

|                       | <b>2024</b>                                            | 2023                                      |
|-----------------------|--------------------------------------------------------|-------------------------------------------|
|                       | <b>Fixture,<br/>fittings &amp;<br/>equipment<br/>£</b> | Fixtures,<br>fittings &<br>equipment<br>£ |
| <b>Cost</b>           |                                                        |                                           |
| At beginning of year  | <b>7,682</b>                                           | 7,682                                     |
| Additions             | <b>1,451</b>                                           | -                                         |
|                       | <hr/> <b>9,133</b>                                     | <hr/> 7,682                               |
| At end of year        | <hr/> <b>9,133</b>                                     | <hr/> 7,682                               |
| <b>Depreciation</b>   |                                                        |                                           |
| At beginning of year  | <b>6,310</b>                                           | 4,937                                     |
| Charge for the year   | <b>1,735</b>                                           | 1,373                                     |
|                       | <hr/> <b>8,045</b>                                     | <hr/> 6,310                               |
| At end of year        | <hr/> <b>8,045</b>                                     | <hr/> 6,310                               |
| <b>Net Book Value</b> |                                                        |                                           |
| At end of year        | <hr/> <b>1,088</b>                                     | <hr/> 1,372                               |

### 10. Debtors

|             | <b>2024</b>        | <b>2023</b> |
|-------------|--------------------|-------------|
|             | <b>£</b>           | <b>£</b>    |
| Prepayments | <b>3,369</b>       | 5,409       |
|             | <hr/> <b>3,369</b> | <hr/> 5,409 |

### 11. Creditors: amounts falling due within one year

|                              | <b>2024</b>        | 2023         |
|------------------------------|--------------------|--------------|
|                              | <b>£</b>           | <b>£</b>     |
| Trade Creditors              | <b>1,564</b>       | 4,124        |
| Taxation and social security | <b>1,121</b>       | 1,102        |
| Accruals                     | <b>2,300</b>       | 2,200        |
| Deferred income              | <b>1,500</b>       | -            |
| Overpayment                  | <b>-</b>           | 7,500        |
|                              | <hr/> <b>6,485</b> | <hr/> 14,926 |

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2024

## Notes to the financial statements (continued)

### 12. Funds

| <b>2024</b>               | Balance at<br>beginning of<br>year<br>£ | <b>Income</b><br>£ | <b>Expenditure</b><br>£ | <b>Balance<br/>at end of<br/>year<br/>£</b> |
|---------------------------|-----------------------------------------|--------------------|-------------------------|---------------------------------------------|
| <b>Restricted funds</b>   |                                         |                    |                         |                                             |
| BAD Video project         | 6,933                                   | -                  | (5,405)                 | <b>1,528</b>                                |
| Boehringer Video project  | 8,270                                   | -                  | -                       | <b>8,270</b>                                |
| Goldsmiths My Story       | 433                                     | -                  | -                       | <b>433</b>                                  |
| Scottish Event            | 517                                     | -                  | -                       | <b>517</b>                                  |
|                           | <u>16,153</u>                           | <u>-</u>           | <u>(5,405)</u>          | <u><b>10,748</b></u>                        |
| <b>Unrestricted funds</b> |                                         |                    |                         |                                             |
| Designated grant fund     | 10,953                                  | -                  | (1,000)                 | <b>9,953</b>                                |
| Designated legacy fund    | 342,777                                 | -                  | -                       | <b>342,777</b>                              |
| General fund              | 90,460                                  | 91,618             | (117,936)               | <b>64,142</b>                               |
|                           | <u>444,190</u>                          | <u>91,618</u>      | <u>(118,936)</u>        | <u><b>416,872</b></u>                       |
| <b>Total Funds</b>        | <u>460,343</u>                          | <u>91,618</u>      | <u>(124,341)</u>        | <u><b>427,620</b></u>                       |

| <b>2023</b>               | Balance at<br>beginning of<br>year<br>£ | <b>Income</b><br>£ | <b>Expenditure</b><br>£ | <b>Balance<br/>at end of<br/>year<br/>£</b> |
|---------------------------|-----------------------------------------|--------------------|-------------------------|---------------------------------------------|
| <b>Restricted funds</b>   |                                         |                    |                         |                                             |
| BAD Telecon               | 520                                     | -                  | (520)                   | -                                           |
| BAD Quickbooks            | 57                                      | -                  | (57)                    | -                                           |
| BAD Video project         | -                                       | 6,933              | -                       | <b>6,933</b>                                |
| Boehringer Video project  | -                                       | 8,270              | -                       | <b>8,270</b>                                |
| Goldsmiths My Story       | 433                                     | -                  | -                       | <b>433</b>                                  |
| Scottish Event            | 517                                     | -                  | -                       | <b>517</b>                                  |
|                           | <u>1,527</u>                            | <u>15,203</u>      | <u>(577)</u>            | <u><b>16,153</b></u>                        |
| <b>Unrestricted funds</b> |                                         |                    |                         |                                             |
| Designated grant fund     | 12,153                                  | -                  | (1,200)                 | <b>10,953</b>                               |
| Designated legacy fund    | 342,777                                 | -                  | -                       | <b>342,777</b>                              |
| General fund              | 77,650                                  | 84,856             | (72,046)                | <b>90,460</b>                               |
|                           | <u>432,580</u>                          | <u>84,856</u>      | <u>(73,246)</u>         | <u><b>444,190</b></u>                       |
| <b>Total Funds</b>        | <u>434,107</u>                          | <u>100,059</u>     | <u>(73,823)</u>         | <u><b>460,343</b></u>                       |

#### Restricted funds are for the following purposes:

Video Project – funded by BAD & Boehringer Ingelheim to produce a range of videos giving insight into the lives of people/families affected by ichthyosis, sharing the experiences & challenges they face.

BAD grants - Grants from BAD Quickbooks, Zoom & Zoho for ongoing subscriptions

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## Notes to the financial statements (continued)

Goldsmiths My Story – Grant from the Goldsmiths charity to cover the cost of writing and creating the ISG My story booklet.

### Designated funds are for the following purposes:

General Grant fund – grants for research purposes

Legacy fund – legacy money set aside whilst review conducted to agree its use

### 13. Analysis of net assets between funds

| <b>2024</b>              | <b>Un-<br/>restricted<br/>£</b> | <b>Designated<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|--------------------------|---------------------------------|-------------------------|-------------------------|--------------------|
| Fixed assets             | 1,088                           | -                       | -                       | 1,088              |
| Debtors                  | 3,369                           | -                       | -                       | 3,369              |
| Cash at bank and in hand | 66,170                          | 352,730                 | 10,748                  | 429,648            |
| Creditors                | (6,485)                         | -                       | -                       | (6,485)            |
| <b>Funds</b>             | <b>64,142</b>                   | <b>352,730</b>          | <b>10,748</b>           | <b>427,620</b>     |

  

| <b>2023</b>              | <b>Un-<br/>restricted<br/>£</b> | <b>Designated<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|--------------------------|---------------------------------|-------------------------|-------------------------|--------------------|
| Fixed assets             | 1,372                           | -                       | -                       | 1,372              |
| Debtors                  | 5,409                           | -                       | -                       | 5,409              |
| Cash at bank and in hand | 98,605                          | 353,730                 | 16,153                  | 468,488            |
| Creditors                | (14,926)                        | -                       | -                       | (14,926)           |
| <b>Funds</b>             | <b>90,460</b>                   | <b>353,730</b>          | <b>16,153</b>           | <b>460,343</b>     |

### 15. Related party transactions

Mandy Aldwin-Easton, a Trustee to 1 April 2024 and daughter of Margaret Aldwin, was paid £6,293 including pension contributions for employment as Medical and Communications manager from 1 April 2024. A fair and open recruitment campaign was carried out for the position and neither Mrs Aldwin-Easton or Mrs M Aldwin were part of the decision making process. Remuneration was set by the other trustees & at a level applicable to the role in the marketplace. Mrs Aldwin-Easton resigned as Trustee in order to take up the role.

There were no further transactions with related parties during the year.

### 16. Controlling Interests

The charity is controlled by the Trustees.

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for the year ended 30 June 2024

## Notes to the financial statements (continued)

### 17. Prior year comparative Statement of Financial Activities

|                                                      | Un-<br>restricted<br>funds<br>2023 | Restricted<br>funds<br>2023 | Total<br>2023  |
|------------------------------------------------------|------------------------------------|-----------------------------|----------------|
| Income from:                                         | £                                  | £                           | £              |
| Donations and legacies                               | 39,860                             | 15,203                      | 55,063         |
| Charitable Activities                                | 42,500                             | -                           | 42,500         |
| Trading Activities                                   | 1,534                              | -                           | 1,534          |
| Investments                                          | 962                                | -                           | 962            |
| <b>Total income</b>                                  | <b>84,856</b>                      | <b>15,203</b>               | <b>100,059</b> |
| <b>Expenditure on:</b>                               |                                    |                             |                |
| Raising funds                                        | 5,770                              | -                           | 5,770          |
| Charitable activities                                | 67,476                             | 577                         | 68,053         |
| <b>Total Expenditure</b>                             | <b>73,246</b>                      | <b>577</b>                  | <b>73,823</b>  |
| <b>Net income and net movement in funds for year</b> | <b>11,610</b>                      | <b>14,626</b>               | <b>26,236</b>  |
| <b>Reconciliation of funds</b>                       |                                    |                             |                |
| Total funds brought forward                          | 432,580                            | 1,527                       | 434,107        |
| <b>Total funds carried forward</b>                   | <b>444,190</b>                     | <b>16,153</b>               | <b>460,343</b> |

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# Accounts

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# Ichthyosis Support Group

(a Company Limited by Guarantee)

Trustees' Report and Financial Statements  
for the year ended 30 June 2023

Registered Company number 07609904

Registered Charity number 1142457

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2023

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## Report of the Trustees

The directors of Ichthyosis Group Support Ltd (“the charitable company”) are its Trustees for the purpose of charity law and throughout this report are collectively referred to as its Trustees. The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association, and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (updated 1 January 2019).

The Trustees have pleasure in presenting the charitable company’s report and financial statements for the year ended 30 June 2023.

## OBJECTIVES AND ACTIVITIES

### Objects of the Charity as set out in the governing document:

1. Promote and protect the physical and mental health of sufferers of ichthyosis and any associated condition in the United Kingdom and the Republic of Ireland through the provision of financial assistance, support, education and practical advice;
2. Advance the education of the general public and medical profession in all areas relating to ichthyosis and any related condition, and its implication for the family;
3. Promote research into the management of ichthyosis and any associated condition and to publish the useful results of that research, and to support organisations worldwide promoting research into ichthyosis, and
4. Such other purposes as are charitable according to the laws of England and Wales for the benefit of the public.

