



2020 IMPACT REPORT

Our Strength Begins With Hope.

JANUARY 1 - DECEMBER 31, 2020



LETTER FROM CHAIR OF THE BOARD OF DIRECTORS & PRESIDENT/CEO

In 2020, the COVID-19 global pandemic disrupted daily life as we all knew it, affecting the global population and impacting healthcare systems and services worldwide. The Ehlers-Danlos Society worked to ensure the community felt supported, had additional COVID-19 support and resources, and understood that we hadn't lost sight of our mission.

As our lives were all shifted drastically to a more virtual world, we utilized our online platforms to empower and connect the community around the world, and to reach more health professionals than ever before.

Virtual support groups were increased dramatically, for new time zones, and for different demographics of our community to support as many as possible. May Awareness for the very first time was fully virtual and our community, globally, came together in an astounding display of advocacy and awareness efforts. All of our in-person events became virtual and we saw record numbers of attendees from six continents around the world!

The virtual educational program, EDS ECHO, continued to grow, offering education and case management advice to clinicians all over the world. In 2020 we introduced new programs for Allied Health Professionals, Nursing, Pediatrics, and vascular Ehlers-Danlos syndrome (vEDS), to an already comprehensive portfolio. Our inaugural EDS ECHO Virtual Summit was our most attended health professional event to date.

Our community is resilient, strong, and passionate: people came together to play their part in creating bigger global change together, and we appreciate that from the bottom of our hearts.

At The Society we have always believed that when you see a problem, you need to already be working on the solution. Where there is challenge, there is opportunity to learn and grow. Where there is pain and loss, a reason to be reminded of all there is to be grateful for. We will continue to pursue our mission, all while making sure we help support our community as best we can through these hard times.

Our strength begins with hope.

Susan Hawkins and Lara Bloom
Chair, Board of Directors; President and CEO



SUSAN HAWKINS



LARA BLOOM

OUR MISSION

The Ehlers-Danlos Society is a global community of individuals, caregivers, healthcare professionals, and supporters, dedicated to saving and improving the lives of those affected by the Ehlers-Danlos syndromes (EDS), hypermobility spectrum disorders (HSD), and related conditions.

Many around the world face a diagnostic odyssey: years, sometimes lifetimes, fighting for recognition, diagnosis, and care. The Ehlers-Danlos Society is working towards a time when geography and wealth no longer determine your quality of life.

We are proudly working to provide global learning conferences, collaborative research and education initiatives, awareness campaigns, advocacy, community-building, and care for the EDS and HSD population: Giving HOPE to all those whose lives are affected by EDS and HSD.

WHAT WE DO

Our goals are world-wide awareness—and a better quality of life for all who suffer from these conditions. Research is at the center of what we do, so that one day we will have a cure.

We are committed to our global mission, supporting communities worldwide and educating health professionals to diagnose, care for, and treat them. Education is needed to advance early diagnosis and intervention—and post-diagnosis, patients urgently need support and guidance. We will work hard to support, inform, and guide those affected by and living with EDS and HSD with up-to-date, accessible information to improve their care and well-being.

By uniting support groups and charities from around the world, we aim to provide resources and information where they are needed. We work with our affiliates on local issues and projects that affect our communities around the globe. Our strength begins with hope.



BREAKING DOWN BARRIERS

In January 2020, the Breaking Down Barriers initiative was introduced to help inform and guide Society programming and advocacy efforts to better address inequalities and access to resources.

Many face barriers to diagnosis and care, which impacts quality of life. The Ehlers-Danlos Society is committed to dismantling inequality and inequity as we continue to strive in our mission to give hope to and improve the lives of people affected by EDS and HSD. We recognize our community's experiences of inequality and desire to use our platforms to highlight these historically underrepresented narratives.

Disparities in healthcare are very real. We do not accept inequality or inequity, and we recognize our community's experiences of inequality when it comes to race, gender, sexuality, age, body shape, mental health, disability, and economic situation.

