

THE EHLERS-DANLOS SUPPORT UK

England & Wales · Charity number 1157027

Details

Status	Registered
Legal form	Charitable company
Company number	08924646
Registered	2014-05-13
Register	View on the Charity Commission register

Contact

Address	International House 66 Lavender Hill London SW11 5RQ
Phone	02087365604
Email	info@ehlers-danlos.org
Website	www.ehlers-danlos.uk

Activities

Objects: FOR THE RELIEF OF PERSONS SUFFERING FROM EHLERS-DANLOS SYNDROME AND TO ADVANCE MEDICAL RESEARCH INTO THE CAUSE, CURE, PREVENTION OF THE SYNDROME.

Activities: Key objectives for the Charity include providing support and guidance to members; growing the membership; increasing awareness of the condition and the charity both amongst the medical community and the general public; promoting/encouraging medical research; and fundraising. 'MAKING OUR INVISIBLE VISIBLE'

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£434,770	£392,489	-	-
2024-03-31	£380,301	£428,558	-	-
2023-03-31	£423,719	£537,080	-	-
2022-03-31	£483,707	£496,377	-	-
2021-03-31	£406,887	£405,498	-	-

Trustees

Name	Role	Appointed
Charlotte Emily Williams	Chair	2020-03-07
Alison Jane Roux		2022-02-19
Anne Dominique Myra Lavery		2022-02-19
Dr Jill Harrison		2024-09-14
Helen Ball		2024-11-23
Kathryn Jayne Caldwell		2024-11-23
Laure Francoise Marie Nas De Tourris		2022-06-15
Natasha Larkin		2025-11-22
Sarah Bullock		2025-11-22
Timothy Peter de Winter		2024-07-25
Yanina Graciela Aubrey-Gimenez		2024-05-11

THE EHLERS-DANLOS SUPPORT UK

England & Wales - Charity number 1157027

Accounts

Company number: 8924646
Charity number: 1157027 (England & Wales)
Charity number: SC046712 (Scotland)

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' ANNUAL REPORT AND FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

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REFERENCE AND ADMINISTRATIVE DETAILS

Trustees	Yanina Aubrey-Gimenez Sarita Faulkner Helen Ball Kathryn Caldwell Ellie Cannell Tim de Winter Anne Lavery Laure Nas de Tourris Alison Roux Charlotte Williams
Registered Charity numbers	1157027 (England & Wales) SC046712 (Scotland)
Company number	8924646
Principal/Registered Office	International House 45-55 Commercial Street London E1 6BD
Independent examiner	Jason Foxwell FCCA FCIE 12 Hillbourne Road Poole BH17 7JB

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025

The Trustees (who are also directors for the purposes of the Companies Act 2006) present their annual report together with the financial statements of the charitable company for the year ended 31 March 2025.

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).

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 (EDS) or hypermobility spectrum disorders (HSD) 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 trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

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 and 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 and HSD.
- Knowledge – We build knowledge through information, training and enabling research. We confront misunderstanding and challenge inequality.

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.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

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

Advocacy and Access

"Knowing that this organisation is here whenever I need them helps me to live a happier, healthier life. They helped me to self-advocate and get diagnosed. I rely on them as my condition changes and progresses, not just for me but for my 16 y/o child who potentially has inherited this (I was only diagnosed at 41)."

We continued to work with policy makers and senior contacts within the NHS to develop new care pathways, raise awareness of the condition with the Department of Work and Pensions and increase knowledge and confidence of medical professionals.

"The service you provide is essential for so many and you do such a great job. I would love to see more information that we can pass on to the professionals we see, that can help them as much as us too. Some professionals recently have wanted to help me but don't know how, or refer me on but then don't get any help from them because they say they can't. It's like going round in circles."

In Wales we became part of a working group as subject matter experts to co-create a new primary care pathway of care for EDS and HSD. This was as a direct result of the petitions work from the Enough is Enough campaign that started in 2023 where we called for care pathways, NICE guidelines, integrated multi-disciplinary teams and training and support for healthcare professionals.

"Thank you for doing what you are doing. You are so essential to people with EDS and HSD in gaining support and advice so that their healthcare practitioners, education providers etc get the information they need to support users of your services and improve their welfare."

In England we led a debate in Westminster Hall in May which delivered a promise from the Minister for Health and Secondary Care to meet with us to discuss how we can improve the lives of people across the country with EDS. Shortly after making this headway though, the general election was announced and we have had to start again building relationships with new MPs. We also kept a close eye on the new manifesto promises and draft legislation. We actively contributed to the government consultation on the Pathways to Work green paper which included the Personal Independence Payments (PIP) review. And as part of our membership with ARMA (Arthritis and Musculoskeletal Alliance) we also contributed to the consultation on the NHS 10 year plan.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

"The work that you do to educate about EDS and campaign for better NHS care is invaluable. Going forward many of us will be severely impacted financially by changes to benefits - particularly those of us no longer able to work but not eligible for PIP."

We also worked with NHS East Sussex to create a new pathway for primary care for EDS and HSD based on the work we have been doing in Wales.

"Thank you for all your hard work. It was a lifeline to me finding EDS UK once diagnosed at age 32. As my consultant had no guidance or materials for me."

In Scotland, we held an exhibition in Holyrood in May and a round table meeting in September. The petition was discussed several times and is still live into 2025-26.

In Northern Ireland, MLA Connie Eagan handed in the EDS UK petition to Stormont in December. Connie promised to follow up with a letter to the Minister for Health requesting a meeting to discuss issues.

We delivered training for Capita who provide assessors for PIP. We discussed EDS and HSD and issues with PIP assessments with their staff in July.

In November we delivered a conference for GPs in London to learn how to diagnose and manage EDS and HSD in primary care. We had over 70 registrations and attendees reported that the session was hugely beneficial.

"Please continue with the GP toolkit to educate them on EDS as they know nothing about it and look at me as if I'm talking nonsense."

We asked those who attended how they would share their knowledge after the event comments included 'More confident to diagnose and encourage colleagues to think EDS.' We also asked how their own practice would change and comments included 'Be more curious, share possible diagnosis with patients. Advocate for patients more.' And 'Has given me the confidence to identify and diagnose patients early.'

Dr Emma Reinhold – speaker, medically retired GP, Researcher and Medical Advisory Panel member *"It was a privilege to witness a group of clinicians going from curious to confident over the course of an afternoon, thanks to the hard work of an amazing team led by Jill and Susan. It's also great to see the EDS UK GP Toolkit still delivering value for doctors and patients 6 and a half years on from its launch."*

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

Sophie Roberts – Podiatrist and speaker

"A fantastic event simplifying and demystifying the presentation and diagnosis of hEDS/HSD patients for GP's so they can lead patients on the appropriate treatment pathways to empower them to manage their symptoms and improve quality of life"

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. As last year almost all the respondents to our 2025 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 ran support groups to facilitate peer-to-peer support in a safe space. These groups attracted over 3,000 attendances in the year under review. We had over 85 volunteers (90 in 2022-23) either with EDS themselves or caring for someone with EDS. Our volunteers ran over 300 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.

In our annual member survey support from EDS UK had become much more important in the past year, specifically in the devolved nations.

"Unfortunately there is no help or support in my area (Wales) for EDS. I've been told to carry on after my diagnosis with no support. If support was to stop from yourselves I'd have nothing."