### Activities during the Period to Achieve its Objects and Obligations of Public Benefit:

- a) Maintain the telephone help line available 24 hours per day, 7 days a week.
- b) Maintain the ISG website, Facebook, Twitter, Instagram, LinkedIn and email help line.
- c) Produce regular newsletters.
- d) Regular directors’ meetings at the office in addition to bi-monthly conference calls.
- e) Stage in person and online member events:
  - November 2022 Epidermolytic ichthyosis online discussion and Q&A
  - September 2022 Skincare treatment online discussion and Q&A
  - August 2022 Children’s activity camp – PGL Liddington
  - July 2022 Online ichthyosis webinar with St John’s Dermatology Academy
  - July 2022 Children’s activity camp – PGL Caythorpe
  - July 2022 Netherton syndrome online discussion and Q&A

Ichthyosis Support Group  
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## Report of the Trustees (continued)

- a) Work closely with a team of consultant dermatologists and an ophthalmologist known as the Medical Advisory Board, who provide appropriate information and answer questions posed by individuals affected by ichthyosis and the public.
- b) Work closely with the Dermatology Council for England on dermatology issues affecting ichthyosis patients.
- c) Encourage and support all fund-raising efforts by way of promotional materials and sharing individuals' online fundraising pages via social media and other outlets.
- d) Apply for grants from other funding organisations.
- e) Continually raise awareness of ichthyosis particularly during the month of May, Ichthyosis Awareness Month.
- f) Directors and members representing ISG attended conferences, such as the British Society of Pediatric and Adolescent Dermatology (BSPAD) British Association of Dermatologists (BAD) Annual meeting, and the British Dermatological Nursing Group (BDNG) Annual Conference in person, manning a stand advocating ichthyosis and the Ichthyosis Support Group. Also at this BDNG meeting, a director teamed up with a clinical nurse specialist to present a session about the ichthyoses. Director presented online educating pediatricians, junior dermatologists and other healthcare professionals in May, June and November on 4 different pediatric dermatology courses.
- g) Liaise with researchers to share research news and developments including actively recruiting prospective participants.
- h) Started attending the monthly ichthyosis clinic at Birmingham Children's hospital on the 1<sup>st</sup> Thursday of each month.
- i) Representing the Ichthyosis Support Group at international dermatology meetings including the European Society of Dermatology Research (ESDR) and Global Skin Conference.

### Grant Making

Should we receive suitable project applications and if funds allow, the Charity makes a grant for an amount to be decided from year to year and to be available for research projects. Applications are welcomed and assessed by the Medical Advisory Board.

### Volunteer's Contribution

Unpaid volunteers made valuable contributions to the efforts of the Charity during the year by networking with affected families, by raising funds and providing help at our national and other events, and to our administrator in the ISG office. We also have a number of dedicated volunteers that participate and are actively involved during our annual national event and children's camps. The dedicated team of 'Ambassadors' continue to support ISG members and activities.

### ACHIEVEMENTS AND PERFORMANCE

In exercising their duties to achieve the objects of the Charity as set out above, the directors have paid due regard to the Charity Commissioners' guidance on public benefit in deciding what the activities should be.

Ichthyosis Support Group  
Financial Statements  
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## Report of the Trustees (continued)

The following are the major achievements of the Charity during the reporting and subsequent period in fulfilling its objects and duty of public benefit:

- **ISG membership** continues to grow with over 1300 families from the UK and Ireland and a further 500 affected families worldwide;
- **The on-going reference service** to the general public on questions arising in relation to ichthyosis, through our help line, website and social networking, providing information from personal experiences and the professional knowledge of our Medical Advisory Board;
- **Increasing awareness** of ichthyosis amongst the general public by liaising with the media and known affected individuals to highlight the condition, resulting in nationwide media exposure;
- **Liaison with a number of pharmaceutical companies** to encourage grant provision, more research and commitment into better treatments for ichthyosis;
- **Liaison with hospitals** and NHS England to assist and advise their development of specialised clinics for ichthyosis and other rare genetic skin conditions;
- **Unity Lottery.** Maintain involvement to secure a regular monthly income for the charity;
- **Annual national event.** Since 1999, the ISG has organised and run a national event, welcoming members of all ages and severity of ichthyosis, to come together for either an informative and educational conference, or a relaxed Family Day at a suitable venue. These events are key in bringing individuals and families affected by ichthyosis together to gain and share knowledge about living with and managing ichthyosis. These events include medical professionals and pharmaceutical companies who bring their knowledge to help inform members on how better to live with ichthyosis, and to provide relevant updates on subjects related to managing life with a rare genetic skin condition;
- **ISG Youth Camps.** The ISG has since 2014 used PGL organised Youth Camps for young, affected individuals and their siblings. Organised activities include zip wire, orienteering, climbing etc. which helps the children meet with other affected children where they would not usually due to the rarity of the condition, increase their confidence, work as a team, and participate in ISG led discussions on social/psychological issues;
- **Fundraising.** 25<sup>th</sup> Anniversary fundraising reached its goal of £25,000 for research. Fundraising events were held including: Challenge 25 campaign raised money through themed challenges by a number of member's efforts, Thames Bridges Trek £4629.32, Tea Parties, James Cook London Marathon £935.00, Women's Mini Marathon in Dublin;
- **Grants and Sponsorship.** We obtained support from Fontus Health (£10,000), Quoin Pharmaceuticals (£25,000) & Almirall (£7,500) and Dermal (£2,862.43) in sponsorship of a newsletter;
- **Website.** The ISG's website continues to be maintained and developed.

## FUTURE PLANS

We have organised a Family Conference in Shrewsbury for September 2023 and Children's camps during Autumn 2023. To make plans to expand the ISG's operational structure and activities and implement projects that resources and funds had not previously allowed.

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2023

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## **Report of the Trustees (continued)**

### **FINANCIAL REVIEW**

As can be seen from the Statement of Financial Activities on page 11, largely due to a sizeable legacy received in 2021/22, there are unrestricted funds in excess of £460,000. To utilize our resource we are considering the following:

- Investment.
- Research grants.
- Grants for individuals affected by ichthyosis.
- Ichthyosis registry.
- Securing the future of the ISG via core costs.

Restricted funds of £16,153 remain to be spent in future years. After designated funds of £10,953 set aside for grants for research purposes, general funds of £90,460 in addition to the legacy fund of £342,777 are available for ongoing charitable purpose. Depending on decisions to be made with the legacy monies, additional funds may be allocated accordingly in the future.

Even though we received a generous legacy amount, once this is invested, we remain reliant on individual members and others carrying out fundraising efforts on the Charity's behalf, and our success at winning grants. In the future this could leave us vulnerable to substantial fluctuations of income and therefore we need to rigorously continue our efforts to keep them in good shape.

### **General Reserve Policy**

In view of the fact that much of the charity's income arises from grants, proceeds of special events, sponsorships and other fundraising efforts on a "one-off" basis, the reoccurrence of which cannot be guaranteed from one year to another, it is considered desirable to maintain a General Reserve Level equal to the core expenditure and other known commitments budgeted to occur in the following accounting year, less anticipated regular income in that year. This would require an amount of around £65,000. As at 30<sup>th</sup> June 2023, un-restricted free reserves were £90,460, which is above that required by our policy.

### **Review of the Reserve Policy**

The Reserve Policy is reviewed annually after the end of the financial year in the light of the results for that financial year, or earlier if there is any substantial change in the Charity's financial circumstances.

### **Risk Assessment**

Trustees endeavour to identify the major risks to which the Charity is exposed and put in place procedures to manage such risks on an on-going basis. Appropriate insurance cover is held or taken out covering employment risks and such other risks that may be identified from time to time.

### **FUNDS HELD AS A CUSTODIAN TRUSTEE**

No such funds are held.

## **Report of the Trustees (continued)**

### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

#### **Organisational Structure and Decision Making**

The Board of directors meet a minimum of four times a year or more often as necessary, administer the Charity and take major and strategic decisions. Day-to-day functions are carried out by the Administrator and by some Board members.

#### **Governing Document**

The governing document is the Articles of Association and subject to the provisions set out in the Companies Act 2006 and the Charities Act 2011, where applicable.

#### **Method of Recruitment and Appointment of Directors**

Directors must be a member of the Charity and not be disqualified as a Director or Trustee by the Articles. No body or individual external to the Charity is permitted to appoint directors. Members are invited to put themselves forward or be nominated by other members as directors by means of newsletters circulated to all members by post or electronically, and invited to do so at General Meetings.

Directors are elected by the members at General Meetings for a term of three years. Directors may offer themselves for re-election at the end of their term of office.

The Board may at any time co-opt any individual who is qualified to be appointed as a director to fill a vacancy in their number or as an additional director. A co-opted director holds office until the next General Meeting at which they must stand for election by the members.

#### **Induction and Training of Directors**

Once appointed, new directors receive appropriate training in their duties and responsibilities by reference to relevant literature including publications issued by the Charity Commissioners and advice and assistance from existing directors. Where possible, directors are encouraged to attend related training courses and seminars.

### **REFERENCE AND ADMINISTRATIVE INFORMATION**

#### **Trustees**

Mandy Helen Aldwin-Easton

Margaret Aldwin

Susan Corbett (resigned 1 January 2023)

Raymond James Rowley

Paul William Whitehouse

Mudassar Ulhaq

Lee James Lancashire

Sarah Griffiths-Little

Baljinder Sohi (appointed 10 June 2023)

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for the year ended 30 June 2023

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## Report of the Trustees (continued)

### Registered Office

Ichthyosis Support Group Also known as "ISG"  
562 Wokingham Road  
Earley  
Reading  
Berkshire  
RG6 7JB

**Company Registration Number:** 07609904

**Charity Registration Number:** 1142457

### Postal Address

Ichthyosis Support Group  
PO Box 1242  
Yateley  
GU47 7FL

### Office Address (storage only)

Ichthyosis Support Group  
Unit 7 Beacontree Plaza  
Gillette Way  
Reading  
RG2 0BS

### Office Address

1st Floor Left  
3 The Court Yard  
Denmark Street  
Wokingham  
RG40 2AZ

### Bankers

CAF Bank Limited  
25 Kings Hill Avenue  
Kings Hill  
West Malling  
Kent, ME19 4JQ

HSBC  
16-17 The Broadway  
Thatcham  
Newbury  
Berkshire, RG19 4HX

### Independent Examiner

Karen Hanlan  
Karen Hanlan Independent Examiner Ltd  
1 Saracen Close  
Ettington  
CV37 7SZ

### Solicitors

Blandy and Blandy LLP  
One Friar Street  
Reading  
Berkshire  
RG1 1DA

Approved by the Board and signed on its behalf by:

Lee Lancashire  
*Trustee*

Date: 21 January 2024

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2023

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## **Statement of Trustees' responsibilities**

The Trustees are required to prepare financial statements for each financial year which give a true and fair view of the state of the affairs of the charitable company and of the surplus or deficit incurred by the charitable company for that year. In preparing those financial statements the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue to exist.

