

The Sandhu Charitable Foundation Impact Report 2020-21

Ehlers-Danlos Support UK (EDS UK) is extremely grateful for the generous support of The Sandhu Charitable Foundation during the last year. Your donation of £30,000 over the year has helped the charity to keep all its staff and even slightly expand during the pandemic. We are proud to have increased our support services in response to the needs of our community during the pandemic. We have also been able to attract additional funding and move ahead with a major new project conducting a UK-wide health needs assessment for people with hypermobile EDS and hypermobility spectrum disorders.

Expansion of support services

Throughout 2020 our support groups and new clubs continued uninterrupted online via the Zoom platform. As more of our volunteers became comfortable with Zoom, the frequency of meetings and clubs increased due to the commitment of our volunteers and the level of support being requested by our members. Towards the end of 2020 we were pleased to partner with the vascular EDS (vEDS) charity Annabelle's Challenge to run dedicated virtual support groups for our members affected by vEDS. During 2020-21 our support groups and clubs benefited over 2,000 people and almost 5,000 people engaged with the closed Facebook groups associated with our support groups.

Towards the end of 2020, aware that sufferers have been unable to attend exercise classes, physiotherapy sessions, pain management programmes etc., because of the pandemic, we introduced a range of webinars run by health professionals and therapists. These have included Pilates, tapping and emotional freedom technique, mindfulness for chronic illness and pain management, muscle conditioning, and bladder problems in children with hypermobility. Over 400 people engaged with the webinars in real time.



A Northern Ireland Support Group Meeting

The National Lottery funds this work in England. The Sandhu Charitable Foundation donations help us to deliver the same support in Scotland, Wales, Northern Ireland and Jersey (new in 2020).

Thanks to the support of The Sandhu Charitable Foundation, we have been able to attract an additional £69,000 from trusts and foundations towards the helpline and other core costs during 2020-21. This meant we could finally achieve our ambition of doubling

our helpline capacity. In October 2020, our helpline increased from two to five days per week. We now have two helpline advisors; Asya who has run our helpline for over five years, has a background in genetics and is multilingual and able to offer help and support to people who speak Hindi, Urdu and Punjabi; Sarah, who has been providing support and information to our volunteers for five years moved to the helpline in October. At a time when many people with

EDS were extremely anxious about the impact of Covid-19 on their condition and continued healthcare, Sarah and Asya were able to provide reassurance, advice and up to date information.

“As community lockdowns have affected us in so many ways, physically, mentally and in terms of access to services, thank you for being a lifeline and leading a community of moral support and advice during times that have hit us personally so hard.”

Feedback from one of our beneficiaries during the Covid-19 pandemic

Health needs assessment for hEDS and HSD

As a result of The Sandhu Charitable Foundation’s support, in April 2020 we had started to plan a UK-wide audit of NHS services for people with hypermobile EDS or HSD and were looking for a research partner. We were very pleased to secure resource from Public Health England, shortly followed by a legacy donation of £20,000 towards the project. Work started in October 2020 with an initial focus on collecting information from the NHS in England. We expect the report about services in England to be completed in late summer 2021 and we are in discussions with potential research partners in Northern Ireland to repeat the work there. It will also be expanded to Scotland and Wales if suitable partners can be identified. This is the first study of its kind looking at hEDS and HSD and is expected to provide essential evidence of the gaps in health services for people living with these challenging conditions across the UK. We plan to use this work as a springboard for policy and public affairs work and to highlight the importance and potential impact of legacy donations.



Raphael Michilis Marques da Fonseca, whose legacy donation has enabled this key project.

Board development and governance review

Our Chair, Mark Redhead, stood down in November 2020 after six years in the post. He is ably succeeded by trustee Stephen Stacey, who has been in post since 2017. Stephen has a background in the motor industry with senior management, strong public affairs and research experience. We were also very pleased to attract two excellent new trustees during the year. More information is available on our website: <https://www.ehlers-danlos.org/about-us/contact-us/trustees/>.

We felt the timing was right to conduct our first formal governance review and we commissioned DigiBoard to help with this in October 2020. The review confirmed several strengths including decision-making, openness, accountability and safeguarding. Our Board has put together an action plan to further develop the skills of our trustees and to increase the diversity of our Board.

The support from The Sandhu Charitable Foundation enabled this important piece of work which directly impacts our sustainability.

Challenges

GP toolkit

In December 2020, we were surprised and disappointed to receive notification from the Royal College of GPs (RCGP) that they were planning to withdraw the EDS toolkit for GPs which we had developed together. Challenges from the Royal College of Paediatrics and Child Health about the evidence for the validity of the toolkit for children were cited as the reason for its withdrawal. After some discussion and a patient-led petition, a compromise was reached – to add a statement saying the toolkit was valid for over 16s only – and the RCGP agreed to host the toolkit until the end of July 2021. We are working with a small group of medical professionals to find a new host for the toolkit from then.

EDS Specialist Nurse

The new specialist nurse post we are due to co-fund with the University College London Hospital (UCLH) remains on hold. As expected, the pandemic has further delayed the re-opening of the hypermobility service where the post is due to be based. The clinical lead for the service remains optimistic about its reopening as a national service and the continued need for the specialist nurse post. We have learned that a new CEO will be appointed to the Trust shortly. We plan to pursue discussion about the funding once the appointment is made.

Plans for 2021-22

During 2021-22 we plan to continue to deliver high quality support and information services and make them accessible to as many people as we can. We have started to look at how we can improve the accessibility of our information and support for people with additional needs.

We have a small amount of funding to continue our Breaking Down Barriers project which aims to reach more people of South Asian and African ethnicity to raise awareness about the signs and symptoms of EDS and the support we offer. There is some evidence that people from some ethnic groups may be more susceptible to symptomatic hypermobility. The project will include producing high-quality images and videos of EDS UK members and volunteers with South Asian or African heritage and routinely using these across our communication channels, running two social media advertising campaigns and developing a new area of our website dedicated to discussing cultural challenges associated with living with chronic invisible conditions.

We continue to develop our support for children and young people with EDS or HSD. We will be launching a new website for school staff in May and we are looking for funding for a dedicated young people's support service. We have applied for funding for a pilot mentoring programme for young people with EDS in Scotland to start to implement some of the recommendations from our consultation with young people there in 2018-9.

We are also pleased to be working towards the nationally-recognised Investing in Volunteers accreditation and further developing the skills and capacity within the staff team to make sure we can continue to meet the needs of everyone affected by EDS or HSD in the UK.

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, Asya, Sarah, Kirsty, Katie, Catherine and Kane.