

Charity registration number 1157027 (England and Wales)

Charity registration number SC046712 (Scotland)

Company registration number 08924646 (England and Wales)

THE EHLERS-DANLOS SUPPORT UK
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023

THE EHLERS-DANLOS SUPPORT UK

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees

Sarita Aujla
Ellie Cannell
Anne Lavery
Leah Mansfield
Laure Nas de Tourris
Jason Pearce
Alison Roux
Stephen Stacey
Adrian Steel
Charlotte Williams

(Appointed 15 June 2022)

Charity number (England and Wales) 1157027

Charity number (Scotland) SC046712

Company number 08924646

Registered office
Devonshire House
Manor Way
Borehamwood
Herts
WD6 1QQ

Independent examiner
Sobell Rhodes LLP
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THE EHLERS-DANLOS SUPPORT UK

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THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 31 MARCH 2023

The trustees present their report and accounts for the period ended 31 March 2023.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's governing document, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended) 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 (FRS 102)' (effective 1 January 2019).

Objectives and activities

Purpose

The charity's purpose as set out in its objects is as follows:

The objects are primarily for the relief of persons suffering from Ehlers-Danlos syndrome through the provision of support, education and practical advice; and to advance medical research into the cause, cure, prevention or relief of the syndrome and that useful results of such research are placed in the public domain.

The main activities of the charity pursuant to this purpose include:

- a. Providing information and support to people with, affected by, or involved with the diagnosis and treatment of EDS.
- b. Linking members with each other for mutual support and exchange of ideas.
- c. Publishing booklets, leaflets, and online toolkits.
- d. Organising conferences.
- e. Producing a bi-annual magazine (Fragile Links) available on payment of a small subscription, digitally, and in hard copy.
- f. Maintaining a website and social media presence to promote public awareness and provide information and support.
- g. Running social events to bring our community together for both adults and children.
- h. Facilitating local support meetings through trained area coordinators.
- i. Running a free-phone information and advice line for all members of our community.
- j. Supporting research projects that will benefit those living with EDS.

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

A round-up of achievements against our areas of strategic focus

Our strategy has four pillars. These were confirmed by the board in February 2022 and are:

1. Support
2. Education and awareness
3. Research
4. Fundraising and organisational health.

A summary of our activities is provided under each of these headings.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

Support

Our helpline

The telephone and email helpline is highly appreciated by our community. In the period under review, we took 1,171 calls (in 2021-22, 1,717 calls) with an average call time of 20 minutes (in 2021-22, 20 minutes) and responded to approximately 1,756 emails (in 2021-22, approximately 2,000 emails). There was some staff sickness absence in the year that may have adversely affected the number of calls logged.

Last year we said that many callers wanted support in their struggle to access NHS services and benefits and for help in the difficulties they experience in navigating the education system for children with disabilities. There has been no fall-off in these needs; indeed, to the contrary with the NHS finding itself under increasing strain. Our 2023 members' survey showed just how important our helpline services are. 75% of members said that the advice and support they received from our helpline was important, very important, or essential to them.

Building community

Our community continues to grow.

We run support groups to facilitate peer-to-peer support in a safe space. These groups have attracted over 3,000 attendances in the year under review. We have over 90 volunteers (76 in 2021-22) who either have EDS themselves or are caring for someone with EDS. Our volunteers run over 100 support groups, which are often the only occasions for people to learn how to manage their symptoms themselves and share treatment options and ideas about how to live independent and fulfilling lives.

We also run seven special interest groups: for 18–25-year-olds, teens, parents, elders, LGBTQIA+, men, and family and friends. Over 49,000 people engage with each other on the main Facebook page and share suggestions for pain management, discuss symptoms, celebrate fundraising achievements, and support each other. In addition, over 8,000 people (6,500 in 2021-22) connect regularly with each other in 24 closed Facebook groups. In 2021 we were awarded the Investing in Volunteers accreditation.

82% of members responding to our 2023 members survey said that our support groups both virtual and face-to-face were important or extremely important to them. 64% of our members said the closed Facebook groups were important or extremely important to them, and 83% of members said they thought having locally trained support volunteers in place was important or extremely important.

Helping our community to better access services

We want to make more services more widely available for people living with EDS.