The Trustees have overall responsibility for ensuring that the charitable company has an appropriate system of controls, financial and otherwise.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy, at any time, the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006.

They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities and to provide reasonable assurance that:

- the charitable company is operating efficiently and effectively;
- its assets are safeguarded against un-authorised use or disposition;
- proper records are maintained and financial information used within the charity or for publication is reliable;
- the charitable company complies with relevant laws and regulations.

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for the year ended 30 June 2023

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## **Independent Examiner's Report to the Trustees of Ichthyosis Support Group ('the Company')**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 June 2023 which are set out on pages 11 to 23.

### **Responsibilities and basis of report**

As the charity trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

### **Independent examiner's statement**

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

- 1) accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- 2) the accounts do not accord with those records; or
- 3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
- 4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102).

I have no concerns and have come across no matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Karen Hanlan,  
Member of Institute of Chartered Accountants England & Wales  
Karen Hanlan Independent Examiner Ltd  
1 Saracen Close  
Ettington  
CV37 7SZ

Date: 21 January 2024

Ichthyosis Support Group  
Financial Statements  
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**Statement of Financial Activities (including an Income & Expenditure Account)**

|                                                                    |             | Un-<br>restricted<br>funds<br>2023 | Restricted<br>funds<br>2023 | Total<br>2023  | Total<br>2022  |
|--------------------------------------------------------------------|-------------|------------------------------------|-----------------------------|----------------|----------------|
| <b>Income from:</b>                                                | <b>Note</b> | <b>£</b>                           | <b>£</b>                    | <b>£</b>       | <b>£</b>       |
| Donations and legacies                                             | 1           | 39,860                             | 15,203                      | <b>55,063</b>  | 57,835         |
| Charitable Activities                                              | 2           | 42,500                             | -                           | <b>42,500</b>  | 500            |
| Trading Activities                                                 | 3           | 1,534                              | -                           | <b>1,534</b>   | 10,475         |
| Investments                                                        | 4           | 962                                | -                           | <b>962</b>     | 21             |
| Other income                                                       |             | -                                  | -                           | -              | 117            |
| <b>Total income</b>                                                |             | <b>84,856</b>                      | <b>15,203</b>               | <b>100,059</b> | <b>68,948</b>  |
| <b>Expenditure on:</b>                                             |             |                                    |                             |                |                |
| Raising funds                                                      | 5           | 5,770                              | -                           | <b>5,770</b>   | 5,330          |
| Charitable activities                                              | 6           | 67,476                             | 577                         | <b>68,053</b>  | 72,591         |
| <b>Total Expenditure</b>                                           |             | <b>73,246</b>                      | <b>577</b>                  | <b>73,823</b>  | <b>77,921</b>  |
| Net gains on investments                                           |             | -                                  | -                           | -              | 633            |
| <b>Net income/(expenditure) and net movement in funds for year</b> |             | <b>11,610</b>                      | <b>14,626</b>               | <b>26,236</b>  | <b>(8,340)</b> |
| <b>Reconciliation of funds</b>                                     |             |                                    |                             |                |                |
| Total funds brought forward                                        |             | 432,580                            | 1,527                       | 434,107        | 442,447        |
| <b>Total funds carried forward</b>                                 |             | <b>444,190</b>                     | <b>16,153</b>               | <b>460,343</b> | <b>434,107</b> |

The statement of financial activities includes all gains and losses recognised in the year.  
All income and expenditure derive from continuing activities.

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## Balance sheet

|                                                |       |                 |                |
|------------------------------------------------|-------|-----------------|----------------|
| Company registered number 07609904             | Notes | <b>2023</b>     | 2022           |
|                                                |       | <b>£</b>        | <b>£</b>       |
| <b>Fixed Assets</b>                            |       |                 |                |
| Tangible assets                                | 9     | <b>1,372</b>    | 2,745          |
| Investments                                    | 10    |                 | -              |
|                                                |       | <b>1,372</b>    | 2,745          |
| <b>Current Assets</b>                          |       |                 |                |
| Debtors                                        | 11    | <b>5,409</b>    | 10,087         |
| Cash at bank and in hand                       |       | <b>468,488</b>  | 426,058        |
|                                                |       | <b>473,897</b>  | 436,145        |
| <b>Current Liabilities</b>                     |       |                 |                |
| Creditors: amounts falling due within one year | 12    | <b>(14,926)</b> | (4,783)        |
|                                                |       |                 |                |
| Net current assets                             |       | <b>458,971</b>  | 413,362        |
| <b>Net assets</b>                              |       | <b>460,343</b>  | <b>434,107</b> |
| <b>The funds of the Charity:</b>               |       |                 |                |
| Restricted Funds                               | 13    | <b>16,153</b>   | 1,527          |
| Unrestricted Funds                             |       |                 |                |
| - general                                      |       | <b>90,460</b>   | 77,650         |
| - designated grant fund                        |       | <b>10,953</b>   | 12,153         |
| - designated legacy fund                       |       | <b>342,777</b>  | 342,777        |
|                                                |       | <b>444,190</b>  | 432,580        |
| <b>Total charity funds</b>                     |       | <b>460,343</b>  | <b>434,107</b> |

The accompanying accounting policies and notes form part of these financial statements.

For the year ended 30 June 2023 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Responsibilities of directors/Trustees:

(a) The members have not required the charitable company to obtain an audit of its financial statements for the year in question in accordance with section 476 of the Companies Act 2006 - however, in accordance with section 145 of the Charities Act 2011 the financial statements have been examined by an independent examiner whose report appears on page 10.

(b) The directors/Trustees acknowledge their responsibility for complying with the requirements of the Companies Act with respect to accounting records and the preparation of accounts.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

Approved by the Trustees and signed on their behalf by:  
Lee Lancashire, Trustee

Date 21 January 2024

Ichthyosis Support Group  
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for the year ended 30 June 2023

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## Principal accounting policies

### Status of the company

The charitable company is limited by guarantee and does not have share capital. The liability of members is limited to £10 per member.

### Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (updated 1 January 2019) - (Charities SORP (FRS102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) and the Companies Act 2006.

Ichthyosis Support Group meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

### Going concern statement

The financial statements have been prepared on a going concern basis which assumes that the Charitable Company will continue to operate. The validity of this assumption is dependent upon the continuance of support from the Charitable Company's supporters and donors. The Charitable Company's current business plan shows that the Charitable Company will be able to operate in the foreseeable future. Based on this understanding, the directors believe that it remains appropriate to prepare the financial statements on a going concern basis. The financial statements do not include any adjustments, which would result from the basis of preparation being inappropriate.

### Funds

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations and grants subject to conditions imposed by the provider or by specific terms of the appeal under which the funds were raised. The restrictive conditions are binding upon the Charitable Company.

### Income

Income is recognised when the charitable company has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income relating to future periods, as a result of donor imposed conditions specifying the time period, has been treated as deferred income.

Income dependent on certain conditions, amounting to more than mere administrative requirements, is recognised when the conditions have been fulfilled.

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## Principal accounting policies (continued)

### Donated services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charitable company of the item is probable and the economic benefit can be measured reliably. In accordance with the Charities SORP FRS102, general volunteer time is not recognised.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charitable company which is the amount the charitable company would have been willing to pay to obtain the services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

### Investment income receivable

Bank interest and dividends are shown on the basis of amounts receivable in the year.

### Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charitable company to the expenditure. All expenditure is accounted for on an accruals basis. Expenditure is classified under the following activity headings:

- Costs of raising funds comprises the costs of staff time, publicity and other costs associated with raising income.
- Expenditure on charitable activities includes the costs of direct charitable activities undertaken to further the purposes of the charity and their associated support & governance costs.

### Tangible fixed assets

Depreciation is provided at a rate calculated to write off the cost on a straight line basis over a period of less than the estimated useful life of the assets as follows:

|                                                  |               |
|--------------------------------------------------|---------------|
| Computer equipment, Office equipment & furniture | 20% per annum |
|--------------------------------------------------|---------------|

Fixed asset purchases above £500 are capitalised.

### Fixed asset investments

Fixed asset investments comprise listed investments and are included at market value. Listed investments are included at closing mid-market value at the balance sheet date. Any gain or loss on revaluation is taken to the Statement of Financial Activities.

### Cash and cash equivalents

Cash and cash equivalents include cash at bank and in hand and short term deposits repayable within a three month notice period.

### Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Ichthyosis Support Group  
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## Principal accounting policies (continued)

### Creditors

Creditors are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.

### Taxation

As a registered charity with no trading activities, no provision is considered necessary for taxation.

### Pension costs

The charity contributes into a Group Personal Pension Plan for employees. This pension plan is defined contribution in nature and as required under FRS102 the annual cost is recognised as incurred and included in the Statement of Financial Activities.

### Foreign exchange movements

The charity has a Euro bank account to receive funds raised by members in the Republic of Ireland. The balance is converted to sterling at the year end rate and any exchange movements are taken to the Statement of Financial Activities and treated as 'Other income/Expense'.

### Cash flow

Under Charities SORP FRS102, update bulletin 1, as a small charity there is no requirement to produce a cashflow statement.

## Notes to the financial statements

### 1. Income from donations and legacies

|                                                 | 2023          | 2022          |
|-------------------------------------------------|---------------|---------------|
|                                                 | £             | £             |
| <b>Un-restricted:</b>                           |               |               |
| Donations                                       | 29,498        | 27,890        |
| Grants                                          | 2,862         | -             |
| Legacies receivable                             | -             | 19,945        |
| Gifts in kind                                   | 7,500         | 10,000        |
| Total un-restricted grants & donations          | 39,860        | 57,835        |
| <b>Restricted grants &amp; donations:</b>       |               |               |
| British Association of Dermatologists ('BAD')   | 6,933         | -             |
| Boehringer Ingelheim International GmbH         | 8,270         | -             |
| Total restricted grants                         | 15,203        | -             |
| <b>Total income from donations and legacies</b> | <b>55,063</b> | <b>57,835</b> |

Gifts in kind relate to office & meetings space provided free of charge.