"There are no support services in Scotland except for you!"

"Northern Ireland has no specialist here so the community is all I have for help. I have been on a waiting list to see rheumatology for 5 years and the average wait to be seen is 8 years and rising. So EDS UK is essential for me."

Many of the feedback questions mentioned concerns around PIP and benefits support.

"The benefits and work help changed my life. Thank you so very much."

"I have been enabled to effectively fill in DLA forms through the knowledge imparted."

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

We had seven special interest groups: for 18–25-year-olds, teens, parents, elders, LGBTQ+, 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) connected regularly with each other in 20 closed Facebook groups.

"I think what is provided nationally and then by regions is beyond amazing. Once I finally got my diagnosis I joined and instantly felt less alone. Being able to ask and answer questions with what others and what I am going through, is incredibly valuable and more helpful than I can describe. Thank you for the work that gets put into these, the volunteers are unsung heroes in my opinion."

We began a new paid webinar series and these have proven to be very successful with excellent feedback from attendees.

"Love the webinars with experts on the topics. I gain a heap of information from these sources and it prevents me from needing to see my GP all the time for things that they may not be able to help me with anyways. Thank you!"

Using funding from Sport England we were able to begin a programme of virtual, online exercise classes which have been adapted for people with hypermobility.

"The monthly Web calls have been absolutely vital for helping manage my conditions and the free exercise classes have got me exercising a little again."

One of the strongest themes to emerge in the March 2025 survey was the emotional and psychological toll of living with EDS or HSD, particularly when isolated.

- **81%** said EDS UK helped reduce their feelings of isolation
- **75%** felt better able to manage their mental health
- **84%** reported improved understanding of health management

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 15,000 registered members during the year.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

Information and Knowledge

Our Adviceline

Our UK focused adviceline line delivering targeted information and advice on EDS and HSD remained open two days a week throughout the year. Despite the reduction in opening hours from last year we increased our response to queries by 20%. This is a significant shift in approach and efficiency whilst still delivering excellent support to our community. There are no other UK-specific advice and information hubs on EDS and HSD and so we are proud to provide a unique resource.

"EDS UK is a vital lifeline. I wasn't getting any treatment or support before I discovered this charity and thought I was a malingering hypochondriac with 20 different illnesses. The webinars, support groups and helpline have helped me understand my hEDS, explain it to others and get medical support."

Our 2025 members' survey showed just how important our adviceline services continue to be. 84% of members said that the advice and support they received from our adviceline was important, very important, or essential to them. This is an increase of 4% on last year. In the period under review, we handled nearly 4,000 contacts. With top topics including diagnosis, joint pain and diet queries.

"The advice that I have received has literally saved my life during a medical procedure as I was able to advocate for myself and instruct the medical professional of what to do to stop the issue they caused through their lack of knowledge around EDS."

Our website

We provide a comprehensive website with a wealth of information and knowledge collected on it over many years.

"I have found the EDS UK website a valuable source of information that I have used to pass on information to my GP. The work you all do is brilliant. Thank you."

"I direct patients to your website at least weekly. I've been in healthcare for 3 decades and having your website as a resource is essential to those newly diagnosed. Latest research is also essential for the professionals to make better and more informed decisions with their patients."

In the 2025 members' survey 99% of respondents stated that they felt the information about EDS and HSD on the website was important, very important or essential. A further 94% said the recordings and videos by professionals on the website were important, very important or essential.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

"You provide invaluable information! Without the information that you provide here I would have few if any explanations. I am grateful for the information that you provide."

"Hi, firstly, thank you for existing. This page is a lifeline. The information you provide is invaluable, and so spot on sometimes I could cry as it shows I'm not crazy."

Our GP and Schools Toolkits

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/>

"Please continue the good work, and raising awareness of hEDS, especially in the medical profession, and schools/universities. My daughter's teachers did not understand!"

Research

We announced a jointly funded a PhD in Sheffield with Annabelle's Challenge to research an exercise based intervention programme for people living with vascular EDS. This project will start during the 2025 2026 financial year and run for three years. Starting with a literature review the aim of the study is to produce evidence based exercise guidelines which will make a tremendous impact for this rare type of EDS.

"When you are struggling with chronic pain and mobility issues and being continually rejected for treatment by the NHS, it helps to know someone is on your side. Raising awareness is so important and EDS UK helps us by linking our stories to make our voices heard by those who can change future treatment and research. I now have hope for improved treatment in the future. Alone, I was continually silenced by people who did not understand how much I was suffering. Hope keeps me alive and as active as possible."

We promote research studies to our members through our 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.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

Fundraising and infrastructure

Our income and expenditure position

We ended the year with income of £434,770 and operating costs of £392,489.

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; everything from walking the Camino Portugues and a white collar boxing event, to a cabaret evening and swing concert! These are some of the highlights:

Dazzle Walk

Dazzle Walk was back for its fifth year 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 £22,136.

"Attending the first dazzle walk in Northern Ireland was the first time I was able to meet anyone with EDS and this will forever be a very special and memorable moment in my life to which I am very grateful for."

13 for 13

In October we launched our new community fundraising initiative, 13 for 13, which saw fundraisers getting sponsored to do 13 things for the 13 types of EDS. Highlights included a 13-book reading challenge, 13-hour gaming marathon and playing the handpan for 13 days. Some amazing creative ideas. We're looking forward to seeing what 13 for 13 2025 will bring!

London Marathon

Our six-person strong 2025 London Marathon team took on this iconic event and raised an incredible £12,653. We've got four guaranteed entries in the 2026 event and can't wait to support Team EDS UK.

"Honestly it was one of the most incredible experiences of my life with the amount of support from start to finish line, the very best of community spirit was on show. The heat was a lot but the pride I felt crossing the finishing line was so worth it."

"It makes my heart so happy that more awareness and importance is being placed on EDS."

At The Ehlers-Danlos Support UK, "support" is at the heart of everything we do. And that extends to the incredible individuals who choose to fundraise for us.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

We are proud to offer dedicated, personalised support to each and every fundraiser, helping them every step of the way as they raise vital funds and awareness. Whether they're running a marathon, organising a cake sale, or taking on another creative challenge, our fundraisers feel part of a bigger team and a wider community. They are valued, motivated, and able to enjoy every moment of their journey with us.

It is our privilege to empower them to give back and to contribute to everything outlined throughout this report. The positive feedback we receive from our fundraisers speaks volumes and is always a joy to hear:

"My sister has EDS and found your organisation to be a really supportive resource, particularly through her pregnancy. I'm delighted I can run for her and EDS UK in the Scottish Half Marathon."

"I really appreciate everything that you are doing in the fundraising/marketing Team at EDS UK- it makes all the difference and allows us to continue to do what we do as Area Coordinators. Our members really value the support we can provide."

"I also want to say a heartfelt thank you for the awareness vests you sent – they've been brilliant for spreading visibility and starting important conversations. It means a lot to feel supported by the community, and I'm proud to be contributing to such a vital cause."

"Thank you so much for the lovely and supportive email. I wish I could do more for my friend and her EDS, but it felt good being able to raise some awareness and some money for yourselves too."

These kind words remind us just how important our role is in helping our fundraisers feel connected, confident, and proud of their achievements, while making a real difference to our shared mission.

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.