Having EDS can be isolating, scary and overwhelming. Through our helpline we support people on their entire journey with these conditions, providing not only practical advice but emotional support and a true understanding of their experience. Without this service many would be left without diagnosis or management, leading to deterioration in symptoms and a much larger impact on their day-to-day lives. We are often lucky enough to receive feedback from those we support. Recently a desperate parent seeking diagnosis for their child so they could be supported, reported back that they were able to get diagnosis and management for their child, directly because of the support we provided them. (Sarah, UK Advice and Information Manager, EDS UK)

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

We have re-committed ourselves to the concept of centres of excellence in the nations and intend to make progress in planning to secure them. In doing so we are aware that the NHS's planned model of care, at least in England, sees the diagnosis and management of hEDS and HSD being shifted more into primary care. There is thus a debate to be had – with our members, the NHS, and public authorities – about the need for flexibility in applying the model.

In collaboration with public health colleagues in NHS England we continued our work to assess the health needs of people with the most common type of EDS, and the targeted NHS services available to them. Challenges in accessing NHS data have delayed the work but we have identified hospitals in England and Scotland to collect the necessary information on our behalf. The outputs from this key project will provide the framework for our campaigning activities next year.

Education and awareness

During 2022-23 we will highlight the issues faced by our community by campaigning for change.

GP toolkit

Our online EDS toolkit for GPs and primary care staff, developed in partnership with The Royal College of General Practitioners (RCGP) and launched in 2018, is now hosted on our own website. The toolkit remains a vital part of the support we offer on the helpline as our most frequently asked questions are around how to manage the patient/GP relationship.

Conferences

In May 2022 we delivered a successful and well received vascular EDS conference with the charity Annabelle's Challenge and the National EDS Diagnostic Service. It was an excellent example of collaboration and demonstrated the collective strengths of the parties in supporting one of the rarest and more life-limiting types of EDS. We hosted 130 adults and 38 children from across the UK over the weekend. We thank the National Lottery Awards for All Programme England for their flexibility in funding the event.:

Excellent conference. Some fantastic speakers and great to hear about the research planned as well as what has been going on since the last conference. Thank you to everyone involved in the EDS team and Annabelle's Challenge for organising a successful weekend. (An attendee)

Training and Information

We continue to deliver training and provide information on EDS at schools for both teachers and students. In addition during 2022 we held a Parent Hypermobility Workshop in October for the Richmond Carer Forum and training sessions in May for Sunshine Support UK and in November for The Children's Bowel and Bladder Charity.

In March 2023 we held a Change Makers weekend for young people living with EDS. We are grateful to the Pears Foundation for their financial support for this event.

The Change Makers weekend brought together 25 young people with EDS or HSD from across the UK aged between 13 and 21 years old to explore the current lack of information and support for young people with EDS or HSD and to brainstorm what type of support they need and would like and how that support might be delivered. 14 parents attended the weekend event to support their young people.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

The event helped us to focus on the particular needs of young people with EDS, well summarized by the following:

I would really like EDS UK to improve its provision and support for young people, especially teenagers. Having EDS or HSD in a school environment can be very isolating and it can make friendships challenging. I would really like to befriend other young people who understand the challenges of having EDS/HSD. Such a support network would be invaluable and would make a massive difference to my life. I would also love to participate in online social events for teenagers and young people, since we live all across the country and many people with EDS/ HSD (such as myself) really struggle with travelling, so running online events would be a good way to connect us with each other and would provide a really important support network for teenagers with EDS and HSD. (2023 members' survey response)

The most significant of the many outputs from the Change Makers Weekend was the need for a framework for shaping the information and support we offer young people living with EDS in the UK. This will guide further work in this area.

We host an online toolkit for schools to support pupils with EDS and hypermobility-related disorders. The kit was launched by EDS UK and the Hypermobility Syndromes Association (HMSA) in May 2021. The free resource aims to provide school staff with information about symptomatic hypermobility and the Ehlers-Danlos syndromes and how they may affect primary and secondary pupils at school. It emphasises that the conditions affect children and young people in different ways and that often simple, low-cost adjustments can make a big difference. During the year under review we achieved some 9,500 unique visits to the toolkit.

The period also saw publication of the rare disease report 'A Fairer Future: Towards a more equitable delivery of care for those with rare diseases and conditions,' to which EDS UK contributed. The report is the result of a series of workshops convened by independent global policy institute Public Policy Projects with patient advocates and experts from clinical medicine, research, policy, and industry. It provides an important commentary on the experiences of individuals and families living with rare conditions and makes detailed recommendations, based on real world experience, to be considered during the further development and implementation of rare disease action plans by the governments of the four UK nations. To our knowledge, this is the first time that the Ehlers-Danlos syndromes have been specifically mentioned in a report of this type.