Ichthyosis Support Group  
Financial Statements  
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## Notes to the financial statements (continued)

### 2. Income from charitable activities

|                                                | 2023          | 2022 |
|------------------------------------------------|---------------|------|
|                                                | £             | £    |
| National Conference/family day                 | -             | 500  |
| Corporate sponsorship                          | <b>42,500</b> | -    |
| <b>Total income from charitable activities</b> | <b>42,500</b> | 500  |

### 3. Income from trading activities

|                                             | 2023         | 2022   |
|---------------------------------------------|--------------|--------|
|                                             | £            | £      |
| Promotional material                        | 436          | 9,388  |
| Unity Lottery                               | <b>1,098</b> | 1,087  |
| <b>Total income from trading activities</b> | <b>1,534</b> | 10,475 |

### 4. Income from investments

|                                      | 2023       | 2022 |
|--------------------------------------|------------|------|
|                                      | £          | £    |
| Bank interest                        | 334        | 21   |
| Dividends                            | <b>628</b> | -    |
| <b>Total income from investments</b> | <b>962</b> | 21   |

### 5. Analysis of expenditure on raising funds

|                                    | 2023         | 2022  |
|------------------------------------|--------------|-------|
|                                    | £            | £     |
| Staff costs                        | 5,239        | 5,108 |
| Administrative costs               | <b>531</b>   | 222   |
| <b>Total cost of raising funds</b> | <b>5,770</b> | 5,330 |

Ichthyosis Support Group  
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## Notes to the financial statements (continued)

### 6. Analysis of expenditure on charitable activities

| <b>2023</b>                                       | <b>Un-<br/>restricted<br/>£</b> | <b>Designated<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|---------------------------------------------------|---------------------------------|-------------------------|-------------------------|--------------------|
| Staff costs                                       | 20,957                          | -                       | -                       | <b>20,957</b>      |
| Family day/Youth Camp                             | 7,349                           | -                       | -                       | <b>7,349</b>       |
| Training                                          | 300                             | -                       | -                       | <b>300</b>         |
| Research grant                                    | -                               | 1,200                   | -                       | <b>1,200</b>       |
| Printing, office and administration costs         | 5,768                           | -                       | 520                     | <b>6,288</b>       |
| Rent – in kind                                    | 7,500                           | -                       | -                       | <b>7,500</b>       |
| Insurance                                         | 573                             | -                       | -                       | <b>573</b>         |
| Newsletter production & postage                   | 9,632                           | -                       | -                       | <b>9,632</b>       |
| Telephone, postage & IT costs                     | 3,063                           | -                       | 57                      | <b>3,120</b>       |
| Travel & accommodation                            | 180                             | -                       | -                       | <b>180</b>         |
| CRM                                               | 417                             | -                       | -                       | <b>417</b>         |
| Membership fees                                   | 212                             | -                       | -                       | <b>212</b>         |
| Trustee expenses                                  | 5,730                           | -                       | -                       | <b>5,730</b>       |
| Independent examiner fees                         | 1,100                           | -                       | -                       | <b>1,100</b>       |
| Legal/professional fees                           | 1,835                           | -                       | -                       | <b>1,835</b>       |
| Bank charges                                      | 287                             | -                       | -                       | <b>287</b>         |
| Other expenses (inc foreign exchange difference)  | -                               | -                       | -                       | -                  |
| Depreciation                                      | 1,373                           | -                       | -                       | <b>1,373</b>       |
| <b>Total expenditure on charitable activities</b> | <b>66,276</b>                   | <b>1,200</b>            | <b>577</b>              | <b>68,053</b>      |

| <b>2022</b>                                       | <b>Un-<br/>restricted<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|---------------------------------------------------|---------------------------------|-------------------------|--------------------|
| Staff costs                                       | 12,830                          | 9,998                   | <b>22,828</b>      |
| Family day                                        | 12,770                          | -                       | <b>12,770</b>      |
| Printing, office and administration costs         | 10,260                          | 372                     | <b>10,632</b>      |
| Rent – in kind                                    | 10,000                          | -                       | <b>10,000</b>      |
| Advertising and promotion                         | 4,232                           | -                       | <b>4,232</b>       |
| Telephone, postage & IT costs                     | 1,366                           | 533                     | <b>1,899</b>       |
| CRM                                               | 29                              | 616                     | <b>645</b>         |
| Membership fees                                   | 89                              | -                       | <b>89</b>          |
| Trustee expenses                                  | 4,284                           | -                       | <b>4,284</b>       |
| Independent examiner fees                         | 950                             | -                       | <b>950</b>         |
| Legal fees                                        | 107                             | -                       | <b>107</b>         |
| Bank charges                                      | 361                             | -                       | <b>361</b>         |
| Other expenses (inc foreign exchange difference)  | 2,421                           | -                       | <b>2,421</b>       |
| Depreciation                                      | 1,373                           | -                       | <b>1,373</b>       |
| <b>Total expenditure on charitable activities</b> | <b>61,072</b>                   | <b>11,519</b>           | <b>72,591</b>      |

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## Notes to the financial statements (continued)

### 7. Net expenditure for the year

|                                                        | 2023  | 2022  |
|--------------------------------------------------------|-------|-------|
|                                                        | £     | £     |
| Net expenditure for the year is stated after charging: |       |       |
| Depreciation                                           | 1,373 | 1,373 |
| Independent examiners fees -                           |       |       |
| Independent examination                                | 940   | 810   |
| Accountancy services                                   | 160   | 140   |

### 8. Analysis of staff costs, trustee remuneration and expenses

|                                    | 2023          | 2022          |
|------------------------------------|---------------|---------------|
|                                    | £             | £             |
| Salaries                           | 23,965        | 23,043        |
| National Insurance                 | 1,601         | 1,994         |
| Pension                            | 532           | 504           |
| Payments in respect of prior years | 98            | 2,395         |
| Total                              | <u>26,196</u> | <u>27,936</u> |

### Staff Numbers

|                                                           | Number      | Number      |
|-----------------------------------------------------------|-------------|-------------|
| Average number of full-time equivalent excluding Trustees | <u>0.67</u> | <u>0.67</u> |

No employees had employee benefits in excess of £60,000 (2022: nil).

The charitable company's trustees were not paid or received any other benefits from employment with the charity in the year. Trustee expenses of £5,590 for travel, subsistence and family day costs were reimbursed to 9 Trustees during the year (2022: £4,284, 5 Trustees).

The key management personnel of the charity comprise the trustees and the part time administrator, Trustees receive no remuneration or other benefits from the charity. The remuneration of key management personnel (including pension contributions) for the year was £26,098 (2022: £23,547).

Ichthyosis Support Group  
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## Notes to the financial statements (continued)

### 9. Tangible fixed assets

|                       | <b>2023</b>                                            | 2022                                      |
|-----------------------|--------------------------------------------------------|-------------------------------------------|
|                       | <b>Fixture,<br/>fittings &amp;<br/>equipment<br/>£</b> | Fixtures,<br>fittings &<br>equipment<br>£ |
| <b>Cost</b>           |                                                        |                                           |
| At beginning of year  | <b>7,682</b>                                           | 7,682                                     |
| Additions             | -                                                      | -                                         |
|                       | <b>7,682</b>                                           | 7,682                                     |
| <b>Depreciation</b>   |                                                        |                                           |
| At beginning of year  | <b>4,937</b>                                           | 3,565                                     |
| Charge for the year   | <b>1,373</b>                                           | 1,372                                     |
|                       | <b>6,310</b>                                           | 4,937                                     |
| <b>Net Book Value</b> |                                                        |                                           |
| <b>At end of year</b> | <b>1,372</b>                                           | <b>2,745</b>                              |

### 10. Fixed asset Investments

|                                     | <b>2023</b> | 2022     |
|-------------------------------------|-------------|----------|
|                                     | <b>£</b>    | £        |
| <b>Listed Investments</b>           |             |          |
| Market value at beginning of year   | -           | 14,973   |
| Disposal of investments             | -           | (15,606) |
| Net gains in year                   | -           | 633      |
|                                     | -           | -        |
| <b>Market value at end of year</b>  | -           | -        |
| <b>Historic cost at end of year</b> | -           | -        |

Investments comprised 1,737 shares in Aggreko Plc and were originally donated to the charitable company.

Ichthyosis Support Group  
Financial Statements  
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## Notes to the financial statements (continued)

### 11. Debtors

| 2023         | 2022          |
|--------------|---------------|
| £            | £             |
| -            | -             |
| 5,409        | 10,087        |
| <b>5,409</b> | <b>10,087</b> |

Other debtors  
Prepayments

### 12. Creditors: amounts falling due within one year

| 2023          | 2022         |
|---------------|--------------|
| £             | £            |
| 4,124         | -            |
| 1,102         | 1,566        |
| 2,200         | 3,217        |
| 7,500         | -            |
| <b>14,926</b> | <b>4,783</b> |

Trade Creditors  
Taxation and social security  
Accruals  
Overpayment

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## Notes to the financial statements (continued)

### 13. Funds

| <b>2023</b>               | Balance at<br>beginning of<br>year<br>£ | <b>Income<br/>£</b> | <b>Expenditure<br/>£</b> | <b>Balance<br/>at end of<br/>year<br/>£</b> |
|---------------------------|-----------------------------------------|---------------------|--------------------------|---------------------------------------------|
| <b>Restricted funds</b>   |                                         |                     |                          |                                             |
| BAD Telecon               | 520                                     | -                   | (520)                    | -                                           |
| BAD Quickbooks            | 57                                      | -                   | (57)                     | -                                           |
| BAD Video project         | -                                       | 6,933               | -                        | <b>6,933</b>                                |
| Boehringer Video project  | -                                       | 8,270               | -                        | <b>8,270</b>                                |
| Goldsmiths My Story       | 433                                     | -                   | -                        | <b>433</b>                                  |
| Scottish Event            | 517                                     | -                   | -                        | <b>517</b>                                  |
|                           | <u>1,527</u>                            | <u>15,203</u>       | <u>(577)</u>             | <u><b>16,153</b></u>                        |
| <b>Unrestricted funds</b> |                                         |                     |                          |                                             |
| Designated grant fund     | 12,153                                  | -                   | (1,200)                  | <b>10,953</b>                               |
| Designated legacy fund    | 342,777                                 | -                   | -                        | <b>342,777</b>                              |
| General fund              | 77,650                                  | 84,856              | (72,046)                 | <b>90,460</b>                               |
| Total                     | <u>434,107</u>                          | <u>100,059</u>      | <u>(73,823)</u>          | <u><b>460,343</b></u>                       |