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 and The Sandhu Charitable Foundation for their continued support of our work.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

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

Financial review

The Statement of Financial Activities on page 16 shows net increase in funds for the year of £42,281 (2024: decrease of £48,257), which results in an increase in total funds at the balance sheet date to £275,889 (2024: £233,608).

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 but we are pleased to report that by year end coverage had improved to 5 months' operating expenditure and we expect to be operating at or around our target of six months coverage by March 2026.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

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. During this year we started a refresh of the panel and reached out to potential new members.

Our trustees

The trustees are able to appoint honorary officers and have done so in respect of a Chair (Charlotte Williams), Deputy Chairs (Laure Nas de Tourris and Tim de Winter), and a Treasurer (Helen Ball). The trustees, who are also the directors for the purpose of company law and who served during the year and to the date of approval of these accounts were:

Trustee	Date first appointed	Most recent appointment / end of current term
Yanina Aubrey-Gimenez	Jan 2025	2025/2028
Helen Ball	Jan 2025	2025/2028
Kathryn Caldwell	Jan 2025	2025/2028
Ellie Cannell	February 2022	2022/2025
Sarita Faulkner	June 2020	2022/2025
Jill Harrison	Jan 2025	2025/2028
Anne Lavery	February 2022	2022/2025
Leah Mansfield	June 2014	Resigned Nov 2024
Laure Nas de Tourris	June 2022	2022/2025
Jason Pearce	April 2018	Resigned Dec 2024
Alison Roux	February 2022	2022/2025
Stephen Stacey	April 2017	Resigned Dec 2024
Adrian Steel	Sept 2021	Resigned Dec 2024
Charlotte Williams	March 2020	2023/2026
Tim de Winter	Jan 2025	2025/2028

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

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.

In the year we ran a successful trustee recruitment campaign and were delighted to welcome Yanina Aubrey-Gimenez, Tim de Winter, Helen Ball, Kathryn Caldwell and Jill Harrison to the board. We further strengthened our governance by introducing a new Finance Sub Committee in February.

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.

Chief Executive, Susan Booth leads the work of the senior management team. The team is made up of Nikki Casey (Senior Communities Manager), and Laura Kyriacou (Senior Fundraising Manager).

EDS UK maintains working relationships and memberships 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. Memberships include ARMA, AECVO and NCVO. 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.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 31 MARCH 2025 (Continued)

Trustees' Responsibility Statement

The Trustees (who are also directors for the purposes of company law) are responsible for preparing the Trustees' Report and financial statements in accordance with applicable law and UK Accounting Standards.

Company law requires the directors to prepare financial statements for each financial year. Under company law, the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of the income and expenditure of the charitable company for that period.

In preparing these financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charities SORP;
- Make judgements and accounting estimates that are reasonable and prudent;
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue to operate.

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statement 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.

In preparing this report, the Trustees have taken advantage of the small companies exemptions provided by Section 415A of the Companies Act 2006.

This report was approved by the Trustees and signed on their behalf by:



Charlotte Williams
Chair of Trustees

Date: 22/11/25

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE EHLERS-DANLOS SUPPORT UK FOR THE YEAR ENDED 31 MARCH 2025

I report to the charity trustees on my examination of the accounts of the Charitable Company.

Responsibilities and basis of report

As the trustees of the Charity (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) and the Companies Act 2006 ('the 2006 Act'). You are satisfied that the accounts of the Charity 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 accounts of the Charity 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 accounts 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 the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Since the Charity has gross income exceeding £250,000, is required by company law to prepare its accounts on an accruals basis and 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 can confirm that I am qualified to undertake the examination because I am a registered member of ACCA and ACIE, both of them 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 as required by section 386 of the 2006 Act and Regulation 4 of the 2006 Accounts Regulations; or
2. The accounts do not accord with those records with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006; 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.

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 accounts to be reached.



Jason Foxwell FCCA FCIE

independent-examiner.net, 12 Hillbourne Road, Poole, BH17 7JB

Date: 5 December 2025

THE EHLERS-DANLOS SUPPORT UK
YEAR ENDED 31 MARCH 2025

STATEMENT OF FINANCIAL ACTIVITIES
(incorporating an Income and Expenditure Account)
FOR THE YEAR ENDED 31 MARCH 2025

	Notes	Unrestricted Funds	Restricted Funds	Total Funds 2025	Total Funds 2024 (restated)
		£	£	£	£
Income from:					
Donations and legacies	2	322,374	67,245	389,619	341,002
Charitable activities	3	12,873	-	12,873	10,875
Other trading activities		27,756	-	27,756	24,159
Investment income		4,522	-	4,522	4,265
Total income		367,525	67,245	434,770	380,301
Expenditure on:	4				
Cost of raising funds		44,015	-	44,015	45,412
Charitable activities		264,882	83,592	348,474	383,146
Total expenditure		308,897	83,592	392,489	428,558
Net income/(expenditure)		58,628	(16,347)	42,281	(48,257)
Transfer of funds		-	-	-	-
Net movement in funds		58,628	(16,347)	42,281	(48,257)
Reconciliation of funds:					
Total funds brought forward		87,755	145,853	233,608	281,865
Total funds carried forward		146,383	129,506	275,889	233,608

The Statement of Financial Activities includes all gains and losses recognised in the year.

All of the charity's activities derive from continuing operations.

The notes on pages 10 to 15 form an integral part of these accounts.

THE EHLERS-DANLOS SUPPORT UK
YEAR ENDED 31 MARCH 2025

BALANCE SHEET AS AT 31 MARCH 2025

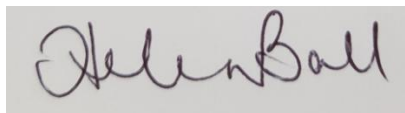
		2025	2024
	Notes	£	£
Fixed Assets			
Tangible assets	7	-	1,275
Current Assets			
Debtors	8	170	239
Cash at bank and in hand		287,163	244,004
		287,333	244,243
Creditors: amounts falling due within one year	9	(11,444)	(11,910)
Net current assets		275,889	232,333
NET ASSETS		275,889	233,608
The funds of the charity:			
Restricted funds	10	129,506	145,853
Unrestricted income funds		146,383	87,755
		275,889	233,608

The trustees consider that the charitable company is entitled to exemption from the requirement to have an audit under the provisions of section 477 of the Companies Act 2006 (the Act) and members have not required the company to obtain an audit for the year in accordance with section 476 of the Act.

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

These accounts are prepared in accordance with the special provisions of Part 15 of the Companies Act relating to small companies.

The accounts were approved by the trustees, authorised for issue and signed on their behalf by:



Helen Ball

Trustee

Date: 22/11/25

The notes on pages 18 to 22 form an integral part of these accounts.

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2025

1. ACCOUNTING POLICIES

1.1. Basis of preparation of the accounts

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)), and the Companies Act 2006.

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.

The charity has taken advantage of the SORP Bulletin 1 published on 2 February 2016 to not publish a cash flow statement in these accounts.

1.2. Going Concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern nor any significant areas of uncertainty that affect the carrying value of assets held by the charity.

1.3. Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the 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 and legacies are recognised when the charity has been notified in writing of both the amount of settlement date. In the event that a donation/legacy 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.

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2025 (continued)

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.

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.

Tangible fixed assets are depreciated over a 3 year period on a straight line basis.

