

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 2024

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
Charity number (England and Wales)	1157027
Charity number (Scotland)	SC046712
Company number	08924646
Registered office	International House 45-55 Commercial Street London E1 6BD
Independent examiner	Sobell Rhodes LLP The Kinetic Centre Theobald Street Elstree Borehamwood Hertfordshire United Kingdom WD6 4PJ

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 2024

The trustees present their report and accounts for the period ended 31 March 2024.

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 new Theory of Change, vision, mission and three year strategy

In October 2023 we undertook a strategic review and developed a new theory of change, vision, mission and three year strategy.

Our vision

Across the UK, people with EDS or HSD will be connected, heard, supported and have equitable access to care.

Mission

- We are the voice of the EDS/HSD community in the UK.
 - We bring together people with EDS and HSD in the UK to equitably access diagnosis, treatment and care.
- We do this through:
- Awareness – We advocate for and empower our community to drive change. We raise their voices, and work with the NHS across the UK in pursuit of services accessible by all.
 - Support – We provide a platform to support and connect our community. We deliver information and advice on living with EDS/HSD.
 - Knowledge – We build knowledge through information, training and enabling research. We confront misunderstanding and challenge inequality.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

Strategic pillars

Based on our theory of change there are three main areas of focus:

- Advocacy and access
- Community and connections
- Information and knowledge.

Underpinning all three pillars to achieve our vision are our fundraising and infrastructure strategies.

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

Advocacy and Access

Our Enough is Enough campaign garnered over 33,000 signatures across all four nations of the UK and significantly increased awareness of EDS amongst key decision makers in our public policy audience.

How did we achieve this?

We created two digital applications to be the forefront of our campaign. The first allowed members of our community easily to email their local MP and to share their experiences of using the NHS, asking their MP to support our campaign. The second allowed them to create a personalised graphic highlighting their challenges of living with EDS or HSD and promoting the wider campaign. By using the petitions committees where available in the four nations, we were able to ask the committee members to discuss the issues raised with the relevant Ministers.

We delivered a 28,700 signature petition to Downing Street in November 2023 after holding a briefing for parliamentarians in Portcullis House. From the briefing our host Andrew Selous MP undertook to apply for a Westminster Hall debate on the subject of the provision of services for EDS/HSD.

In Wales we secured a date for an exhibition event in the Senedd. Our petition was discussed several times. In March we received a response from the Minister for Health in Wales offering a meeting with the National Clinical Director for Musculoskeletal Care to discuss primary care pathways.

In Scotland we were also fortunate to be given a date for an exhibition in Holyrood. The petition was discussed several times and is still live into 2024-25.

In Northern Ireland we worked on arranging a Dazzle Walk to hand in the petition to Stormont. Conversations have been held with the Rare Disease Partnership and APPG to make further progress.

In February we attended an NHS MSK workshop in London to represent the EDS UK community. The workshop was hosted by the National Clinical Director for MSK and was called Designing the Future of MSK Care.

In just a year we have made a significant impact by raising the voices of our community to the highest levels of power and decision making. In our strategic planning process we identified the need for systems change and our role within that. Almost all the respondents to our 2024 members' survey (99%) said that campaigning and lobbying to raise issues with the government and the NHS were important, very important or essential to them.

Community and Connections

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 85 volunteers (90 in 2022-23) either with EDS themselves or caring for someone with EDS. Our volunteers run over 100 support groups (over 100 in 2022-23), 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 have seven special interest groups: for 18-25-year-olds, teens, parents, elders, LGBTQIA+, men, and family and friends. Over 52,000 people (49,000 in 2022-23) 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 10,000 people (8,000 in 2022-23) connect regularly with each other in 24 closed Facebook groups.

71% of members responding to our 2024 members survey said that our support groups both virtual and face-to-face were important or extremely important to them. 81% of our members said the information, advice and support provided by us positively affected the isolation they felt and their engagement in the community.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

Our Changemakers or young people's project started taking shape in the year with regular drop-ins for the young people on our online working group to get together and create content for their new website. The project continues and the quote below from one of the young people involved illustrates the impact it has had on them personally.

'Being a part of this project has really boosted my confidence and really consolidated an understanding of things I didn't know I understood and has also helped me to challenge some of my own mindsets. It has really helped me grow personally so much. That'll really help me in life and I'll never forget this project for that reason.'