| <b>2022</b>               | Balance at<br>beginning of<br>year<br>£ | <b>Income<br/>£</b> | <b>Expenditure<br/>£</b> | <b>Investme<br/>nt gains<br/>£</b> | <b>Balance<br/>at end of<br/>year<br/>£</b> |
|---------------------------|-----------------------------------------|---------------------|--------------------------|------------------------------------|---------------------------------------------|
| <b>Restricted funds</b>   |                                         |                     |                          |                                    |                                             |
| BAD Telecon               | 1,053                                   | -                   | (533)                    | -                                  | <b>520</b>                                  |
| BAD Quickbooks            | 429                                     | -                   | (372)                    | -                                  | <b>57</b>                                   |
| BAD CRM                   | 616                                     | -                   | (616)                    | -                                  | -                                           |
| Pears Foundation          | 9,997                                   | -                   | (9,997)                  | -                                  | -                                           |
| Goldsmiths My Story       | 433                                     | -                   | -                        | -                                  | <b>433</b>                                  |
| Scottish Event            | 518                                     | -                   | (1)                      | -                                  | <b>517</b>                                  |
|                           | <u>13,046</u>                           | <u>-</u>            | <u>(11,519)</u>          | <u>-</u>                           | <u><b>1,527</b></u>                         |
| <b>Unrestricted funds</b> |                                         |                     |                          |                                    |                                             |
| Designated grant fund     | 12,153                                  | -                   | -                        | -                                  | <b>12,153</b>                               |
| Designated legacy fund    | 342,777                                 | -                   | -                        | -                                  | <b>342,777</b>                              |
| General fund              | 74,471                                  | 68,948              | (66,402)                 | <b>633</b>                         | <b>77,650</b>                               |
| Total                     | <u>442,447</u>                          | <u>68,948</u>       | <u>(77,921)</u>          | <u><b>633</b></u>                  | <u><b>434,107</b></u>                       |

#### Restricted funds are for the following purposes:

Video Project – funded by BAD & Boehringer Ingelheim to produce a range of videos giving insight into the lives of people/families affected by ichthyosis, sharing the experiences & challenges they face.

BAD grants - Grants from BAD Quickbooks, Zoom & Zoho for ongoing subscriptions

Pears Foundation – Grant towards salary costs for 2 years to 31 March 2022

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2023

## Notes to the financial statements (continued)

Goldsmiths My Story – Grant from the Goldsmiths charity to cover the cost of writing and creating the ISG My story booklet.

### Designated funds are for the following purposes:

General Grant fund – grants for research purposes

Legacy fund – legacy money set aside whilst review conducted to agree its use

### 14. Analysis of net assets between funds

| <b>2023</b>              | <b>Un-<br/>restricted<br/>£</b> | <b>Designated<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|--------------------------|---------------------------------|-------------------------|-------------------------|--------------------|
| Fixed assets             | 1,372                           | -                       | -                       | 1,372              |
| Debtors                  | 5,409                           | -                       | -                       | 5,409              |
| Cash at bank and in hand | 98,605                          | 353,730                 | 16,153                  | 468,488            |
| Creditors                | (14,926)                        | -                       | -                       | (14,926)           |
| <b>Funds</b>             | <b>90,460</b>                   | <b>353,730</b>          | <b>16,153</b>           | <b>460,343</b>     |

| <b>2022</b>              | <b>Un-<br/>restricted<br/>£</b> | <b>Designated<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|--------------------------|---------------------------------|-------------------------|-------------------------|--------------------|
| Fixed assets             | 2,745                           | -                       | -                       | 2,745              |
| Investments              | -                               | -                       | -                       | -                  |
| Debtors                  | 10,087                          | -                       | -                       | 10,087             |
| Cash at bank and in hand | 69,601                          | 354,930                 | 1,527                   | 426,058            |
| Creditors                | (4,783)                         | -                       | -                       | (4,783)            |
| <b>Funds</b>             | <b>77,650</b>                   | <b>354,930</b>          | <b>1,527</b>            | <b>434,107</b>     |

### 15. Related party transactions

There were no transactions with related parties during the year.

### 16. Controlling Interests

The charity is controlled by the Trustees.

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2023

## Notes to the financial statements (continued)

### 17. Prior year comparative Statement of Financial Activities

|                                                                    | Un-restricted<br>funds<br>2022 | Restricted<br>funds<br>2022 | Total<br>2022  |
|--------------------------------------------------------------------|--------------------------------|-----------------------------|----------------|
| <b>Income from:</b>                                                | <b>£</b>                       | <b>£</b>                    | <b>£</b>       |
| Donations and legacies                                             | 57,835                         | -                           | <b>57,835</b>  |
| Charitable Activities                                              | 500                            | -                           | <b>500</b>     |
| Trading Activities                                                 | 10,475                         | -                           | <b>10,475</b>  |
| Investments                                                        | 21                             | -                           | <b>21</b>      |
| Other income                                                       | 117                            | -                           | <b>117</b>     |
| <b>Total income</b>                                                | <b>68,948</b>                  | <b>-</b>                    | <b>68,948</b>  |
| <b>Expenditure on:</b>                                             |                                |                             |                |
| Raising funds                                                      | 5,330                          | -                           | <b>5,330</b>   |
| Charitable activities                                              | 61,072                         | 11,519                      | <b>72,591</b>  |
| <b>Total Expenditure</b>                                           | <b>66,402</b>                  | <b>11,519</b>               | <b>77,921</b>  |
| Net gains on investments                                           | 633                            | -                           | <b>633</b>     |
| <b>Net income/(expenditure) and net movement in funds for year</b> | <b>3,179</b>                   | <b>(11,519)</b>             | <b>(8,340)</b> |
| <b>Reconciliation of funds</b>                                     |                                |                             |                |
| Total funds brought forward                                        | 429,401                        | 13,046                      | 442,447        |
| <b>Total funds carried forward</b>                                 | <b>432,580</b>                 | <b>1,527</b>                | <b>434,107</b> |

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# Accounts

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# Ichthyosis Support Group

(a Company Limited by Guarantee)

Trustees' Report and Financial Statements  
for the year ended 30 June 2022

Registered Company number 07609904

Registered Charity number 1142457

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2022

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## Report of the Trustees

The directors of Ichthyosis Group Support Ltd (“the charitable company”) are its Trustees for the purpose of charity law and throughout this report are collectively referred to as its Trustees. The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association, and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (updated 1 January 2019).

The Trustees have pleasure in presenting the charitable company’s report and financial statements for the year ended 30 June 2022.

### OBJECTIVES AND ACTIVITIES

#### Objects of the Charity as set out in the governing document:

1. Promote and protect the physical and mental health of sufferers of ichthyosis and any associated condition in the United Kingdom and the Republic of Ireland through the provision of financial assistance, support, education and practical advice;
2. Advance the education of the general public and medical profession in all areas relating to ichthyosis and any related condition, and its implication for the family;
3. Promote research into the management of ichthyosis and any associated condition and to publish the useful results of that research, and to support organisations worldwide promoting research into ichthyosis, and
4. Such other purposes as are charitable according to the laws of England and Wales for the benefit of the public.

#### Activities during the Period to Achieve its Objects and Obligations of Public Benefit:

- a) Maintain the telephone help line available 24 hours per day, 7 days a week.
  - b) Maintain the ISG website, Facebook, Twitter, Instagram, LinkedIn and email help line.
  - c) Produce regular newsletters.
  - d) Regular directors’ meetings at the office in addition to bi-monthly conference calls. Note- during the COVID-19 pandemic lock down periods we shifted to holding regular meetings via video conferencing.
  - e) Stage an annual national Family event and online events:
    - June 2022 Children’s activity camp online discussion
    - June 2022: Online discussion about caring for your feet
    - May 2022: ISG Family Day Chessington
    - May 2022 25<sup>th</sup> Anniversary Cruise
    - May 2022: IOnline discussion about caring for children with ichthyosis.
    - April 2022: Online discussion about Aging in ichthyosis
    - December 2021: Online ISG Family Winter Quiz.
- October 2021: Online discussion about Managing the psychological impact of living with ichthyosis.

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## Report of the Trustees (continued)

- a) Work closely with a team of consultant dermatologists, an ophthalmologist, ENT nurse practitioner and specialised dermatology nurses, known as the Medical Advisory Board, who provide appropriate information and answer questions posed by individuals affected by ichthyosis and the general public.
- b) Work closely with the dermatology council for England and All-Party Parliamentary Groups on Skin on dermatology issues affecting ichthyosis patients.
- c) Encourage and support all fund-raising efforts by way of promotional materials and sharing individuals' online fundraising pages via social media and other outlets.
- d) Apply for grants from other funding organisations.
- e) Continually raise awareness of ichthyosis particularly during the month of May, Ichthyosis Awareness Month.
- f) Directors and members representing ISG attend, and (by invitation) made presentations virtually due to the pandemic at a number of conferences, such as the British Association of Dermatologists (BAD) Annual meeting.
- g) Due to travel restrictions our annual residential camp for children was replaced with an online virtual camp discussion and planning (June 2022).
- h) Liaise with researchers to share research news and developments including actively recruiting prospective participants.

### Grant Making

Should we receive suitable project applications and if funds allow, the Charity makes a grant for an amount to be decided from year to year and to be available for research projects. Applications are welcomed and assessed by the Medical Advisory Board.

### Volunteer's Contribution

Unpaid volunteers made valuable contributions to the efforts of the Charity during the year by networking with affected families, by raising funds and providing help at our national and other events, and to our administrator in the ISG office. We also have a number of dedicated volunteers that help plan and run the camps. In 2021 the ISG introduced dedicated 'Ambassadors' to its team of volunteers to include ISG members in a proactive way to engage and support people with ichthyosis.

### ACHIEVEMENTS AND PERFORMANCE

In exercising their duties to achieve the objects of the Charity as set out above, the directors have paid due regard to the Charity Commissioners' guidance on public benefit in deciding what the activities should be.

The following are the major achievements of the Charity during the reporting and subsequent period in fulfilling its objects and duty of public benefit:

- a) **ISG membership** continues to grow with over 1200 families from the UK and Ireland and a further 450 affected families worldwide.
- b) **The on-going reference service** to the general public on questions arising in relation to ichthyosis, through our help line, website and social networking, providing information from personal experiences and the professional knowledge of our Medical Advisory Board.