2. DONATIONS AND LEGACIES

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025 £	Total funds 2024 £ (restated)
Donations	220,698	-	220,698	282,202
Legacies	20,376	-	20,376	-
Grants	81,300	67,245	148,545	58,800
	£322,374	£67,245	£389,619	£341,002

3. CHARITABLE ACTIVITIES

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025 £	Total funds 2024 £
Membership subscriptions	12,873	-	12,873	10,875

THE EHLERS-DANLOS SUPPORT UK
YEAR ENDED 31 MARCH 2025

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2025 (continued)

4. EXPENDITURE

	2025	2024
	£	£
		(restated)
Restricted funds – charitable activities	83,592	69,036
Unrestricted funds – charitable activities	211,721	251,034
Unrestricted funds – cost of raising funds	44,015	45,412
	<u>339,328</u>	<u>365,482</u>
Share of support costs (see note 5)	31,088	39,253
Share of governance costs (see note 5)	22,073	23,823
	<u>£392,489</u>	<u>£428,558</u>
	<u><u>£392,489</u></u>	<u><u>£428,558</u></u>
Analysis by fund		
Unrestricted funds	308,897	359,521
Restricted funds	83,592	69,037
	<u>£392,489</u>	<u>£428,558</u>
	<u><u>£392,489</u></u>	<u><u>£428,558</u></u>

5. SUPPORT AND GOVERNANCE COSTS

	Support	Governance	Total	Total
	costs	costs	costs	costs
	2025	2025	2025	2024
	£	£	£	£
Staff costs	117	-	117	1,304
Depreciation	1,275	-	1,275	2,581
IT costs	22,456	-	22,456	9,276
Rent	3,340	-	3,340	19,296
Telephone	2,751	-	2,751	4,670
Subscriptions	1,149	-	1,149	2,126
Bookkeeping and examiner's fees	-	21,230	21,230	22,737
Legal and professional fees	-	843	843	1,086
	<u>£31,088</u>	<u>£22,073</u>	<u>£53,161</u>	<u>£63,076</u>
	<u><u>£31,088</u></u>	<u><u>£22,073</u></u>	<u><u>£53,161</u></u>	<u><u>£63,076</u></u>

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2025 (continued)

6. TRUSTEES

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

7. TANGIBLE FIXED ASSETS

	Plant and equipment £	Fixtures and fittings £	Computers £	Total £
Cost				
At 1 April 2024	3,624	1,988	17,212	22,824
Disposals	(3,624)	(1,988)	-	(5,612)
At 31 March 2025	-	-	17,212	17,212
Depreciation				
At 1 April 2024	3,624	1,988	15,937	21,549
Disposals	(3,624)	(1,988)	-	(5,612)
Depreciation charge for the year	-	-	1,275	1,275
At 31 March 2025	-	-	17,212	17,212
Net book value				
At 31 March 2025	-	-	-	-
At 31 March 2024	-	-	1,275	1,275

8. DEBTORS

	2025 £	2024 £
Trade debtors	-	68
Other debtors	170	171
	£170	£239

THE EHLERS-DANLOS SUPPORT UK
YEAR ENDED 31 MARCH 2025

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2025 (continued)

9. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025	2024
	£	£
Trade creditors	9,444	7,110
Accruals and deferred income	2,000	4,800
	<u>£11,444</u>	<u>£11,910</u>

10. RESTRICTED FUNDS

	Balance as at 1 Apr 2024	Income	Expenditure	Transfers	Balance as at 31 Mar 2025
	£	£	£	£	£
National Lottery CF – NI	8,216	-	(8,216)	-	-
Candi	69,488	-	(7,460)	-	62,028
Vascular	21,043	-	-	-	21,043
England	-	19,985	(19,985)	-	-
GP Conference	-	30,000	(30,000)	-	-
Scotland	-	5,000	(5,000)	-	-
Sport England	-	12,260	(7,797)	-	4,463
Other restricted funds	47,106	-	(5,134)	-	41,972
	<u>£145,853</u>	<u>£67,245</u>	<u>(£83,592)</u>	<u>-</u>	<u>£129,506</u>

11. RELATED PARTY TRANSACTIONS

There were no related party transactions during the year (2024 – none).

12. RESTATEMENT OF COMPARATIVE FIGURES

Although the total reported figures for 2024 have not changed (there is no change to total income, total expenditure, or the balance sheet), the income and expenditure analysis has been amended to more accurately reflect the correct position. The following changes were made:

Income

The majority of fundraising income has been re-categorised as donations. The income from charitable activities is just the membership subscriptions.

Expenditure

Cost of raising funds has been split out from charitable expenditure.

THE EHLERS-DANLOS SUPPORT UK

England & Wales - Charity number 1157027

Accounts

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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Balance sheet	12
Notes to the financial statements	13 - 19

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.

===== D:\CFS\0009-6427-6208-C\CFE-08000A\FAS\FD =====

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



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>
	<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).

THE EHLERS-DANLOS SUPPORT UK

England & Wales - Charity number 1157027

Accounts

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
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 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

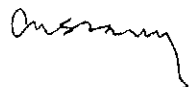
New trustees are recruited by personal approach or recommendation by a current trustee, response to the advertisements we place, and through the use of recruitment companies specialising in the not-for-profit sector.

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:

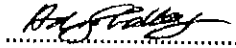
- 1 accounting records were not kept in respect of the as required by section 386 of the 2006 Act and Regulation 4 of the 2006 Accounts Regulations; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of Regulation 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 31 March 2023
	Balance at 1 April 2021	Incoming resources	Resources expended	Balance at 1 April 2022	Incoming resources	Resources expended	
	£	£	£	£	£	£	£
Unrestricted fund	218,503	314,601	(320,420)	212,684	342,091	(413,080)	141,695
	<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>141,695</u>

13 Related party transactions

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

THE EHLERS-DANLOS SUPPORT UK

England & Wales - Charity number 1157027

Accounts

Charity Registration No. 1157027 (England and Wales)

Charity Registration No. SC046712 (Scotland)

Company Registration No. 08924646 (England and Wales)

THE EHLERS-DANLOS SUPPORT UK
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2022



Sobell Rhodes LLP
The Kinetic Centre
Theobald Street
Elstree
Borehamwood
Hertfordshire
WD6 4PJ

THE EHLERS-DANLOS SUPPORT UK

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees

Jason Pearce	
Leah Mansfield	
Stephen Stacey	
Adrian Steel	
Charlotte Williams	
Sarita Aujla	
Ellie Cannell	(Appointed 19 February 2022)
Anne Lavery	(Appointed 19 February 2022)
Alison Roux	(Appointed 19 February 2022)
Ms Laure Nas De Tourris	(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
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 2022

The trustees present their report and accounts for the period ended 31 March 2022.

Purpose

The charity's purpose as set out in our 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 and information sheets;
- d. Organising day and residential conferences;
- e. Producing a bi-annual magazine (Fragile Links) which is available on payment of a small subscription, online and in hard copy;
- f. Maintaining a website and social media presence to promote public awareness and provide 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 areas of strategic focus are:

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

A summary of our activities is provided under these headings.

During 2022-23 we plan to take a more active role in highlighting the issues faced by the community we support and campaigning for change.

Support

Our helpline

The telephone and email helpline are an important part of the charity's offer to beneficiaries. In 2021-22, we took 1,717 calls with an average call time of 20 minutes and responded to approximately 2,000 emails.