We run a membership scheme for our community to provide safeguarding for our online spaces and support meetings. There is a free membership option to ensure inclusivity and a paid option for people to choose to receive our Fragile Links magazine. We had an average of around 12,000 registered members during the year.

We engage with a community of over 90,000 across our social media platforms. We also have an e-news subscriber list of 17,000 where we communicate with them weekly. The number of website users continues to grow: over 641,000 unique users during the year (compared to over 500,000 in 2022-23). The website continues to be a very valuable resource for members and people looking for information on EDS/HSD with 100% of members responding to our 2024 survey saying they felt it was essential or important to them.

Information and Knowledge

Our Adviceline

In the UK there are still no official care pathways within the NHS for EDS/HSD. This continues to create confusion amongst both patients and healthcare professionals. Not surprisingly the positive impact of our telephone and email Adviceline is huge. There are no other UK-specific advice and information hubs on EDS/HSD and so we are proud to provide a unique resource.

Our 2024 members' survey showed just how important our helpline services are. 80% of members said that the advice and support they received from our helpline was important, very important, or essential to them. In the period under review, we took 962 calls (in 2022-23, 1,171 calls) with an average call time of 19 minutes (in 2022-23, 20 minutes) and responded to 1,550 emails (in 2022-23, 1,756 emails); staff changes in the year may have adversely affected the number of calls logged).

"Thank you for your email & getting back to me so quickly. I will definitely email the ICB in my area & see if I can get the geneticist test expedited. I'm trying to work out how to word it all but I will get there. I'm just so tired with it all at the moment. Thank goodness for Ehlers-Danlos Support UK."

Following our strategic review and work on our Theory of Change, we began to deliver a more targeted approach to maximise the impact for our community. We rebranded the Helpline to an Adviceline in January 2024 and focused our communications around the targeted purpose of the service with reduced phone opening hours. We provided a new FAQ webpage and robust signposting for crisis support services. All of this, alongside better handling of conversations to avoid escalations to safeguarding incidents, meant that between January and March we saw a steep decline in safeguarding calls to the service. This enables us to take more focused advice calls.

"Wow! Great support thank you. Once again I would like to point out how nice it is to have someone "There" for us. Prompt, polite and understanding."

We continued to provide a unique GP toolkit to enable diagnosis and management within primary care. <https://gptoolkit.ehlers-danlos.org/> and a unique schools toolkit to support young people in education. <https://theschooltoolkit.org/>

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

Research

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 has completed during the year. Output from the study has been published in two peer-reviewed journals. 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 2024-2025 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 condition through the mobilisation of our members. As resources permit, we will grow this area and look forward to having enough evidence to influence transformational systems change in due course.

Fundraising and infrastructure

Our income and expenditure position

We ended the year with income of £380,301 and operating costs of £428,906. 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. The impact of the pandemic accelerated the process. We are grateful to the following for their support:

Despite the very challenging financial climate for all charities, it has been a positive year of fundraising for The Ehlers-Danlos Support UK. There has been some fabulous (and imaginative!) fundraising taking place; everything from Ride London and coffee/cake sales to head shaves and a 25-hour musicathon. These are some of the highlights:

Dazzle Walk:

Dazzle Walk was back for the fourth year running and saw 63 Dazzle Walks taking place, with fundraisers donning their razzliest, dazziest zebra attire to raise money for EDS UK. Collectively our wonderful team raised an amazing £23,875.

New fundraising pack

In December we launched a new fundraising pack, which has received hugely positive feedback from our fundraisers. We were delighted to complete this project as it's a great resource for helping us give our fundraisers the best possible support.

Dedication wall

During the year we launched an online dedication wall for people to remember those who have passed away and were affected by EDS or HSD during their lifetime. We are privileged that supporters have been sharing their precious memories and cherished photographs with us in this space.

Legacies

We are grateful to those who choose to leave a gift to The Ehlers-Danlos Support UK in their Will. Gifts given in Wills are incredibly special and help us to confront misunderstanding and challenge inequalities around EDS and HSD.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

Trusts, foundations and corporate support

We are delighted to have received support from numerous trusts, foundations and companies this year. Special thanks to Green People, National Lottery Awards for All England, Awards for All Northern Ireland and The Sandhu Charitable Foundation for their continued support of our work.

