

The Sandhu Charitable Foundation Impact Report: 2022-23

The Ehlers-Danlos Support UK (EDS UK) is extremely grateful for the continued generous support of The Sandhu Charitable Foundation. Your unrestricted donation of £30,000 in 2022-23 has helped the charity to keep core services running, despite a drop in income. A new CEO has also been recruited and will work with Kay in June, before taking over on 1 July 2023.

Our financial position

During 2022/23 our income decreased by almost 15% compared to the previous year.

This was mainly due to a 70% reduction in income from trusts and foundations, even though many more applications were submitted compared to previous years. Fundraising by the EDS community held steady and donations (including corporate support) increased, along with sales of our own merchandise.

Generous donations of prizes enabled us to run our first raffle in December 2022/January 2023, raising a fantastic sum of over £8,000. We plan to hold a summer raffle during June and July 2023.

Our support and information services

During 2022-23 The Sandhu Charitable Foundation donations have helped us continue to provide volunteer-led support in England and Wales, keep our helpline open five days a week and provide up to date, essential information to people with EDS or HSD across the UK and beyond.

Support groups



North London Support Group, August 2022

Our community has really enjoyed getting back to in person support group meetings, although we still offer virtual meetings across the UK for those who find travel difficult. We've found that some groups work better online, for example our 18-25 group, which has gone from strength to strength and now has almost 250 members. The group is led by young volunteers Ellie, Jess and Victoria.

Responding to requests from our beneficiaries, in March, we introduced a new support group for people who are neurodiverse and have EDS or HSD.

During 2022-23, we had our highest number of volunteers in post (over 80), donating over 2,300 hours of their time. There were more than 2,500 attendances at over 370 support groups and almost 8,000 engaged with the closed Facebook groups associated with them – 3% more than the last two years.

We were pleased to receive a two-year grant from a funder in Scotland for support services there and we are delighted to have just been awarded a grant for support in Wales, from the National Lottery Awards for All programme.

Helpline

Our helpline continues to be well-used, five days a week. The service directly helped 4,000 people during 2022-23, despite a period of reduced hours due to staff sickness. Sarah, our helpline manager, does a live session on Facebook each month, regularly reaching over 2,000 people. These sessions are often themed and enable people to comment and ask questions in real time. They can be a lifeline to those who find it difficult to get out and we regularly have people joining from hospital. In March 2023, Sarah talked about the bowel problems often associated with EDS and HSD and reached over 6,000 people.

We were very proud when Sarah was named Runner Up in the Helpline Employee of the Year category in the Helplines Partnership Awards 2022. She was nominated for the unwavering commitment and passion she demonstrates towards her job and her efforts to keep improving and adapting the service the helpline offers to its users.

Webinars

We hosted regular webinars by healthcare and exercise professionals and researchers during the year, covering topics such as posture and pain, hypermobility and neurodiversity, postural tachycardia syndrome and hypermobile feet and shoulders. The webinars are free to attend and open to anyone. Over 400 people have joined some of them live and they are all available to watch on our website. We recently built a new webinar viewer to make finding and watching them easier.



Young change makers



We know from speaking to parents and younger people with EDS and HSD that there is a desperate need for targeted information and support for teenagers and young adults.

Thanks to funding from The Sandhu Charitable Foundation, we have been able to direct more staff time to applying for grants and were delighted to be awarded a two-year grant by the Pears Foundation, through disabled children's charity Contact. This is being used to start a programme of co-creation with young people with EDS or HSD.

Last month, we brought together almost thirty 14–21-year-olds for a weekend event in Solihull where they told us what they wanted in terms of information and support and how they'd like it to be delivered. It was great to get clear, detailed recommendations and to see lots of enthusiasm for getting involved in creating what is needed. We certainly saw some future volunteers and staff members in our opinion!

Accompanying parents talked together across the two days and said how much the event helped them. Many hadn't previously met another parent of a child with EDS. We're in the process of putting together some new funding bids, based on the outputs from the event, to take the ideas forward.



Improving NHS services

We continue to work with supportive colleagues in the NHS to develop an accurate picture of the gaps in services for adults with hEDS and hypermobility spectrum disorders (HSD). This important evidence will support our new campaigning work. This project has thrown up many challenges, mainly related to analysing NHS data, but has also helped to identify some new allies who are keen to help.

Through a small team at the University of Edinburgh, we have identified some interesting data from NHS Scotland. We also hope to partner with a GP-led team in Northumberland to expand a pilot study there, looking at how people with EDS and HSD use local health services.

New CEO



As you are aware, Kay has decided to leave at the end of June. The trustees ran a recruitment process during the autumn and are delighted to have appointed Susan Booth, recently Executive Director, Development at Target Ovarian Cancer, to succeed Kay. Susan will take up the position from 1 July and work alongside Kay from mid-June.

Challenges

Essential cost reducing measures have impacted our capacity over the past four months. We have prioritised the delivery of core services and income generating work but plans to revamp the EDS information on our website, relaunch the GP toolkit, publish a new research funding strategy and integrate more of our systems have been delayed.

Plans for 2023-24

During 2022-23 we will strive to keep our support services running and make them accessible to as many people as we can.

The availability of appropriate NHS services for those with hypermobile EDS or hypermobility spectrum disorders has been severely hampered by the pandemic. The situation is worse than ever, and change is urgently needed. For that reason, in May, we will be launching our #EnoughisEnough campaign, petitioning each government in the UK to commission appropriate NHS services for people with EDS and HSD. Taking forward opportunities to meet with parliamentarians and commissioners as a result of the campaign will be a priority for the rest of the year and beyond.

The trustees and staff team look forward to welcoming new CEO Susan Booth and working with her to transition EDS UK to its next phase.

A huge thank-you to The Sandhu Charitable Foundation from everyone at The Ehlers-Danlos Support UK for enabling the work we do. Very best wishes from Kay, Guy, Nikki, Laura, Sarah, Sabine and Catherine.