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## Report of the Trustees (continued)

- c) **Increasing awareness** of Ichthyosis amongst the general public by liaising with the media and known affected individuals to highlight the condition, resulting in nationwide media exposure.
- d) **Liaison with a number of pharmaceutical companies** to encourage grant provision, more research and commitment into better treatments for ichthyosis.
- e) **Liaison with hospitals** and NHS England to assist and advise their development of specialised clinics for ichthyosis and other rare genetic skin conditions.
- f) **Unity Lottery.** Maintain involvement to secure a regular monthly income for the charity.
- g) **ISG Youth Camps.** The ISG has since 2014 used PGL organised Youth Camps for young affected individuals and their siblings. Organised activities include zip wire, orienteering, climbing etc. which helps the children meet with other affected children where they would not usually due to the rarity of the condition, increase their confidence, work as a team, and participate in ISG led discussions on social/psychological issues. During 2021/2022 these were held online
- h) **ISG office.** In February 2022 the ISG opened a new office in Wokingham, provided by Wokingham Council free of charge providing space for staff, administration and director's meetings. Centric Community Projects continues to provide the ISG with some free office space in Beacontree Plaza, Reading. The office, officially opened on the 1<sup>st</sup> October 2015 by the Mayor of Reading is primarily used for ISG's administration and storage.
- i) **Fundraising.** Additional fundraising events were held including: ISG Snowdon Climb £6,000; Shane Kennedy Cork Marathon £2,000; Catherine and Alfie Lancashire IAM £1,200;
- j) A very generous legacy from David Bryant was received to the sum of £342,777 and another legacy of £19,945 was received from the Will of Victoria Tierney;
- k) **Grants and Sponsorship.** We obtained £1500 from Beiersdorf towards our family day. £1500 from Molnlyke, again for the family day. Merlin magic wand donated entry tickets into Chessington for this event. We received £9998 from the Pears Foundation towards 5 months of salary.
- l) **Website.** The ISG's new website was launched, maintained and developed.;
- m) These included online discussion sessions for members, partnership clinics and discussions with Talkhealth, webinar with clinical psychologists, ISG Family Day, ISG Climb Snowdon challenge and ISG Members fundraising events, initiatives and activities such as the 'Great British Bath Off';
- n) Annual Family Day at Chessington World of Adventure during May 2022 including a 25<sup>th</sup> anniversary year celebration on a Thames Cruise;
- o) **Virtual Fundraising Quiz** in December 2021 the ISG held its 2nd online virtual family quiz.

## FUTURE PLANS

We will organise activities and a Family Day/Event in 2023. To reinstate ISG in person Children's camps during 2022/2023. To make plans to expand the ISG's operational structure and activities and implement projects that resources and funds had not previously allowed.

## **Report of the Trustees (continued)**

### **FINANCIAL REVIEW**

As can be seen from the Statement of Financial Activities on page 11, largely due to a sizeable legacy received in 2021/22, there are unrestricted funds of in excess of £400,000. To protect this investment we are considering the following:

- Investment.
- Research grants.
- Grants for individuals affected by ichthyosis.
- Ichthyosis Nurse.
- Ichthyosis registry.
- Securing the future of the ISG via core costs.

Restricted funds of £1,527 remain to be spent in future years. After designated funds of £12,153 set aside for grants for research purposes, general funds of £77,650 in addition to the legacy fund of £342,777 are available for ongoing charitable purpose. Depending on decisions to be made with the legacy monies, additional funds may be allocated accordingly in the future.

Even though we received a generous legacy amount, once this is invested, we remain reliant on individual members and others carrying out fundraising efforts on the Charity's behalf, and our success at winning grants. In the future this could leave us vulnerable to substantial fluctuations of income and therefore we need to rigorously continue our efforts to keep them in good shape.

### **General Reserve Policy**

In view of the fact that much of the Group's income arises from grants, proceeds of special events, sponsorships and other fundraising efforts on a "one-off" basis, the reoccurrence of which cannot be guaranteed from one year to another, it is considered desirable to maintain a General Reserve Level equal to the core expenditure and other known commitments budgeted to occur in the following accounting year, less anticipated regular income in that year. This would require an amount of around £65,000. As at 30<sup>th</sup> June 2022, un-restricted free reserves were £77,650, which is above that required by our policy.

### **Review of the Reserve Policy**

The Reserve Policy is reviewed annually after the end of the financial year in the light of the results for that financial year, or earlier if there is any substantial change in the Charity's financial circumstances.

### **Risk Assessment**

Trustees endeavour to identify the major risks to which the Charity is exposed and put in place procedures to manage such risks on an on-going basis. Appropriate insurance cover is held or taken out covering employment risks and such other risks that may be identified from time to time.

Ichthyosis Support Group  
Financial Statements  
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## **Report of the Trustees (continued)**

### **FUNDS HELD AS A CUSTODIAN TRUSTEE**

No such funds are held.

### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

#### **Organisational Structure and Decision Making**

The Board of directors meet a minimum of four times a year or more often as necessary, administer the Charity and take major and strategic decisions. Day-to-day functions are carried out by the Administrator and by some Board members.

#### **Governing Document**

The governing document is the Articles of Association and subject to the provisions set out in the Companies Act 2006 and the Charities Act 2011, where applicable.

#### **Method of Recruitment and Appointment of Directors**

Directors must be a member of the Charity and not be disqualified as a Director or Trustee by the Articles. No body or individual external to the Charity is permitted to appoint directors. Members are invited to put themselves forward or be nominated by other members as directors by means of newsletters circulated to all members by post or electronically, and invited to do so at General Meetings.

Directors are elected by the members at General Meetings for a term of three years. Directors may offer themselves for re-election at the end of their term of office.

The Board may at any time co-opt any individual who is qualified to be appointed as a director to fill a vacancy in their number or as an additional director. A co-opted director holds office until the next General Meeting at which they must stand for election by the members.

#### **Induction and Training of Directors**

Once appointed, new directors receive appropriate training in their duties and responsibilities by reference to relevant literature including publications issued by the Charity Commissioners and advice and assistance from existing directors. Where possible, directors are encouraged to attend related training courses and seminars.

### **REFERENCE AND ADMINISTRATIVE INFORMATION**

#### **Trustees**

Mandy Helen Aldwin-Easton  
Margaret Aldwin  
Susan Corbett  
Raymond James Rowley  
Paul William Whitehouse  
Mudassar Ulhaq  
Lee James Lancashire

#### **Patron**

Phillip Schofield

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## Report of the Trustees (continued)

### Registered Office

Ichthyosis Support Group Also known as "ISG"  
562 Wokingham Road  
Earley  
Reading  
Berkshire  
RG6 7JB

**Company Registration Number:** 07609904

**Charity Registration Number:** 1142457

### Postal Address

Ichthyosis Support Group  
PO Box 1242  
Yateley  
GU47 7FL

### Office Address

Ichthyosis Support Group  
Unit 7 Beacontree Plaza  
Gillette Way  
Reading  
RG2 0BS

### Bankers

CAF Bank Limited  
25 Kings Hill Avenue  
Kings Hill  
West Malling  
Kent, ME19 4JQ

HSBC  
16-17 The Broadway  
Thatcham  
Newbury  
Berkshire, RG19 4HX

### Independent Examiner

Karen Hanlan  
Karen Hanlan Independent Examiner Ltd  
1 Saracen Close  
Ettington  
CV37 7SZ

### Solicitors

Blandy and Blandy LLP  
One Friar Street  
Reading  
Berkshire  
RG1 1DA

Approved by the Board and signed on its behalf by:

Lee Lancashire  
*Trustee*

Date: 29 March 2023

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2022

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## **Statement of Trustees' responsibilities**

The Trustees are required to prepare financial statements for each financial year which give a true and fair view of the state of the affairs of the charitable company and of the surplus or deficit incurred by the charitable company for that year. In preparing those financial statements the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue to exist.

The Trustees have overall responsibility for ensuring that the charitable company has an appropriate system of controls, financial and otherwise.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy, at any time, the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006.

They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities and to provide reasonable assurance that:

- the charitable company is operating efficiently and effectively;
- its assets are safeguarded against un-authorised use or disposition;
- proper records are maintained and financial information used within the charity or for publication is reliable;
- the charitable company complies with relevant laws and regulations.

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2022

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## **Independent Examiner's Report to the Trustees of Ichthyosis Support Group ('the Company')**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 June 2022 which are set out on pages 11 to 23.

### **Responsibilities and basis of report**

As the charity trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

### **Independent examiner's statement**

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

- 1) accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- 2) the accounts do not accord with those records; or
- 3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
- 4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102).

I have no concerns and have come across no matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Karen Hanlan,  
Member of Institute of Chartered Accountants England & Wales  
Karen Hanlan Independent Examiner Ltd  
1 Saracen Close  
Ettington  
CV37 7SZ

Date: 29 March 2023

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2022

**Statement of Financial Activities (including an Income & Expenditure Account)**

|                                                                    |             | Un-<br>restricted<br>funds<br>2022 | Restricted<br>funds<br>2022 | Total<br>2022  | Total<br>2021  |
|--------------------------------------------------------------------|-------------|------------------------------------|-----------------------------|----------------|----------------|
| <b>Income from:</b>                                                | <b>Note</b> | <b>£</b>                           | <b>£</b>                    | <b>£</b>       | <b>£</b>       |
| Donations and legacies                                             | 1           | 57,835                             | -                           | <b>57,835</b>  | 386,807        |
| Charitable Activities                                              | 2           | 500                                | -                           | <b>500</b>     | -              |
| Trading Activities                                                 | 3           | 10,475                             | -                           | <b>10,475</b>  | 5,752          |
| Investments                                                        | 4           | 21                                 | -                           | <b>21</b>      | 1,160          |
| Other income                                                       |             | 117                                | -                           | <b>117</b>     | -              |
| <b>Total income</b>                                                |             | <b>68,948</b>                      | <b>-</b>                    | <b>68,948</b>  | <b>393,719</b> |
| <b>Expenditure on:</b>                                             |             |                                    |                             |                |                |
| Raising funds                                                      | 5           | 5,330                              | -                           | <b>5,330</b>   | 4,998          |
| Charitable activities                                              | 6           | 61,072                             | 11,519                      | <b>72,591</b>  | 37,062         |
| <b>Total Expenditure</b>                                           |             | <b>66,402</b>                      | <b>11,519</b>               | <b>77,921</b>  | <b>42,060</b>  |
| Net gains on investments                                           |             | 633                                | -                           | <b>633</b>     | <b>7,282</b>   |
| <b>Net income/(expenditure) and net movement in funds for year</b> |             | <b>3,179</b>                       | <b>(11,519)</b>             | <b>(8,340)</b> | <b>358,941</b> |
| <b>Reconciliation of funds</b>                                     |             |                                    |                             |                |                |
| Total funds brought forward                                        |             | 429,401                            | 13,046                      | 442,447        | 83,506         |
| <b>Total funds carried forward</b>                                 |             | <b>432,580</b>                     | <b>1,527</b>                | <b>434,107</b> | <b>442,447</b> |

The statement of financial activities includes all gains and losses recognised in the year.  
All income and expenditure derive from continuing activities.

