

The Sandhu Charitable Foundation Impact Report 2021-22

The Ehlers-Danlos Support UK (EDS UK) is extremely grateful for the generous support of The Sandhu Charitable Foundation over the last year. Your unrestricted donation of £30,000 has enabled the charity to continue its post-pandemic recovery and benefit more people. We have attracted repeat funding from trusts and foundations and strengthened relationships with our corporate partners. The £45,000 donation made in February 2022 to support the CANDI-hEDS research study enabled us to commit to the continued funding of this important research, whilst working through the Charity Commission's failed appeals process.

Growth and our financial position

Income has increased by 18% since 2020-21.

We have seen growth across all of our main income streams. Thanks to support from The Sandhu Charitable Foundation, we have been able to attract an additional £85,870 from trusts and foundations during 2021-22.

The National Lottery funding, which has underpinned our support group work in England for almost seven years will end in August 2022. We have secured £9,850 from the National Lottery Awards for All programme in Northern Ireland to expand our support services there and we continue to seek additional funding to deliver this core service across the UK. We were disappointed to have applications to the National Lottery Community Fund in Scotland and Wales declined in March 2022 but we plan to reapply. The Sandhu Charitable Foundation donations

have helped us to deliver support in Scotland, Wales, Northern Ireland and Jersey during 2021-22.

Meeting demand for our support services

As the pandemic restrictions eased, our community asked that we restarted some in person support group meetings. After consultation with our volunteers, virtual meetings are continuing across the UK, with those who want to changing to or adding in face to face meetings. During 2021-22 over 2,000 people attended our support groups and almost 7,000 engaged with the closed Facebook groups associated with them. This is around 30% more than in the previous year.

Volunteers are at the heart of our work and we have more than ever (74). We couldn't do what we do without them, which is why we were very pleased to be awarded the Investing in Volunteers accreditation in August 2022. We continue to support a diverse range of volunteers – transgender, LGBTQ+, ethnically diverse, volunteers aged from 18-78 and those who are registered disabled. We ran a specific recruitment drive to attract more male volunteers and were delighted that this attracted five new recruits.



Our helpline continues to go from strength to strength, helping more people than ever. The service is open five days a week and directly helped over 4,000 people during 2021 (up almost 40% compared to 2020). The Childwick Trust, James Tudor Foundation, Golden Bottle Trust and CAF Patient Organisation Recovery Fund have supported the helpline during 2020-21.

Toolkit for schools



May 2021 saw the launch of our much-anticipated online toolkit for schools (theschooltoolkit.org). This was a collaboration with the Hypermobility Syndromes Association (HMSA), with content led by one of our volunteers who has a background in education. The toolkit, aimed at school staff, explains what hypermobility and EDS are, how they affect children and young people at school and the often simple adjustments which can make a big difference. The toolkit has had almost 17,000 unique visitors since its launch.

Member survey results

Over 1,600 people responded to our annual member survey in August 2021. Highlights included:

- 78% said that EDS UK had positively impacted on their feelings of isolation
- 84% said that EDS UK had helped them to increase their understanding of how to manage their health through gentle exercise and healthy eating
- Information on our website was again considered to be the most important of our services
- 92% of members told us that the GP toolkit was important to them
- 72% said the new school toolkit was useful and had helped or will help in the future
- 98% said working with the NHS to reduce the time to diagnosis and campaigning for better awareness and services was essential.

Influencing policy

During the past year we have increased our participation in consultations to influence health policy. We are giving input to the implementation of the UK's Rare Disease Framework via a series of workshops in England and Scotland. We are also involved in a campaign to raise awareness of the issues surrounding access to cannabis-based medicinal products (CBMP) via the NHS. We see opportunities for CBMPs to be good alternatives for the treatment of chronic pain and share the frustrations around barriers to access, despite the law allowing their prescription.

Health needs assessment for hEDS and HSD

We continue to work with colleagues in the NHS to develop an accurate picture of the gaps in services for adults with hEDS and hypermobility spectrum disorders (HSD). Since the publication in February 2021 of an NHS report recommending that those with hypermobility-related problems are treated outside of hospitals, we have seen a steady increase in the number of rheumatology referrals being rejected. Against a back-drop of very low awareness about EDS and HSD in primary care, this is leaving people in an increasingly desperate situation. Despite the merger of Public Health England with NHS England and the effects of the pandemic on their workload, we have retained the commitment of ex-Public Health England colleagues to this project. While there have been some delays and challenges, there has also been increased interest in the project from a number of NHS Trusts and a group of GPs in the North East. This will continue to be a key project during 2022-23.

Board development

Two of our longstanding trustees stood down in 2021 and we were fortunate to attract some excellent applicants during an open recruitment process. Three new trustees were appointed in February 2022, filling a skills gap in human resources management and providing continuity of safeguarding knowledge and experience. While not a requirement for the positions, we value the lived experience of EDS that all our new trustees bring to their role. Information about the new trustees is available on our website: <https://www.ehlers-danlos.org/about-us/contact-us/trustees/>.

Challenges

GP toolkit

The EDS GP toolkit is now hosted by EDS UK (gptoolkit.ehlers-danlos.org). Previous hosts, the Royal College of GPs, declined to set up diverts to the site after the end of January 2022. However there have been over 4,000 unique visits to the new site since 1 December without any promotion. This important and valued resource will be relaunched in 2022 following some updates to its content to reflect recent research.

EDS Specialist Nurse

We have taken the difficult decision to withdraw funding for a specialist nurse post from University College Hospital London. The hypermobility service where the post was due to be located, was closed to new referrals by the hospital's management shortly before the pandemic and recruitment was put on hold. Following continued uncertainty about the status of the service, our Board decided to reallocate the funds. We are considering using an open, competitive process to offer funding for a similar position to NHS services across the UK.



Raphael Michilis Marques da Fonseca, whose legacy donation, along with support from The Sandhu Charitable Foundation, enabled this key project.

Plans for 2022-23

During 2021-22 we will continue to deliver high quality support services and make them accessible to as many people as we can. We plan to overhaul the information about EDS and HSD on our website and fill the gaps our beneficiaries have identified.

We are looking forward to finally being able to hold our vascular EDS conference in May, with the charity Annabelle's Challenge. This was postponed from May 2020 due to the pandemic.

We plan to petition government to improve health services for people with EDS and HSD, backed by evidence from our ongoing health needs assessment.

Our five-year strategy and a new research strategy will also be published.

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, Katie, Catherine, Kane and Nick.