Research

During the period trustees committed to develop a research funding strategy and, resources permitting, aim to finalise this during the 23/24 financial year. We are focused on supporting research contributing to the development of clinical guidelines for the diagnosis, treatment, and management of any type of EDS or HSD in the UK and to expanding EDS research capacity in the UK. Details of current and recent research facilitated by EDS UK may be found at <https://www.ehlers-danlos.org/research/>

A major research project ('Comprehensive Assessment of Nutrition and Dietary Intervention in Hypermobile Ehlers-Danlos Syndrome – the CANDI-hEDS study') undertaken by a team led by Professor Qasim Aziz of the Wingate Institute of Gastroenterology at Queen Mary University, London is nearing completion. Professor Aziz's work has been strongly supported by our members, many of whom have participated in the research. We expect the project to present its results in the 2023-2024 financial year.

We promote research studies to our members through our weekly e-news and dedicated webpages. We are proud to be able to contribute to the growth of the evidence base for this misunderstood syndrome through the mobilisation of our members. We will continue to grow this area and look forward to having enough evidence to influence transformational systems change in due course.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

Fundraising and organisational health

Our income and expenditure position

We ended the year with Income of £411,719 and operating costs of £525,080. Income growth from trusts and gift aid went some way to offset a decrease in funds raised from community fundraising and events.

We had decided before the pandemic that we should reduce our reliance on member-generated income by strengthening our appeal to grant makers and developing contacts with companies and the impact of the pandemic accelerated the process. We are grateful to the following for their support:

Trusts and Foundations

Garfield Weston Foundation
Golden Bottle Trust
Pears Foundation
The Eveson Trust
The National Lottery Community Fund Northern Ireland
The National Lottery Community Fund Wales
The Sandhu Charitable Foundation

Corporate Partners

Green People
UK Railtours

How we fundraise

We are reliant on voluntary donations to fund our work. We are registered with the Fundraising Regulator and are open about how we raise our funds. We adhere to the Code of Fundraising Practice and are committed to the Fundraising Promise. We are also a member of the Chartered Institute of Fundraising.

This part of our report complies with the good practice recommendations for smaller charities as set out in the Charities Act 2016. We seek to minimise the risk of breaches of fundraising compliance through the recruitment of experienced fundraising staff and by keeping our knowledge up to date through attending relevant webinars, background reading and training. We will proactively engage with the Fundraising Regulator and other bodies as needed to ensure that any concerns raised are addressed as a priority.

We have partnerships with a number of organisations, including some commercial participator agreements. Our fundraising policy and ethical framework covers our approach to working with commercial partners. We are supported in our applications to Trusts and Foundations by carefully selected consultants with whom we have formal agreements. We have safeguards in place with our partners to ensure that we do not compromise our independence in any way. We also ask people to give to us through our regular appeals, giving in memory or by leaving a gift in their Will.

Our website outlines our complaints process clearly. Any complaints are routinely reported to each meeting of our board of trustees.

We train and support our staff to identify and protect people in vulnerable circumstances in accordance with our policies on safeguarding and fundraising and ethical framework. All our direct marketing communications contain clear instructions of how a supporter can easily opt out of receiving any further communication should they wish to. Our framework also covers our approach to accepting and refusing donations.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

Membership

There is no membership subscription for EDS UK. We had an average of around 12,000 members (In 2021-22, 12,000 members) during the year. We engage with a community of almost 103,000 (80,000 2021-22) across our social media platforms. We also have an e-news subscriber list of 17,000 where we communicate with them weekly.

Engagement

We want to reach as many people as possible affected by EDS. Having a dialogue with them will inform our plans for projects making a difference across the UK. We have an impressive number of unique visits to our website: over 567,000 during the year (in 2021-22, 500,000).

Financial review

The Statement of Financial Activities on page 9 shows net movements in funds for the year of (£113,361) 2022: (£12,670) which results in an decrease in total funds at the balance sheet date to £281,865 (2022: £395,226).

The charity set a budget and made a conscious decision to invest in charitable activities in 2022-23 despite challenging macro-economic conditions. Key highlights include the achievement of good growth in our volunteer base enabling us to reach many more people living with EDS/HSD across the UK and the delivery of a significant young person's event enabling us to further develop our support to different age groups.

Principal funding sources

EDS UK raises its funds through fundraising activities, grants and donations, members' subscriptions and through the sale of branded goods through its online shop.

Reserves policy

It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level equivalent to a minimum of six month's operating expenditure. The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised or the operating costs reduced. This level of reserves has been maintained throughout the period.