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2022

## Balance sheet

|                                                |       |                |                |
|------------------------------------------------|-------|----------------|----------------|
| Company registered number 07609904             | Notes | <b>2022</b>    | 2021           |
|                                                |       | <b>£</b>       | <b>£</b>       |
| <b>Fixed Assets</b>                            |       |                |                |
| Tangible assets                                | 9     | <b>2,745</b>   | 4,117          |
| Investments                                    | 10    | -              | 14,973         |
|                                                |       | <b>2,745</b>   | 19,090         |
| <b>Current Assets</b>                          |       |                |                |
| Debtors                                        | 11    | <b>10,087</b>  | 347,105        |
| Cash at bank and in hand                       |       | <b>426,058</b> | 78,153         |
|                                                |       | <b>436,145</b> | 425,258        |
| <b>Current Liabilities</b>                     |       |                |                |
| Creditors: amounts falling due within one year | 12    | <b>(4,783)</b> | (1,901)        |
|                                                |       |                |                |
| Net current assets                             |       | <b>413,362</b> | 423,357        |
| <b>Net assets</b>                              |       | <b>434,107</b> | <b>442,447</b> |
| <b>The funds of the Charity:</b>               |       |                |                |
| Restricted Funds                               | 13    | <b>1,527</b>   | 13,046         |
| Unrestricted Funds                             |       |                |                |
| - general                                      |       | <b>77,650</b>  | 74,471         |
| - designated grant fund                        |       | <b>12,153</b>  | 12,153         |
| - designated legacy fund                       |       | <b>342,777</b> | 342,777        |
|                                                |       | <b>432,580</b> | 429,401        |
| <b>Total charity funds</b>                     |       | <b>434,107</b> | <b>442,447</b> |

The accompanying accounting policies and notes form part of these financial statements.

For the year ended 30 June 2022 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Responsibilities of directors/Trustees:

(a) The members have not required the charitable company to obtain an audit of its financial statements for the year in question in accordance with section 476 of the Companies Act 2006 - however, in accordance with section 145 of the Charities Act 2011 the financial statements have been examined by an independent examiner whose report appears on page 10.

(b) The directors/Trustees acknowledge their responsibility for complying with the requirements of the Companies Act with respect to accounting records and the preparation of accounts.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.

Approved by the Trustees and signed on their behalf by:  
Lee Lancashire, Trustee

Date: 29 March 2023

Ichthyosis Support Group  
Financial Statements  
for the year ended 30 June 2022

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## Principal accounting policies

### Status of the company

The charitable company is limited by guarantee and does not have share capital. The liability of members is limited to £10 per member.

### Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) (updated 1 January 2019) - (Charities SORP (FRS102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) and the Companies Act 2006.

Ichthyosis Support Group meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

### Going concern statement

The financial statements have been prepared on a going concern basis which assumes that the Charitable Company will continue to operate. The validity of this assumption is dependent upon the continuance of support from the Charitable Company's supporters and donors. The Charitable Company's current business plan shows that the Charitable Company will be able to operate in the foreseeable future. Based on this understanding, the directors believe that it remains appropriate to prepare the financial statements on a going concern basis. The financial statements do not include any adjustments, which would result from the basis of preparation being inappropriate.

### Funds

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations and grants subject to conditions imposed by the provider or by specific terms of the appeal under which the funds were raised. The restrictive conditions are binding upon the Charitable Company.

### Income

Income is recognised when the charitable company has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income relating to future periods, as a result of donor imposed conditions specifying the time period, has been treated as deferred income.

Income dependent on certain conditions, amounting to more than mere administrative requirements, is recognised when the conditions have been fulfilled.

Ichthyosis Support Group  
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## Principal accounting policies (continued)

### Donated services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charitable company of the item is probable and the economic benefit can be measured reliably. In accordance with the Charities SORP FRS102, general volunteer time is not recognised.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charitable company which is the amount the charitable company would have been willing to pay to obtain the services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

### Investment income receivable

Bank interest and dividends are shown on the basis of amounts receivable in the year.

### Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charitable company to the expenditure. All expenditure is accounted for on an accruals basis. Expenditure is classified under the following activity headings:

- Costs of raising funds comprises the costs of staff time, publicity and other costs associated with raising income.
- Expenditure on charitable activities includes the costs of direct charitable activities undertaken to further the purposes of the charity and their associated support & governance costs.

### Tangible fixed assets

Depreciation is provided at a rate calculated to write off the cost on a straight line basis over a period of less than the estimated useful life of the assets as follows:

|                                                  |               |
|--------------------------------------------------|---------------|
| Computer equipment, Office equipment & furniture | 20% per annum |
|--------------------------------------------------|---------------|

Fixed asset purchases above £500 are capitalised.

### Fixed asset investments

Fixed asset investments comprise listed investments and are included at market value. Listed investments are included at closing mid-market value at the balance sheet date. Any gain or loss on revaluation is taken to the Statement of Financial Activities.

### Cash and cash equivalents

Cash and cash equivalents include cash at bank and in hand and short term deposits repayable within a three month notice period.

### Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Ichthyosis Support Group  
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## Principal accounting policies (continued)

### Creditors

Creditors are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.

### Taxation

As a registered charity with no trading activities, no provision is considered necessary for taxation.

### Pension costs

The charity contributes into a Group Personal Pension Plan for employees. This pension plan is defined contribution in nature and as required under FRS102 the annual cost is recognised as incurred and included in the Statement of Financial Activities.

### Foreign exchange movements

The charity has a Euro bank account to receive funds raised by members in the Republic of Ireland. The balance is converted to sterling at the year end rate and any exchange movements are taken to the Statement of Financial Activities and treated as 'Other income/Expense'.

### Cash flow

Under Charities SORP FRS102, update bulletin 1, as a small charity there is no requirement to produce a cashflow statement.

## Notes to the financial statements

### 1. Income from donations and legacies

|                                                 | 2022<br>£     | 2021<br>£      |
|-------------------------------------------------|---------------|----------------|
| <b>Un-restricted:</b>                           |               |                |
| Donations                                       | 27,890        | 25,059         |
| Legacies receivable                             | 19,945        | 342,777        |
| Gifts in kind                                   | 10,000        | -              |
| Total un-restricted grants & donations          | 57,835        | 367,836        |
| <b>Restricted grants &amp; donations:</b>       |               |                |
| British Association of Dermatologists ('BAD')   | -             | 1,005          |
| Pears Foundation                                | -             | 17,966         |
| Total restricted grants                         | -             | 18,971         |
| <b>Total income from donations and legacies</b> | <b>57,835</b> | <b>386,807</b> |

Gifts in kind relate to office & meetings space provided free of charge.

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## Notes to the financial statements (continued)

### 2. Income from charitable activities

|                                                | 2022       | 2021     |
|------------------------------------------------|------------|----------|
|                                                | £          | £        |
| National Conference/family day                 | 500        | -        |
| <b>Total income from charitable activities</b> | <b>500</b> | <b>-</b> |

### 3. Income from trading activities

|                                             | 2022          | 2021         |
|---------------------------------------------|---------------|--------------|
|                                             | £             | £            |
| Promotional material                        | 9,388         | 4,518        |
| Unity Lottery                               | 1,087         | 1,234        |
| <b>Total income from trading activities</b> | <b>10,475</b> | <b>5,752</b> |

### 4. Income from investments

|                                      | 2022      | 2021         |
|--------------------------------------|-----------|--------------|
|                                      | £         | £            |
| Bank interest                        | 21        | 3            |
| Dividends                            | -         | 1,157        |
| <b>Total income from investments</b> | <b>21</b> | <b>1,160</b> |

### 5. Analysis of expenditure on raising funds

|                                    | 2022         | 2021         |
|------------------------------------|--------------|--------------|
|                                    | £            | £            |
| Staff costs                        | 5,108        | 4,572        |
| Administrative costs               | 222          | 426          |
| <b>Total cost of raising funds</b> | <b>5,330</b> | <b>4,998</b> |

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## Notes to the financial statements (continued)

### 6. Analysis of expenditure on charitable activities

| <b>2022</b>                                       | <b>Un-<br/>restricted<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|---------------------------------------------------|---------------------------------|-------------------------|--------------------|
| Staff costs                                       | 12,830                          | 9,998                   | <b>22,828</b>      |
| Family day                                        | 12,770                          | -                       | <b>12,770</b>      |
| Printing, office and administration costs         | 10,260                          | 372                     | <b>10,632</b>      |
| Rent – in kind                                    | 10,000                          | -                       | <b>10,000</b>      |
| Advertising and promotion                         | 4,232                           | -                       | <b>4,232</b>       |
| Telephone, postage & IT costs                     | 1,366                           | 533                     | <b>1,899</b>       |
| CRM                                               | 29                              | 616                     | <b>645</b>         |
| Membership fees                                   | 89                              | -                       | <b>89</b>          |
| Trustee expenses                                  | 4,284                           | -                       | <b>4,284</b>       |
| Independent examiner fees                         | 950                             | -                       | <b>950</b>         |
| Legal fees                                        | 107                             | -                       | <b>107</b>         |
| Bank charges                                      | 361                             | -                       | <b>361</b>         |
| Other expenses (inc foreign exchange difference)  | 2,421                           | -                       | <b>2,421</b>       |
| Depreciation                                      | 1,373                           | -                       | <b>1,373</b>       |
| <b>Total expenditure on charitable activities</b> | <b>61,072</b>                   | <b>11,519</b>           | <b>72,591</b>      |

| <b>2021</b>                                       | <b>Un-<br/>restricted<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|---------------------------------------------------|---------------------------------|-------------------------|--------------------|
| Staff costs                                       | 10,315                          | 7,969                   | <b>18,284</b>      |
| Printing, office and administration costs         | 2,938                           | -                       | <b>2,938</b>       |
| Advertising and promotion                         | 4,787                           | -                       | <b>4,787</b>       |
| Telephone, postage & IT costs                     | 3,252                           | 1,072                   | <b>4,324</b>       |
| CRM                                               | 2,879                           | -                       | <b>2,879</b>       |
| Trustee expenses                                  | 107                             | -                       | <b>107</b>         |
| Independent examiner fees                         | 950                             | -                       | <b>950</b>         |
| Legal fees                                        | 210                             | -                       | <b>210</b>         |
| Bank charges                                      | 78                              | -                       | <b>78</b>          |
| Other expenses (inc foreign exchange difference)  | 1,132                           | -                       | <b>1,132</b>       |
| Depreciation                                      | 1,373                           | -                       | <b>1,373</b>       |
| <b>Total expenditure on charitable activities</b> | <b>28,021</b>                   | <b>9,041</b>            | <b>37,062</b>      |

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## Notes to the financial statements (continued)

### 7. Net expenditure for the year

|                                                        | 2022  | 2021  |
|--------------------------------------------------------|-------|-------|
|                                                        | £     | £     |
| Net expenditure for the year is stated after charging: |       |       |
| Depreciation                                           | 1,373 | 1,373 |
| Independent examiners fees -                           |       |       |
| Independent examination                                | 810   | 810   |
| Accountancy services                                   | 140   | 140   |

### 8. Analysis of staff costs, trustee remuneration and expenses

|                                    | 2022          | 2021          |
|------------------------------------|---------------|---------------|
|                                    | £             | £             |
| Salaries                           | 23,043        | 22,372        |
| National Insurance                 | 1,994         | 467           |
| Pension                            | 504           | 484           |
| Payments in respect of prior years | 2,395         | -             |
| Total                              | <u>27,936</u> | <u>23,323</u> |

### Staff Numbers

|                                                           | Number      | Number      |
|-----------------------------------------------------------|-------------|-------------|
| Average number of full-time equivalent excluding Trustees | <u>0.67</u> | <u>0.67</u> |

No employees had employee benefits in excess of £60,000 (2021: nil).