Last year we said that the pandemic had highlighted the need for our helpline support service. Post-pandemic there has been no fall-off in demand. Many callers asked us for support as they struggled to access NHS services and benefits, and experienced difficulties navigating the education system for children with disabilities.

The helpline is open to provide support five days per week. We would like to offer additional digital routes to access our helpline to reach those who find it difficult to make telephone calls or use email.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

Building community

At the close of the year we had 76 volunteer Area Co-ordinators providing support to local members and over 6,500 members in our closed Facebook support groups.

We have continued with online support group meetings which were so successful during the pandemic – as they seem to provide a more accessible service for most – while also reintroducing face-to-face meetings at the request of our members.

In August 2021 we were proud to be awarded the Investing in Volunteers accreditation. Our volunteers are at the heart of the support we provide in the community and we are committed to providing a positive and enjoyable volunteering experience. Volunteers attend support and supervision sessions and meet monthly to share best practice and support each other.

In October 2021 we were awarded the Level 3 Disability Confident Leader Award. This is the highest level of the award and shows our commitment to support other organisations to become disability confident as well as having embedded practices within our working environment to support staff and volunteers and have good and effective recruitment practice for people with disabilities.

Helping our community to better access services

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

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

Education and awareness

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. This followed the RCGP's decision that it no longer had the resources to do so itself. The toolkit will be relaunched next year following a review.

Planning is well underway for our May 2022 vascular EDS conference with charity Annabelle's Challenge and the National EDS Diagnostic service. This was postponed from 2020 due to the pandemic. We thank the National Lottery Awards for All programme England for their flexibility in funding the event.

In May 2021 EDS UK and the Hypermobility Syndromes Association (HMSA) launched an online toolkit for schools to support pupils with EDS and hypermobility-related disorders. The free resource aims to provide school staff with information about symptomatic hypermobility and the Ehlers-Danlos syndromes (EDS) 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 often, simple, low-cost adjustments can make a big difference. Over 16,000 unique visits have been made to the toolkit since its launch.

Research

During the period trustees committed to develop a research funding strategy and hope to finalise this during 2023. A key component of this strategy is likely to include fundraising to support research which contributes towards the development of clinical guidelines for the diagnosis and management of EDS 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/>

We decided in September 2020 to proceed with an application to undertake research into the effects of nutrition on EDS following an appeal for funds that had raised over £200,000. This triggered a complaint to the Fundraising Regulator alleging misuse of the funds. Further details may be found at <https://www.fundraisingregulator.org.uk/more-from-us/resources/ehlers-danlos-support-uk-march-2022>

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

We continued to fund two pioneering vascular EDS research projects at Northwick Park Hospital London and Sheffield Children's Hospital, both part of the National EDS Diagnostic Service. One (Northwick Park) was to seed fund research capacity and capability work and the other (Sheffield) was to assess the effectiveness of a vEDS treatment programme. Outputs from the research will be summarised on our website upon their completion

Fundraising and organisational health

Our income and expenditure position

We ended the year with income of £483,707 and operating costs of £496,377. 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:

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

Trusts and Foundations

CAF Patient Organisation Recovery Fund
Garfield Weston Foundation
Golden Bottle Trust
Grace Trust
James Tudor Foundation
Peter Harrison Foundation
The Childwick Trust
The D'Oyly Carte Charitable Trust
The Hospital Saturday Fund
The Julia and Hans Rausing Trust
The National Lottery Community Fund England
The National Lottery Community Fund Northern Ireland
The Sandhu Charitable Foundation
The Talent Fund

Corporate Partners

Green People
Strata Miniatures

How we fundraise

We are almost entirely reliant on donations to fund our work. Without the public's generosity, we would be unable to support people affected by EDS or work to reduce the time to diagnosis and improve care. We are registered with the Fundraising Regulator and are open about how we raise our funds. We continually strive to 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 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 participant agreements. 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 are supported by a number of charitable Trusts and Foundations, as well as philanthropic gifts from donors. We also ask people to give to us through our regular appeals or by leaving a gift in their Will.

Our website outlines our complaints process clearly. In this reporting period we received two complaints about our fundraising. All 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 Safeguarding Policy and our Fundraising Policy 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.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

Response to the pandemic

Last year we reported that we had enhanced the monitoring of our finances. Although we developed scenarios for different levels of income reduction and re-forecasted our budget and spending, in the event we did not need to take exceptional steps. The trustees decided to maintain this level of vigilance even as the pandemic eased.

Membership

There is no membership subscription for EDS UK. We had an average of around 12,000 members during the year. We engage with a community of almost 80,000 across our social media platforms.

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 500,000 during the year.

Financial review

The Statement of Financial Activities on page 9 shows net movements in funds for the year of £12,670 (2021: £1,389) which results in an increase in total funds at the balance sheet date to £395,226 (2021: £407,896).

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 2022

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, Deputy Chairs and Treasurer. 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	2020 / 2023
Ellie Cannell	19 February 2022	2022/2025
Frances Gawthrop	1 June 2014	2018 / 2022
Angela Hunter	1 June 2014	2018 / 2021
Anne Lavery	19 February 2022	2022/2025
Leah Mansfield	1 June 2014	2021 / 2024
Jason Pearce	28 April 2018	2020 / 2023
Clare Robinson	1 June 2014	2019 / 2022
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.

Two trustees retired from the board during the period: Angela Hunter and Clare Robinson. Angela Hunter was one of EDS UK's founding trustees. In February 2022 Clare Robinson accepted a role as Senior Research Adviser to the board's newly created research committee. At the request of the board Frances Gawthrop delayed her retirement until August 2022. Three new trustees joined the board in February 2022: Ellie Cannell, Anne Lavery, and Alison Roux.

The trustees have appointed a Managing Director, Kay Julier, who attends the board and leads the work of the staff 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 2022

Recruitment, induction, and training of trustees

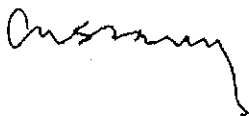
New trustees are recruited either by personal approach or recommendation by a current trustee. We also advertise and use recruitment companies specialising in the not-for-profit sector.

Candidate trustees are invited to attend one or more trustee meetings as active observers 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 Anoushé Husain as our Ambassador.

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



Stephen Stacey

Trustee

Dated: 20th December 2022

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:

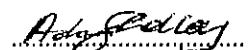
- 1 accounting records were not kept in respect of the as required by section 386 of the 2006 Act and Regulation 4 of the 2006 Accounts Regulations; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of Regulation 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: 20/12/2022

THE EHLERS-DANLOS SUPPORT UK

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 MARCH 2022

		Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £
	Notes						
Income from:							
Donations and legacies	2	193,563	169,106	362,669	204,662	131,515	336,177
Fundraising	3	94,738	-	94,738	49,633	-	49,633
Other trading activities		26,268	-	26,268	20,947	-	20,947
Investment income	4	32	-	32	130	-	130
Total income		314,601	169,106	483,707	275,372	131,515	406,887
Expenditure on:							
Charitable activities	5	320,420	175,957	496,377	273,117	132,381	405,498
Net (expenditure)/income for the year/							
Net movement in funds		(5,819)	(6,851)	(12,670)	2,255	(866)	1,389
Fund balances at 1 April 2021		218,503	189,393	407,896	216,248	190,259	406,507
Fund balances at 31 March 2022		212,684	182,542	395,226	218,503	189,393	407,896

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 2022

	Notes	2022 £	£	2021 £	£
Fixed assets					
Tangible assets	8		6,256		4,314
Current assets					
Debtors	9	528		171	
Cash at bank and In hand		416,025		415,756	
		416,553		415,927	
Creditors: amounts falling due within one year	10	(27,583)		(12,345)	
Net current assets			388,970		403,582
Total assets less current liabilities			395,226		407,896
Income funds					
Restricted funds	12		182,542		189,393
Unrestricted funds			212,684		218,503
			395,226		407,896

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 2022.