Structure, governance and management

The Ehlers-Danlos Support UK (EDS UK) is a charity and a company limited by guarantee. The governing documents are the company's memorandum, and articles of association. There are quarterly meetings of the trustees to agree all matters relating to EDS UK, its broad strategy, and areas of activity. These include:

- Annual income and expenditure budgets
- The allocation of its resources
- The employment of professionals and support staff
- Risk management policies and performance.

A Medical Advisory Panel covering the breadth of specialties in contact with EDS provides the trustees with an expert sounding board and ensures that advice and support is in line with current practice.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

Our trustees

The trustees are appointed in line with the provisions of the articles of association and subject to retirement or re-appointment on a three-yearly rolling basis at the AGM, normally held in November. The trustees are able to appoint honorary officers and have done so in respect of a Chair (Stephen Stacey), Deputy Chairs (Adrian Steel and Charlotte Williams), and a Treasurer (Jason Pearce). The trustees, who are also the directors for the purpose of company law and who served during the period, were:

Trustee	Date of first appointment	Most recent appointment / end of current term *
Sarita Aujla	13 June 2020	2022/2025
Ellie Cannell	19 February 2022	2022/2025
Frances Gawthrop	1 June 2014	2018/2021 (Resigned August 2023)
Anne Lavery	19 February 2022	2022/2025
Leah Mansfield	1 June 2014	2021/2024
Laure Nas de Tourris	15 June 2022	2022/2025
Jason Pearce	28 April 2018	2020/2023
Alison Roux	19 February 2022	2022/2025
Stephen Stacey	22 April 2017	2020/2023
Adrian Steel	28 July 2018	2020/2023
Charlotte Williams	7 March 2020	2020/2023

*3 years or whenever in the retiring third by being longest serving, whichever is sooner.

Frances Gawthrop left us in August having delayed her resignation at the request of the board. Laure Nas de Tourris was appointed in June.

At the AGM in November 2022, we decided to simplify the criteria applying to trustee terms of service. Henceforward a trustee will serve not more than three years from the date of appointment and be eligible for approval by the AGM of a second consecutive term of three years, on the expiry of which they may be approved by the AGM exceptionally for a final term of three years.

The trustees have appointed a Managing Director, Kay Julier, who attends the board and leads the work of the senior leadership team. Members of the senior management team are also present at board meetings. In addition to Kay Julier, the team is made up of Guy Hodgson (Head of Digital and IT), Nikki Casey (Senior Communities Manager), and Laura Kyriacou (Senior Fundraising Manager).

None of the trustees has any beneficial interest in the company. All of the trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

EDS UK maintains working relationships with other charities and umbrella organisations that share common purpose with the charity. None of these relationships is a related party in terms of the SORP.

The trustees are satisfied that systems are in place to mitigate exposure to the major risks to which the charity could be exposed.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

Recruitment, Induction, and training of trustees

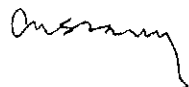
New trustees are recruited by personal approach or recommendation by a current trustee, response to the advertisements we place, and through the use of recruitment companies specialising in the not-for-profit sector.

Candidate trustees are invited to attend a trustee meeting as an active observer before appointment. New trustees are given copies of the trust deed and a guide to the policies and procedures adopted by the charity. They are encouraged to access the Charity Commission's online guidance so that they can better understand their role as a trustee, in particular as to the scope of their responsibilities under the Charities Act.

Patron and Ambassador

We are proud to have Ellie Taylor as our Patron and Cherylee Houston, Anoushe Husain, and Jacob Chandler as our Ambassadors.

The Trustees' report was approved by the Board of Trustees.



Stephen Stacey
Trustee

Dated: 14/12/2023

THE EHLERS-DANLOS SUPPORT UK

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF THE EHLERS-DANLOS SUPPORT UK

I report to the charity Trustees on my examination of the financial statements of The Ehlers-Danlos Support UK for the year ended 31 March 2021.

Responsibilities and basis of report

As the Trustees of The Ehlers-Danlos Support UK (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act), the Charities Accounts (Scotland) Regulations 2006 (as amended), the Charities Act 2011 and the Companies Act 2006 (the 2006 Act). You are satisfied that the financial statements of the are not required by charity or company law to be audited and have chosen instead to have an independent examination.