The charitable company's trustees were not paid or received any other benefits from employment with the charity in the year. Trustee expenses of £4,284 for travel, subsistence and family day costs were reimbursed to 5 Trustees during the year (2021: £107, 2 Trustees).

The key management personnel of the charity comprise the trustees and the part time administrator, Trustees receive no remuneration or other benefits from the charity. The remuneration of key management personnel (including pension contributions) for the year was £23,547(2021: £22,856).

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## Notes to the financial statements (continued)

### 9. Tangible fixed assets

|                       | 2022 Fixture,<br>fittings &<br>equipment<br>£ | 2021 Fixtures,<br>fittings &<br>equipment<br>£ |
|-----------------------|-----------------------------------------------|------------------------------------------------|
| <b>Cost</b>           |                                               |                                                |
| At beginning of year  | 7,682                                         | 2,192                                          |
| Additions             | -                                             | 5,490                                          |
| At end of year        | <u>7,682</u>                                  | <u>7,682</u>                                   |
| <b>Depreciation</b>   |                                               |                                                |
| At beginning of year  | 3,565                                         | 2,192                                          |
| Charge for the year   | 1,372                                         | 1,373                                          |
| At end of year        | <u>4,937</u>                                  | <u>3,565</u>                                   |
| <b>Net Book Value</b> |                                               |                                                |
| At end of year        | <u>2,745</u>                                  | <u>4,117</u>                                   |

### 10. Fixed asset Investments

|                                     | 2022<br>£  | 2021<br>£     |
|-------------------------------------|------------|---------------|
| <b>Listed Investments</b>           |            |               |
| Market value at beginning of year   | 14,973     | 7,691         |
| Disposal of investments             | (15,606)   | -             |
| Net gains in year                   | <u>633</u> | <u>7,282</u>  |
| <b>Market value at end of year</b>  | <u>-</u>   | <u>14,973</u> |
| <b>Historic cost at end of year</b> | <u>Nil</u> | <u>Nil</u>    |

Investments comprised 1,737 shares in Aggreko Plc and were originally donated to the charitable company.

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## Notes to the financial statements (continued)

### 11. Debtors

|                                                   | 2022          | 2021           |
|---------------------------------------------------|---------------|----------------|
|                                                   | £             | £              |
| Accrued income (2021 includes legacy of £342,777) | -             | 343,933        |
| Other debtors                                     | -             | 675            |
| Prepayments                                       | 10,087        | 2,497          |
|                                                   | <b>10,087</b> | <b>347,105</b> |

### 12. Creditors: amounts falling due within one year

|                              | 2022         | 2021         |
|------------------------------|--------------|--------------|
|                              | £            | £            |
| Taxation and social security | 1,566        | 951          |
| Accruals                     | 3,217        | 950          |
|                              | <b>4,783</b> | <b>1,901</b> |

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## Notes to the financial statements (continued)

### 13. Funds

| 2022                      | Balance at<br>beginning of<br>year<br>£ | Income<br>£ | Expenditure<br>£ | Investme<br>nt gains<br>£ | Balance<br>at end of<br>year<br>£ |
|---------------------------|-----------------------------------------|-------------|------------------|---------------------------|-----------------------------------|
| <b>Restricted funds</b>   |                                         |             |                  |                           |                                   |
| BAD Telecon               | 1,053                                   | -           | 533              | -                         | 520                               |
| BAD Quickbooks            | 429                                     | -           | 372              | -                         | 57                                |
| BAD CRM                   | 616                                     | -           | 616              | -                         | -                                 |
| Pears Foundation          | 9,997                                   | -           | 9,997            | -                         | -                                 |
| Goldsmiths My Story       | 433                                     | -           | -                | -                         | 433                               |
| Scottish Event            | 518                                     | -           | 1                | -                         | 517                               |
|                           | 13,046                                  | -           | 11,519           | -                         | 1,527                             |
| <b>Unrestricted funds</b> |                                         |             |                  |                           |                                   |
| Designated grant fund     | 12,153                                  | -           | -                | -                         | 12,153                            |
| Designated legacy fund    | 342,777                                 | -           | -                | -                         | 342,777                           |
| General fund              | 74,471                                  | 68,948      | 66,402           | 633                       | 77,650                            |
| Total                     | 442,447                                 | 68,948      | 77,921           | 633                       | 434,107                           |

| 2021                      | Balance at<br>beginning of<br>year<br>£ | Income<br>£ | Expenditure<br>£ | Investme<br>nt gains<br>£ | Balance<br>at end of<br>year<br>£ |
|---------------------------|-----------------------------------------|-------------|------------------|---------------------------|-----------------------------------|
| <b>Restricted funds</b>   |                                         |             |                  |                           |                                   |
| BAD Telecon               | 1,197                                   | -           | 144              | -                         | 1,053                             |
| BAD Quickbooks            | 739                                     | -           | 310              | -                         | 429                               |
| BAD Database              | 229                                     | -           | 229              | -                         | -                                 |
| BAD CRM                   | -                                       | 1,005       | 389              | -                         | 616                               |
| Pears Foundation          | -                                       | 17,966      | 7,969            | -                         | 9,997                             |
| Goldsmiths My Story       | 433                                     | -           | -                | -                         | 433                               |
| Scottish Event            | 518                                     | -           | -                | -                         | 518                               |
|                           | 3,116                                   | 18,971      | 9,041            | -                         | 13,046                            |
| <b>Unrestricted funds</b> |                                         |             |                  |                           |                                   |
| Designated grant fund     | 12,153                                  | -           | -                | -                         | 12,153                            |
| Designated legacy fund    | -                                       | 342,777     | -                | -                         | 342,777                           |
| General fund              | 68,237                                  | 31,971      | (33,019)         | 7,282                     | 74,471                            |
| Total                     | 83,506                                  | 393,719     | (42,060)         | 7,282                     | 442,447                           |

**Restricted funds are for the following purposes:**

BAD grants - Grants from BAD Quickbooks, Zoom & Zoho for ongoing subscriptions  
Pears Foundation – Grant towards salary costs for 2 years to 31 March 2022

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## Notes to the financial statements (continued)

Goldsmiths My Story – Grant from the Goldsmiths charity to cover the cost of writing and creating the ISG My story booklet.

### Designated funds are for the following purposes:

General Grant fund – grants for research purposes

Legacy fund – legacy money set aside whilst review conducted to agree its use

### 14. Analysis of net assets between funds

| <b>2022</b>              | <b>Un-<br/>restricted<br/>£</b> | <b>Designated<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|--------------------------|---------------------------------|-------------------------|-------------------------|--------------------|
| Fixed assets             | 2,745                           | -                       | -                       | 2,745              |
| Investments              | -                               | -                       | -                       | -                  |
| Debtors                  | 10,087                          | -                       | -                       | 10,087             |
| Cash at bank and in hand | 69,601                          | 354,930                 | 1,527                   | 426,058            |
| Creditors                | (4,783)                         | -                       | -                       | (4,783)            |
| <b>Funds</b>             | <b>77,650</b>                   | <b>354,930</b>          | <b>1,527</b>            | <b>434,107</b>     |

  

| <b>2021</b>              | <b>Un-<br/>restricted<br/>£</b> | <b>Designated<br/>£</b> | <b>Restricted<br/>£</b> | <b>Total<br/>£</b> |
|--------------------------|---------------------------------|-------------------------|-------------------------|--------------------|
| Fixed assets             | 4,117                           | -                       | -                       | 4,117              |
| Investments              | 14,973                          | -                       | -                       | 14,973             |
| Debtors                  | 4,328                           | 342,777                 | -                       | 347,105            |
| Cash at bank and in hand | 52,954                          | 12,153                  | 13,046                  | 78,153             |
| Creditors                | (1,901)                         | -                       | -                       | (1,901)            |
| <b>Funds</b>             | <b>74,471</b>                   | <b>354,930</b>          | <b>13,046</b>           | <b>442,447</b>     |

### 15. Related party transactions

There were no transactions with related parties during the year.

### 16. Controlling Interests

The charity is controlled by the Trustees.

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## Notes to the financial statements (continued)

### 17. Prior year comparative Statement of Financial Activities

|                                                      | Un-<br>restricted<br>funds<br>2021 | Restricted<br>funds<br>2021 | Total<br>2021  |
|------------------------------------------------------|------------------------------------|-----------------------------|----------------|
| Income from:                                         | £                                  | £                           | £              |
| Donations and legacies                               | 367,836                            | 18,971                      | 386,807        |
| Trading Activities                                   | 5,752                              | -                           | 5,752          |
| Investments                                          | 1,160                              | -                           | 1,160          |
| <b>Total income</b>                                  | <b>374,748</b>                     | <b>18,971</b>               | <b>393,719</b> |
| <b>Expenditure on:</b>                               |                                    |                             |                |
| Raising funds                                        | 4,998                              | -                           | 4,998          |
| Charitable activities                                | 28,021                             | 9,041                       | 37,062         |
| <b>Total Expenditure</b>                             | <b>33,019</b>                      | <b>9,041</b>                | <b>42,060</b>  |
| Net gains on investments                             | 7,282                              | -                           | 7,282          |
| <b>Net income and net movement in funds for year</b> | <b>349,011</b>                     | <b>9,930</b>                | <b>358,941</b> |
| <b>Reconciliation of funds</b>                       |                                    |                             |                |
| Total funds brought forward                          | 80,390                             | 3,116                       | 83,506         |
| <b>Total funds carried forward</b>                   | <b>429,401</b>                     | <b>13,046</b>               | <b>442,447</b> |