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 26th November 2022



Jason Pearce
Trustee

Company Registration No. 08924646

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2022

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 2022

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 2022

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 2022 £	Restricted funds 2022 £	Total 2022 £	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £
Donations	136,747	60,492	254,055	131,113	39,891	244,553
Grants	56,816	108,614	108,614	73,549	91,624	91,624
	<u>193,563</u>	<u>169,106</u>	<u>362,669</u>	<u>204,662</u>	<u>131,515</u>	<u>336,177</u>

3 Fundraising

	Fundraising Income 2022 £	Fundraising Income 2021 £
Charitable activities	<u>94,738</u>	<u>49,633</u>

4 Investment income

	Unrestricted funds 2022 £	Unrestricted funds 2021 £
Interest receivable	<u>32</u>	<u>130</u>

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

5 Charitable activities

	2022 £	2021 £
Restricted funds- charitable activities	175,955	132,381
Unrestricted funds- charitable activities	262,335	213,723
	<u>438,290</u>	<u>346,104</u>
Share of support costs (see note 6)	44,949	47,486
Share of governance costs (see note 6)	13,138	11,908
	<u>496,377</u>	<u>405,498</u>
Analysis by fund		
Unrestricted funds	320,420	273,117
Restricted funds	175,957	132,381
	<u>496,377</u>	<u>405,498</u>

6 Support costs

	Support costs £	Governance costs £	2022 Support costs £	Governance costs £	2021 £
Staff costs	7,325	-	7,325	7,680	5,969
Depreciation	3,000	-	3,000	2,279	1,034
Insurance	-	-	-	1,033	799
IT costs	8,344	-	8,344	9,508	4,137
Rent	20,054	-	20,054	20,728	22,995
Telephone	4,092	-	4,092	3,973	2,959
Subscriptions	2,132	-	2,132	2,285	2,307
Examiners fees	-	4,200	4,200	-	4,200
Bookkeeping	-	4,955	4,955	-	6,180
Legal and professional	-	3,983	3,983	-	772
	<u>44,947</u>	<u>13,138</u>	<u>58,087</u>	<u>47,486</u>	<u>59,394</u>

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2022

7 Trustees

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

8 Tangible fixed assets

	Plant and equipment £	Fixtures and fittings £	Computers £	Total £
Cost				
At 1 April 2021	3,624	1,988	10,349	15,961
Additions	-	-	4,942	4,942
At 31 March 2022	3,624	1,988	15,291	20,903
Depreciation and impairment				
At 1 April 2021	3,624	1,988	6,035	11,647
Depreciation charged in the year	-	-	3,000	3,000
At 31 March 2022	3,624	1,988	9,035	14,647
Carrying amount				
At 31 March 2022	-	-	6,256	6,256
At 31 March 2021	-	-	4,314	4,314

9 Debtors

	2022 £	2021 £
Amounts falling due within one year:		
Trade debtors	357	-
Other debtors	171	171
	528	171

10 Creditors: amounts falling due within one year

	Notes	2022 £	2021 £
Bank overdrafts		389	-
Deferred income	11	9,850	-
Trade creditors		16,429	11,429
Accruals and deferred income		915	916
		27,583	12,345

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

11 Deferred Income

	2022 £	2021 £
Other deferred income	9,850	-

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2022

12 Restricted funds

	Balance at 1 April 2020 £	Movement in funds		Balance at 1 April 2021 £	Movement in funds		Balance at 31 March 2022 £
		Incoming resources £	Resources expended £		Incoming resources £	Resources expended £	
The National Lottery Community Fund (Expanding Communities)	20,934	72,148	(70,420)	22,662	71,614	(65,104)	29,172
Other restricted	169,325	47,367	(56,261)	160,431	80,492	(105,153)	135,770
Peter Harrison Foundation	-	10,000	(3,700)	6,300	10,000	(3,700)	12,600
Hospital Saturday Fund	-	2,000	(2,000)	-	2,000	(2,000)	-
Disa's Fund, The Talent Fund	-	-	-	-	5,000	-	5,000
	190,259	131,515	(132,381)	189,393	169,106	(175,957)	182,542

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 2022

13 Unrestricted funds

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

	Balance at 1 April 2020 £	Movement In funds		Balance at 1 April 2021 £	Movement in funds		Balance at 31 March 2022 £
		Incoming resources £	Resources expended £		Incoming resources £	Resources expended £	
Unrestricted fund	216,248	275,372	(273,117)	218,503	314,601	(320,420)	212,684
	<u>216,248</u>	<u>275,372</u>	<u>(273,117)</u>	<u>218,503</u>	<u>314,601</u>	<u>(320,420)</u>	<u>212,684</u>

14 Related party transactions

There were no disclosable related party transactions during the year (2021 - none).

THE EHLERS-DANLOS SUPPORT UK

England & Wales - Charity number 1157027

Accounts

Charity Registration No. 1157027 (England and Wales)

Charity Registration No. SC046712 (Scotland)

Company Registration No. 08924646 (England and Wales)

THE EHLERS-DANLOS SUPPORT UK
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2021



Sobell Rhodes LLP
The Kinetic Centre
Theobald Street
Elstree
Borehamwood
Hertfordshire
WD6 4PJ

THE EHLERS-DANLOS SUPPORT UK

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Jason Pearce Frances Gawthrop Angela Hunter Leah Mansfield Clare Robinson Stephen Stacey Adrian Steel Charlotte Williams Sarita Aujla	(Appointed 13 June 2020)
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 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 2021

The trustees present their report and accounts for the period ended 31 March 2021.

Purpose

The charity's purpose as set out in our 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 and information sheets;
- d. Organising day and residential conferences;
- e. Producing a bi-annual magazine (Fragile Links) which is available on payment of a small subscription, online and in hard copy;
- f. Maintaining a website and social media presence to promote public awareness and provide 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 areas of strategic focus are:

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

A summary of our activities is provided under these headings.

Support

Our helpline

The telephone and email helpline are an important part of the charity's offer to beneficiaries. In 2020-21, we took 1,198 calls with an average call time of 20 minutes.

The pandemic highlighted the need for vital helpline support service. It also featured heavily in content of the calls we received. There was a greater need for emotional support and information on Covid. Many callers asked us for support as they struggled to access NHS services and benefits, and experienced difficulties navigating the education system for children with disabilities.

In October 2020, we were able to achieve our ambition of more than doubling the number of hours the helpline is open to now provide support five days per week. We remain open to developing online support in addition.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

Building community

At the close of the year we had 63 volunteer Area Co-ordinator volunteers and almost 5,500 members in our closed Facebook support groups.

All our support services continued during the Covid pandemic. Although our volunteers stopped face-to-face support group meetings in March 2020, many switched to online meetings. We introduced a weekly technical support session to help people new to online interaction. New virtual clubs and classes ran during the year. To counter the effects of our beneficiaries being unable to access routine medical and therapeutic appointments, we engaged a range of healthcare professionals and therapists to give webinars for our members. Topics covered included pain management, physiotherapy, pilates, and mindfulness for chronic conditions.