We have received some lovely feedback from fundraisers about the support they've received from us, which is so welcome:

"Thank you so much for your email. I genuinely feel a little excitement when I hear from you - thank you for your support."

"Thank you so so much for all of your support and continuously checking in on me, it means a lot."

"I couldn't have done it without YOU! Your support and encouragement, the fundraising packs, the t-shirts, wristbands, flags, everything. Worth the world. Thank you so so so much."

A huge thank you to everyone who has raised money, made a donation and supported our work this year. We could not do what we do without you!

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.

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 recruiting 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.

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. Our website outlines our complaints process clearly.

During the year under review we debated at length the need for an office. Little used of late, we decided to dispense with one. We will bid farewell to Borehamwood early in the next financial year. We have also decided to outsource our shop. This will help us to focus on its product offer and improve the efficiency with which we meet orders.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 31 MARCH 2024*

Financial review

The Statement of Financial Activities on page 9 shows net movements in funds for the year of (£48,257) 2023: (£113,361), which results in a decrease in total funds at the balance sheet date to £233,608 (2023: £281,865).

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 not designated for a specific use should be maintained at a level equivalent to a minimum of six months' 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. The trustees have also agreed that the level of reserves may drop below six months' operating expenditure for a defined length of time. Recourse to this flexibility was made during the year under review.

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 2024

Our trustees

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	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	2023/2024
Alison Roux	19 February 2022	2022/2025
Stephen Stacey	22 April 2017	2023/2024
Adrian Steel	28 July 2018	2023/2024
Charlotte Williams	7 March 2020	2023/2026

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.

Dr Kay Julier resigned as Managing Director on 31 June 2023. She had worked unremittingly for our community and her impact on it and on the charity was significant and enduring. She left with the best wishes of the board and team members. In her stead the trustees have appointed a Chief Executive, Susan Booth, who leads the work of the senior management team. 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. These collaborations include Annabelle's Challenge, POTS UK, EDS Society and HMSA. 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.

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 invited to participate in an induction process designed by the Chief Executive and 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 Ambassadors

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

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) *FOR THE YEAR ENDED 31 MARCH 2024*

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



Stephen Stacey

Trustee

Dated:25/11/2024

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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 2024.

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:25/11/2024.

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THE EHLERS-DANLOS SUPPORT UK

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2024

		Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
	Notes						
Income from:							
Donations and legacies	2	141,109	74,720	215,829	215,895	81,628	297,523
Charitable activities	3	124,904	-	124,904	77,960	-	77,960
Other trading activities		35,303	-	35,303	47,075	-	47,075
Investments	4	4,265	-	4,265	1,161	-	1,161
Total income		305,581	74,720	380,301	342,091	81,628	423,719
Expenditure on:							
Charitable activities	5	359,521	69,037	428,558	413,080	124,000	537,080
Total expenditure		359,521	69,037	428,558	413,080	124,000	537,080
Net income/(expenditure) and movement in funds		(53,940)	5,683	(48,257)	(70,989)	(42,372)	(113,361)
Reconciliation of funds:							
Fund balances at 1 April 2023		141,695	140,170	281,865	212,684	182,542	395,226
Fund balances at 31 March 2024		87,755	145,853	233,608	141,695	140,170	281,865

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 2024

	Notes	2024 £	£	2023 £	£
Fixed assets					
Tangible assets	9		1,275		3,856
Current assets					
Debtors	10	239		796	
Cash at bank and in hand		244,004		287,886	
		244,243		288,682	
Creditors: amounts falling due within one year	11	(11,910)		(10,673)	
Net current assets			232,333		278,009
Total assets less current liabilities			233,608		281,865
The funds of the					
Restricted income funds	12	145,853		140,170	
Unrestricted funds		87,755		141,695	
		233,608		281,865	

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 2024.

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 25/11/2024
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Jason Pearce
Trustee

Company registration number 08924646 (England and Wales)

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

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 International House, 45-55 Commercial Street, London, E1 6BD.