Having satisfied myself that the financial statements of the 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 the charity's financial statements carried out under section 44 (1) (c) of the 2005 Act and section 145 of the Charities Act 2011 (the 2011 Act). In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Since The Ehlers-Danlos Support UK's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. It is required by company law to prepare its accounts on an accruals basis and since it is registered as a charity in Scotland your examiner must be a member of a body listed in Regulation 11(2) of the Charities Accounts (Scotland) Regulations 2006 (as amended). I confirm that I am qualified to undertake the examination because I am a member of Association of Chartered Certified Accountants, which is one of the listed bodies.

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 that in any material respect:

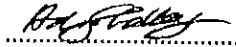
- 1 accounting records were not kept in respect of the as required by section 386 of the 2006 Act and Regulation 4 of the 2006 Accounts Regulations; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and 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 financial statements 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 (FRS 102).

THE EHLERS-DANLOS SUPPORT UK

INDEPENDENT EXAMINER'S REPORT (CONTINUED)

TO THE TRUSTEES OF THE EHLERS-DANLOS SUPPORT UK

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



.....
Adam Shelley (FCCA)
Sobell Rhodes LLP
The Kinetic Centre
Theobald Street
Elstree
Borehamwood
Hertfordshire
WD6 4PJ
United Kingdom

Dated: 15/12/2023

THE EHLERS-DANLOS SUPPORT UK

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 MARCH 2023

	Notes	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
Income from:							
Donations and legacies	2	215,895	81,628	297,523	193,563	169,106	362,669
Fundraising	3	77,960	-	77,960	94,738	-	94,738
Other trading activities		47,075	-	47,075	26,268	-	26,268
Investment Income	4	1,161	-	1,161	32	-	32
Total Income		342,091	81,628	423,719	314,601	169,106	483,707
Expenditure on:							
Charitable activities	5	413,080	124,000	537,080	320,420	175,957	496,377
Net expenditure for the year/ Net movement in funds		(70,989)	(42,372)	(113,361)	(5,819)	(6,851)	(12,670)
Fund balances at 1 April 2022		212,684	182,542	395,226	218,503	189,393	407,896
Fund balances at 31 March 2023		141,695	140,170	281,865	212,684	182,542	395,226

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

THE EHLERS-DANLOS SUPPORT UK

BALANCE SHEET

AS AT 31 MARCH 2023

	Notes	2023 £	£	2022 £	£
Fixed assets					
Tangible assets	8		3,856		6,256
Current assets					
Debtors	9	796		528	
Cash at bank and in hand		287,886		416,025	
		288,682		416,553	
Creditors: amounts falling due within one year	10	(10,673)		(27,583)	
Net current assets			278,009		388,970
Total assets less current liabilities			281,865		395,226
Income funds					
Restricted funds	11	140,170		182,542	
Unrestricted funds		141,695		212,684	
		281,865		395,226	

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2023.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

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

The financial statements were approved by the Trustees on 25/11/2023



Jason Pearce
Trustee

Company registration number 08924646

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

Charity information

The Ehlers-Danlos Support UK is a charity and private company limited by guarantee incorporated in England and Wales. The registered office is Devonshire House, Manor Way, Borehamwood, Herts, WD6 1QQ.

1.1 Accounting convention

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 (FRS 102) (effective 1 January 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102). They also comply with the Companies Act 2006 and Charities Act 2011.

Basis of preparation

The Ehlers-Danlos Support UK 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 notes.

Exemption from preparing a cash flow statement

The charity opted to early adopt Bulletin 1 published on 2 February 2016 and have therefore not included a cash flow statement in these financial statements.

1.2 Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. Thus the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the Trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

1.4 Income

All income is recognised once the charity has entitlement to the income, it is probable that the income will be received and the amount of the income receivable can be measured reliably.

Donations and legacies

Donations are recognised when the charity has been notified in writing of both the amount and settlement date. In the event that a donation is subject to conditions that require a level of performance by the charity before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that these conditions will be fulfilled in the reporting period.

Grants receivable

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

1.5 Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

1.7 Impairment of fixed assets

At each reporting end date, the reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.9 Financial Instruments

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

1.10 Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

1.11 Foreign exchange

Transactions in foreign currencies are recorded at the rate of exchange at the date of the transaction. Monetary assets and liabilities denominated in foreign currencies at the balance sheet date are reported at the rates of exchange prevailing at that date.