We are pleased to share that many of our members fed back positively about our transition from face-to-face to online interaction. Indeed we think that for the future having hybrid meetings – some face-to-face and some online – may provide a more accessible service for most.

Some volunteers found their roles and responsibilities more challenging during the pandemic. To best support them during this difficult time, we ran weekly sessions to help our volunteers led by our Senior Communities Manager. We also provided group counselling, delivered by MIND, for our volunteers with thanks to funding from the National Lottery Community Fund. We are grateful to our volunteers for their flexibility during the pandemic.

Helping our community to better access services

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

One exciting new area of work we began in 2020 was our health needs assessment. We worked with Public Health England to conduct an assessment of the health needs of people with the most common type of EDS who are currently poorly served by NHS services. We plan to expand the work to Scotland, Wales and Northern Ireland and are actively seeking research partners to do this.

In one important area we were not able to make the progress we had anticipated pre-pandemic. We were disappointed that a specialist nurse position, for which we had gathered significant funds, has still not been filled by University College London Hospital. We may need to reallocate the funds so that we achieve a comparable outcome.

We funded an independent researcher to carry out a study consulting young people in Scotland with EDS on their perceived needs. The report, published in December 2020, suggested that understanding of the impact of EDS on this age group ought to be enhanced and greater effort made to improve service provision. We shared the report with Members of the Scottish Parliament, NHS Scotland, and other decision-makers in order to improve their understanding and awareness of EDS. The report is available at <https://www.ehlers-danlos.org/news/summary-of-scottish-youth-consultation/>. We are now reflecting on the report recommendations to consider how we can best support our community in Scotland going forwards.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

Education and awareness

GP toolkit

We continued to deliver our online EDS GP toolkit, developed in partnership with The Royal College of General Practitioners (RCGP) and hosted on the college's website. This provided information about EDS symptoms and symptom management to 2-3,000 unique visitors each month.

Early in the year the RCGP told us that, with effect from 30 July 2021, it would no longer be able to resource the hosting of the GP toolkit. An extension has been negotiated to help us find another host and we hope to ensure a seamless transition.

We were disappointed to have to cancel our vascular EDS conference due to the pandemic. This was planned in collaboration with the National EDS Diagnostic Service and Annabelle's Challenge and due to be delivered in May 2020. On the advice of members of our medical panel, this has been postponed until May 2022.

We were delighted that Emily Joshua has written a new children's picture book called Big Dog, Little Dog or Someone In-between. The book, featuring a character with hEDS, is also raising funds for The Ehlers-Danlos Support UK, was published in April 2020.

We progressed work on a new online toolkit for school staff, in collaboration with one of our volunteers, who is an educationalist, and the Hypermobility Syndromes Association.

Research

We continued to build research funds to support our priority research areas of pain management, EDS and the gut, autonomic dysfunction, and measuring outcomes and healthcare utilisation.

Following positive peer review, we decided in September 2020 to proceed with an application to undertake research into the effects of nutrition on EDS, for which we had raised over £200,000. The project ('Comprehensive Assessment of Nutrition and Dietary Intervention in Hypermobile Ehlers-Danlos Syndrome – the CANDI-hEDS study') will be undertaken by a team led by Professor Qasim Aziz of the Wingate Institute of Gastroenterology at Queen Mary University, London. Professor Aziz's work has been strongly supported by our members, many of whom have registered to participate in the research. We expect the project to complete in 2023.

We continued to fund two pioneering vascular EDS research projects at Northwick Park Hospital London and Sheffield Children's Hospital, both part of the National EDS Diagnostic Service. One (Northwick Park) was to seed fund research capacity and capability work and the other (Sheffield) was to assess the effectiveness of a vEDS treatment programme. Outputs from the research will be summarised on our website upon their completion.

Fundraising and organisational health

Our income and expenditure position

We ended the year with income of £406,887 and operating costs of £405,498. 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:

THE EHLERS-DANLOS SUPPORT UK

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

FOR THE YEAR ENDED 31 MARCH 2021

Trusts and Foundations

Coronavirus Community Support Fund, distributed by The National Lottery Community Fund
Edith Murphy Foundation
Golden Bottle Trust
Hospital Saturday Fund
Million Dollar Round Table Foundation
Peter Harrison Foundation
The D'Oyly Carte Charitable Trust
The Julia and Hans Rausing Trust
The National Lottery Community Fund England
The Sandhu Charitable Foundation
The Sir Jules Thorn Charitable Trust
The Wo Street Charitable Foundation

Corporate Partners

Green People
Just About Group
Strata Miniatures

Individuals

The friends and family of Raphael Michilis Marques da Fonseca

Others

Hertsmere Borough Council 'COVID-19 Business Grant'
NHS Herts Valley Clinical Commissioning Group

How we fundraise

We are almost entirely reliant on donations to fund our work. Without the public's generosity, we would be unable to support people affected by EDS or work to reduce the time to diagnosis and improve care. We are registered with the Fundraising Regulator and are open about how we raise our funds. We continually strive to 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 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. 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 are supported by a number of charitable Trusts and Foundations, as well as philanthropic gifts from donors. We also ask people to give to us through our regular appeals or by leaving a gift in their Will.

Our website outlines our complaints process clearly. In this reporting period we received two complaints about our fundraising. All 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 Safeguarding Policy and our Fundraising Policy 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.

THE EHLERS-DANLOS SUPPORT UK

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

Response to the pandemic

Our office closed on 20 March 2020 and remained so throughout the year with home-working arrangements being introduced and maintained throughout the year under review. We decided not to take advantage of the government's furlough scheme as we did not want to reduce the support we provide for our members.

We enhanced the monitoring of our finances. We developed scenarios for different levels of income reduction and re-forecasted our budget and spending. In the event we did not need to take exceptional steps.

Membership

There is no membership subscription for EDS UK. We had an average of around 12,000 members during the year. We engage with a community of almost 80,000 across our social media platforms.

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 500,000 during the year.

Expanded fundraising capability

Our new Senior Fundraising Manager has improved our capability very significantly. We have also invested in a customer relationship management system to help us to understand our supporters better and to engage with them in line with their interests.

Financial review

The Statement of Financial Activities on page 9 shows net movements in funds for the year of £1,389 (2020: £112,501) which results in an increase in total funds at the balance sheet date to £407,896 (2020: £406,507).

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

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

FOR THE YEAR ENDED 31 MARCH 2021

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.

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, Deputy Chairs and Treasurer. 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	2020 / 2023
Frances Gawthrop	1 June 2014	2018 / 2021
Angela Hunter	1 June 2014	2018 / 2021
Leah Mansfield	1 June 2014	2018 / 2021
Jason Pearce	28 April 2018	2020 / 2023
Mark Redhead	22 November 2014	2019 / 20 March 2021
Clare Robinson	1 June 2014	2019 / 2022
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.

The trustees have appointed a Managing Director, Kay Julier, who attends the board and leads the work of the staff team.

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 2021

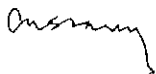
Recruitment, Induction, and training of trustees

New trustees are recruited either by personal approach or recommendation by a current trustee. We also advertise and use recruitment companies specialising in the not-for-profit sector.