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 or grantors 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 2024

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 2024

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 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Donations	125,709	31,320	157,029	178,595	43,982	222,577
Grants	15,400	43,400	58,800	25,300	37,646	62,946
	<u>141,109</u>	<u>74,720</u>	<u>215,829</u>	<u>215,895</u>	<u>81,628</u>	<u>297,523</u>

3 Fundraising

	Fundraising Income 2024 £	Fundraising Income 2023 £
Charitable activities	<u>124,904</u>	<u>77,960</u>

4 Income from investments

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Interest receivable	<u>4,265</u>	<u>1,161</u>

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

5 Charitable activities

	2024 £	2023 £
Restricted funds- charitable activities	69,036	124,000
Unrestricted funds- charitable activities	296,446	358,120
	<u>365,482</u>	<u>482,120</u>
Share of support costs (see note 6)	39,253	38,685
Share of governance costs (see note 6)	23,823	16,275
	<u>428,558</u>	<u>537,080</u>
Analysis by fund		
Unrestricted funds	359,521	413,080
Restricted funds	69,037	124,000
	<u>428,558</u>	<u>537,080</u>

6 Support costs

	Support costs	Governance costs	2024	Support costs	Governance costs	2023
	£	£	£	£	£	£
Staff costs	1,304	-	1,304	1,753	-	1,753
Depreciation	2,581	-	2,581	4,321	-	4,321
IT costs	9,276	-	9,276	7,980	-	7,980
Rent	19,296	-	19,296	19,327	-	19,327
Telephone	4,670	-	4,670	3,590	-	3,590
Subscriptions	2,126	-	2,126	1,713	-	1,713
Examiners fees	-	8,985	8,985	-	4,200	4,200
Bookkeeping	-	13,752	13,752	-	10,506	10,506
Legal and professional	-	1,086	1,086	-	1,569	1,569
	<u>39,253</u>	<u>23,823</u>	<u>63,076</u>	<u>38,685</u>	<u>16,275</u>	<u>54,960</u>

7 Trustees

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

8 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

9 Tangible fixed assets

	Plant and equipment £	Fixtures and fittings £	Computers £	Total £
Cost				
At 1 April 2023	3,624	1,988	17,212	22,824
At 31 March 2024	3,624	1,988	17,212	22,824
Depreciation and impairment				
At 1 April 2023	3,624	1,988	13,356	18,968
Depreciation charged in the year	-	-	2,581	2,581
At 31 March 2024	3,624	1,988	15,937	21,549
Carrying amount				
At 31 March 2024	-	-	1,275	1,275
At 31 March 2023	-	-	3,856	3,856

10 Debtors

	2024 £	2023 £
Amounts falling due within one year:		
Trade debtors	68	625
Other debtors	171	171
	239	796

11 Creditors: amounts falling due within one year

	Notes	2024 £	2023 £
Bank overdrafts		-	420
Trade creditors		7,110	9,338
Accruals and deferred income		4,800	915
		11,910	10,673

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

12 Restricted funds

	Movement in funds			Movement in funds			
	Balance at 1 April 2022	Incoming resources	Resources expended	Balance at 1 April 2023	Incoming resources	Resources expended	Balance at 31 March 2024
	£	£	£	£	£	£	£
The National Lottery Community Fund - Northern Ireland	-	-	-	-	9,950	(1,734)	8,216
The National Lottery Community Fund (Expanding Communities)	29,172	-	(26,684)	2,488	-	(2,488)	-
Other restricted	135,770	81,628	(79,716)	137,682	64,770	(64,815)	137,637
Peter Harrison Foundation	12,600	-	(12,600)	-	-	-	-
Disa's Fund, The Talent Fund	5,000	-	(5,000)	-	-	-	-
	<u>182,542</u>	<u>81,628</u>	<u>(124,000)</u>	<u>140,170</u>	<u>74,720</u>	<u>(69,037)</u>	<u>145,853</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 2024

13 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 31 March 2024
	Balance at 1 April 2022	Incoming resources	Resources expended	Balance at 1 April 2023	Incoming resources	Resources expended	
	£	£	£	£	£	£	£
Unrestricted fund	212,684	342,091	(413,080)	141,695	305,581	(359,521)	87,755
	<u>212,684</u>	<u>342,091</u>	<u>(413,080)</u>	<u>141,695</u>	<u>305,581</u>	<u>(359,521)</u>	<u>87,755</u>

14 Related party transactions

There were no disclosable related party transactions during the year (2023 - none).