

## The Sandhu Charitable Foundation Impact Report 2019-20

Ehlers-Danlos Support UK (EDS UK) is extremely grateful for the generous support of The Sandhu Charitable Foundation during the last year. Your donations of £80,000 over the year have enabled the charity to continue to expand its support services, attract additional funding and plan for a major national audit of services for people with hypermobility-related problems.

### Continued National Lottery Funding for support programme

The Sandhu Charitable Foundation funded staff time during 2019 to apply to The National Lottery Community Fund to continue and expand our volunteer-led support programme for adults. Four years of funding came to an end in March 2019. Having demonstrated positive outcomes and exceeded the agreed targets for the programme, a further three years of funding (£214,612) was awarded to EDS UK in August 2019. The new project expands our support programme to include virtual support groups. These make peer-led support accessible to people with EDS who are unable to travel to physical support group meetings. We planned to reach 240 more people (590 in total) through this approach. Since the new project started in August 2019, over 500 people have attended either a virtual or physical support group meeting and around 8,000 (target 3,000) regularly access other forms of peer support online.

The National Lottery funds this work in England. The Sandhu Charitable Foundation donations enable us to deliver the same support in Scotland, Wales and Northern Ireland.



EDS sufferers holding up how many years it took to be diagnosed

The early success of the virtual support group approach has enabled us to quickly switch the majority of our support online, in light of the COVID-19 pandemic. We have also been able to further expand our services, reducing social isolation through virtual book, craft and puzzle clubs, starting in March 2020.

### Support programme for young people

Following the confidence-building workshops for teenagers which we ran during 2018 and 2019, we have now designed a dedicated programme of regular activities and support for young people aged 13 to 18. This will centre around visits to organisations helping young people with disabilities to gain skills, increase social interaction and develop career aspirations. Alongside this, we will provide a dedicated support system led by a youth-worker and access to a well-established online mental health platform for young people. During 2019-20, we commissioned a consultation with young people with hEDS and HSD in Scotland to find out about their support

needs. The report on this work is expected in April and will be used to further shape the support programme for young people. We have applied to four funders to support this work and are preparing more funding applications.

The Sandhu Charitable Foundation's donations funded the pilot teens' workshop in London, which helped to demonstrate the need for tailored support for young people. In addition, you have funded the staff time needed to design the programme and develop funding applications for it.

In March 2019, we were awarded a small grant to develop an online resource to help school staff support pupils with EDS. We decided to partner with The Hypermobility Syndromes Association (The HMSA) to combine our knowledge and existing information for schools. There has been a short delay to the project, but we expect to complete the new 'toolkit' before the summer. We plan to delay the launch until schools re-open for all pupils. The Sandhu Charitable Foundation's support helped us to gain the funding for this work.

### **Developing our fundraising skills and capacity**

We have continued to implement the recommendations from the independent review of our fundraising strategy, conducted in 2018 and enabled by The Sandhu Charitable Foundation's support. We recruited an experienced Senior Fundraising Manager in September 2019, working 15 hours per week, and we have had a new trusts and grants application programme running since October 2019. So far, this has brought in £20,000 which will be used to expand our helpline from two to five days per week during 2020.



*Asya Choudry, EDS UK Helpline Manager*

### **Increasing awareness**



In January 2020, Kay recorded a podcast about EDS UK's work for a series which has a large following from the international business community. This was part of our strategy to continue broadening our supporter base. The podcast can be accessed here:

<https://itunes.apple.com/gb/podcast/the-sandro-forte-podcast/id1437692205?mt=2>

We have also written a chapter for a new textbook on postural tachycardia syndrome (PoTS) and associated conditions, due to be published in 2020.

### **Challenges**

#### **Diet and EDS research**

During the past year we had hoped that the research into the effects of diet on EDS symptoms would have started. Unfortunately, there have been several setbacks and we are waiting for the

research team at Queen Mary University of London to design a new study. We are working to agree new timelines and remain committed to this research as it is a high priority for our beneficiaries.

### **EDS Specialist Nurse**

We awarded funding to University College London Hospital (UCLH) in April 2019 to jointly fund the world's first EDS nurse specialist with the NHS for two years. Before the position could be filled, the hospital's management decided to look at restructuring the hypermobility service and put recruitment on hold. The service has been closed to new referrals since July 2019 and the restructuring has not yet taken place. We expect the Covid-19 outbreak to delay progress further. Some of our new work, planned for 2020-2021, will help to identify other centres which may benefit from funding for a similar position.

### **Plans for 2020-21**

During 2020-21 we plan to continue to deliver high quality support and information services and make them accessible to as many people as we can. However, we accept that we may need to further adjust how we work and what we can deliver, as a result of the Covid-19 situation. We have started the year in a strong financial position, helped significantly by The Sandhu Charitable Foundation. Our trusts and grants application programme may fill some of the expected drop in income from community fundraising and we are planning some virtual fundraising activities.

We hope to move ahead with plans to increase our helpline hours from two to five days per week. This has been budgeted from April but we will need to delay recruitment slightly. We have had to postpone our vascular EDS conference, due to be held on 9<sup>th</sup>/10<sup>th</sup> May but we intend to reschedule this for the end of 2020.

After almost five years of working with volunteers, and as we increase the numbers further, we plan to gain accreditation through the NCVO's Investing in Volunteers programme. We could not do what we do without our volunteers and we are committed to keeping improving our volunteer management practices, making sure we provide excellent support and help our volunteers to develop, where that is what they want.

In order to provide evidence of the desperate shortage of NHS services for people with hypermobility-related problems, we plan to conduct a UK-wide audit of services, in collaboration with a research partner. The outcomes from this work will then be used to inform a new public affairs programme of work, focused on decreasing the time to diagnosis of EDS by increasing availability of hypermobility services.

***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, Natalie and Kane.***