Candidate trustees are invited to attend one or more trustee meetings as active observers 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.

During the year we decided to ask a third party to review our governance. Conducted by specialist consultancy Digi-Board following competitive tender, we learned that overall our performance compared favourably with a sector-specific benchmark. The consultancy's report has helped us to understand the ways in which we may decide to develop our governance model in the months and years to come.

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



.....
Stephen Stacey

Trustee

Dated: 01/12/2021.....

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.

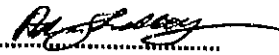
I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 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: 8/12/2021

THE EHLERS-DANLOS SUPPORT UK

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 MARCH 2021

	Notes	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £	Unrestricted funds 2020 £	Restricted funds 2020 £	Total 2020 £
Income from:							
Donations and legacies	2	204,662	131,515	336,177	221,137	102,737	323,874
Fundraising	3	49,633	-	49,633	97,146	1,978	99,124
Other trading activities		20,947	-	20,947	23,382	-	23,382
Investment income	4	130	-	130	463	-	463
Total Income		275,372	131,515	406,887	342,128	104,715	446,843
Expenditure on:							
Charitable activities	5	273,117	132,381	405,498	275,529	58,813	334,342
Net Income/(expenditure) for the year/ Net movement in funds		2,255	(866)	1,389	66,599	45,902	112,501
Fund balances at 1 April 2020		216,248	190,259	406,507	149,649	144,357	294,006
Fund balances at 31 March 2021		218,503	189,393	407,896	216,248	190,259	406,507

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 2021

	Notes	2021 £	£	2020 £	£
Fixed assets					
Tangible assets	8		4,314		4,478
Current assets					
Debtors	9	171		773	
Cash at bank and in hand		415,756		411,713	
		<u>415,927</u>		<u>412,486</u>	
Creditors: amounts falling due within one year	10	<u>(12,345)</u>		<u>(10,457)</u>	
Net current assets			403,582		402,029
Total assets less current liabilities			<u>407,896</u>		<u>406,507</u>
Income funds					
Restricted funds	11	189,393		190,259	
Unrestricted funds		218,503		216,248	
		<u>407,896</u>		<u>406,507</u>	

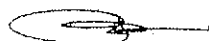
The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2021.

The directors acknowledge their responsibilities for ensuring that the charity keeps accounting records which comply with section 386 of the Act and for preparing financial statements which give a true and fair view of the state of affairs of the company as at the end of the financial year and of its incoming resources and application of resources, including its income and expenditure, for the financial year in accordance with the requirements of sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the company.

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 01/12/2021.....



.....
Jason Pearce
Trustee

Company Registration No. 08924646

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2021

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 2021

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.

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

1 Accounting policies

(Continued)

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.

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 2021 £	Restricted funds 2021 £	Total 2021 £	Unrestricted funds 2020 £	Restricted funds 2020 £	Total 2020 £
Donations	131,113	39,891	244,553	221,137	6,921	228,058
Grants	73,549	91,624	91,624	-	95,816	95,816
	<u>204,662</u>	<u>131,515</u>	<u>336,177</u>	<u>221,137</u>	<u>102,737</u>	<u>323,874</u>

3 Fundraising

	Fundraising Income 2021 £	Fundraising Income 2020 £
Charitable activities	<u>49,633</u>	<u>99,124</u>

4 Investment income

	Unrestricted funds 2021 £	Unrestricted funds 2020 £
Interest receivable	<u>130</u>	<u>463</u>

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

5 Charitable activities

	2021 £	2020 £
Restricted funds- charitable activities	132,381	58,813
Unrestricted funds- charitable activities	213,723	224,177
	<u>346,104</u>	<u>282,990</u>
Share of support costs (see note 6)	47,486	40,200
Share of governance costs (see note 6)	11,908	11,152
	<u>405,498</u>	<u>334,342</u>
Analysis by fund		
Unrestricted funds	273,117	275,529
Restricted funds	132,381	58,813
	<u>405,498</u>	<u>334,342</u>

6 Support costs

	Support costs £	Governance costs £	2021 £	Support costs £	Governance costs £	2020 £
Staff costs	7,680	-	7,680	5,969	-	5,969
Depreciation	2,279	-	2,279	1,034	-	1,034
Insurance	1,033	-	1,033	799	-	799
IT costs	9,508	-	9,508	4,137	-	4,137
Rent	20,728	-	20,728	22,995	-	22,995
Telephone	3,973	-	3,973	2,959	-	2,959
Subscriptions	2,285	-	2,285	2,307	-	2,307
Examiners fees	-	4,200	4,200	-	4,200	4,200
Bookkeeping	-	6,770	6,770	-	6,180	6,180
Legal and professional	-	938	938	-	772	772
	<u>47,486</u>	<u>11,908</u>	<u>59,394</u>	<u>40,200</u>	<u>11,152</u>	<u>51,352</u>

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2021

7 Trustees

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

8 Tangible fixed assets

	Plant and equipment £	Fixtures and fittings £	Computers £	Total £
Cost				
At 1 April 2020	3,624	1,988	8,236	13,848
Additions	-	-	2,113	2,113
At 31 March 2021	3,624	1,988	10,349	15,961
Depreciation and impairment				
At 1 April 2020	3,624	1,388	4,357	9,369
Depreciation charged in the year	-	600	1,678	2,278
At 31 March 2021	3,624	1,988	6,035	11,647
Carrying amount				
At 31 March 2021	-	-	4,314	4,314
At 31 March 2020	-	599	3,879	4,478

9 Debtors

	2021 £	2020 £
Amounts falling due within one year:		
Trade debtors	-	602
Other debtors	171	171
	171	773

10 Creditors: amounts falling due within one year

	2021 £	2020 £
Trade creditors	11,429	9,542
Accruals and deferred income	916	915
	12,345	10,457

THE EHLERS-DANLOS SUPPORT UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2021

11 Restricted funds

	Balance at 1 April 2019 £	Movement in funds		Balance at 1 April 2020 £	Movement in funds		Balance at 31 March 2021 £
		Incoming resources £	Resources expended £		Incoming resources £	Resources expended £	
Big Lottery Grant (Communities Project)	2,296	-	(2,296)	-	-	-	-
The National Lottery Community Fund (Expanding Communities)	-	70,850	(49,916)	20,934	72,148	(70,420)	22,662
Other restricted	142,061	33,865	(6,601)	169,325	47,367	(56,261)	160,431
Peter Harrison Foundation	-	-	-	-	10,000	(3,700)	6,300
Hospital Saturday Fund	-	-	-	-	2,000	(2,000)	-
	144,357	104,715	(58,813)	190,259	131,515	(132,381)	189,393

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 2021

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 2019	Incoming resources	Resources expended	Balance at 1 April 2020	Incoming resources	Resources expended	Balance at 31 March 2021
	£	£	£	£	£	£	£
Unrestricted fund	149,649	342,128	(275,529)	216,248	275,372	(278,308)	213,312
	<u>149,649</u>	<u>342,128</u>	<u>(275,529)</u>	<u>216,248</u>	<u>275,372</u>	<u>(278,308)</u>	<u>213,312</u>
	<u>149,649</u>	<u>342,128</u>	<u>(275,529)</u>	<u>216,248</u>	<u>275,372</u>	<u>(278,308)</u>	<u>213,312</u>

13 Related party transactions

There were no disclosable related party transactions during the year (2020 - none).