2 Donations and legacies

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
Donations	178,595	43,982	222,577	136,747	60,492	254,055
Grants	25,300	37,646	62,946	56,816	108,614	108,614
	<u>215,895</u>	<u>81,628</u>	<u>297,523</u>	<u>193,563</u>	<u>169,106</u>	<u>362,669</u>

3 Fundraising

	Fundraising Income 2023 £	Fundraising Income 2022 £
Charitable activities	<u>77,960</u>	<u>94,738</u>

4 Investment Income

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Interest receivable	<u>1,161</u>	<u>32</u>

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

5 Charitable activities

	2023 £	2022 £
Restricted funds- charitable activities	124,000	175,955
Unrestricted funds- charitable activities	358,120	262,335
	<u>482,120</u>	<u>438,290</u>
Share of support costs (see note 6)	38,685	44,949
Share of governance costs (see note 6)	16,275	13,138
	<u>537,080</u>	<u>496,377</u>
Analysis by fund		
Unrestricted funds	413,080	320,420
Restricted funds	124,000	175,957
	<u>537,080</u>	<u>496,377</u>

6 Support costs

	Support costs £	Governance costs £	2023 Support costs £	Governance costs £	2022 £
Staff costs	1,753	-	1,753	7,325	7,325
Depreciation	4,321	-	4,321	3,000	3,000
IT costs	7,980	-	7,980	8,344	8,344
Rent	19,327	-	19,327	20,054	20,054
Telephone	3,590	-	3,590	4,092	4,092
Subscriptions	1,713	-	1,713	2,132	2,132
Examiners fees	-	4,200	4,200	-	4,200
Bookkeeping	-	10,506	10,506	-	6,180
Legal and professional	-	1,569	1,569	-	772
	<u>38,685</u>	<u>16,275</u>	<u>54,960</u>	<u>44,949</u>	<u>58,087</u>

7 Trustees

None of the Trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

8 Tangible fixed assets

	Plant and equipment £	Fixtures and fittings £	Computers £	Total £
Cost				
At 1 April 2022	3,624	1,988	15,291	20,903
Additions	-	-	1,921	1,921
At 31 March 2023	3,624	1,988	17,212	22,824
Depreciation and Impairment				
At 1 April 2022	3,624	1,988	9,035	14,647
Depreciation charged in the year	-	-	4,321	4,321
At 31 March 2023	3,624	1,988	13,356	18,968
Carrying amount				
At 31 March 2023	-	-	3,856	3,856
At 31 March 2022	-	-	6,256	6,256

9 Debtors

	2023 £	2022 £
Amounts falling due within one year:		
Trade debtors	625	357
Other debtors	171	171
	796	528

10 Creditors: amounts falling due within one year

	Notes	2023 £	2022 £
Bank overdrafts		420	389
Deferred income		-	9,850
Trade creditors		9,338	16,429
Accruals and deferred income		915	915
		10,673	27,583

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

11 Restricted funds

	Movement In funds			Movement In funds			
	Balance at 1 April 2021	Incoming resources	Resources expended	Balance at 1 April 2022	Incoming resources	Resources expended	Balance at 31 March 2023
	£	£	£	£	£	£	£
The National Lottery Community Fund (Expanding Communities)	22,662	71,614	(65,104)	29,172	-	(26,684)	2,488
Other restricted	160,431	80,492	(105,153)	135,770	81,628	(79,716)	137,682
Peter Harrison Foundation	6,300	10,000	(3,700)	12,600	-	(12,600)	-
Hospital Saturday Fund	-	2,000	(2,000)	-	-	-	-
Disa's Fund, The Talent Fund	-	5,000	-	5,000	-	(5,000)	-
	<u>189,393</u>	<u>169,106</u>	<u>(175,957)</u>	<u>182,542</u>	<u>81,628</u>	<u>(124,000)</u>	<u>140,170</u>

The charity has disclosed separately restricted funds as required by the funders.

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

12 Unrestricted funds

These are unrestricted funds which are material to the charity's activities made up as follows:

	Movement in funds			Movement in funds		
	Balance at 1 April 2021	Incoming resources	Resources expended	Balance at 1 April 2022	Incoming resources	Resources expended 31 March 2023
	£	£	£	£	£	£
Unrestricted fund	218,503	314,601	(320,420)	212,684	342,091	(413,080)
	<u>218,503</u>	<u>314,601</u>	<u>(320,420)</u>	<u>212,684</u>	<u>342,091</u>	<u>(413,080)</u>
	<u>218,503</u>	<u>314,601</u>	<u>(320,420)</u>	<u>212,684</u>	<u>342,091</u>	<u>(413,080)</u>

13 Related party transactions

There were no disclosable related party transactions during the year (2022 - none).