Representation

The Society's goal is to amplify community voices. We are committed to have a global outreach, supporting members from all countries and cultures in an effort to better understand our international tribe. Our community is composed of individuals with different cultures, ethnicities, gender identities, disabilities, neurodiversity, religions, sizes, ages, and more. We strive to be able to accurately represent this diversity through our education, awareness campaigns, advocacy, community-building, and care initiatives.

In 2020 we introduced:

Community Voices

Amplifying voices of our community via podcasts, vlogs, blogs, and any other media.

Conversations With... Our Community

A global community webinar series featuring conversations with people living with all types of EDS, HSD, and related conditions, from discussions of racial and gender inequalities impacting care to positive and practical discussions of how care and correct management can improve quality of life.

Mental Health Resources

A global resource list including resources around Black, Indigenous, and people of color (BIPOC) and lesbian, gay, bisexual, and transgender (LGBTQ+) mental health, neurodiversity, eating disorders, substance-use, and age-specific resources.

Additional long-term projects under Breaking Down Barriers include:

- ▶ Translation in different languages
- ▶ Transcribing and captioning videos
- ▶ Providing alternative image text and visual image descriptions
- ▶ Scholarships and grant resources



BREAKING DOWN BARRIERS

Communication

The Society continues to strive to listen to the community to better understand needs, stigma, and barriers to care. We invited community feedback through surveys and polls, such as our Let's Chat Virtual Support Group Community Survey. We also sought community engagement through our Breaking Down Barriers Initiative, which allows individuals to share their personal experiences, needs, and feedback to the Society. We continue to include individual, caregiver, and provider perspectives whenever able, which is reflected within programs such as The International Consortium and Community Coalition.

Research

- Encouraging inclusion in the research we do, share, and fund is a long-term priority:
- Studies that are shared through The Society require researchers to discuss how they have addressed diversity considerations within their study design.
- Through Breaking Down Barriers we are building a community focus group to inform future research guidelines to ensure more inclusive and representative research.

Education

Promoting diversity and increasing accessibility in education.

Professionals:

- Within Project ECHO, we encourage presenters to consider patient diversity factors and how that may have impacted conceptualization/treatment.
- We expanded our scientific days to include poster presentations, allowing a larger pool of professionals to share their research with the community.

Community:

- Community members requested an increased focus on resources aimed towards quality of life, which has shaped our projects over 2020.
- To increase access, we offer a collection of translated materials, which includes conference videos and medical articles.
- When sharing content, we are committed to providing alternative text, transcripts, and/or closed captioning whenever possible.

Awareness

We are committed to continuing relationships with online communities, affiliates, support groups, and other charities, while also creating new relationships by joining the Rare Disease Diversity Coalition and sponsoring events such as The TRUE Project.

The TRUE Project conference was a three-day conference in June of 2020 featuring webinars, instructional videos, kid's corner, and more to commemorate the 30th anniversary of the Americans with Disabilities Act (ADA). The event highlighted disabled BIPOC voices and disabled LGBTQ+ voices.



ADVOCACY & SUPPORT



Supporting our community, around the world

Our support programs grew dramatically in 2020 as global need increased, and more members of our community turned to us for emotional support, advice on managing symptoms at home, and resources to help navigate a healthcare system under unprecedented pressures from COVID-19.

The Society's Inspire message board grew to over **90,000 members**, and the helpline team answered over **4,000 helpline emails (a nearly 50% increase from 2019)**. Over **600 calls** were received on our 28 toll-free international helpline numbers.

"I can't thank you enough for your comprehensive response. It was a riveting read and for the first time (I've seen so many consultants) there was information being given to me that was new and genuinely helpful. For example all the pain management strategies and the patchwork effect of doing lots of things at once! This has given me hope! I only ever tried one thing at a time."

We increased Let's Chat support group meetings tenfold to offer virtual group meetings suitable for all time zones and for the different challenges the community was facing: safe spaces to chat around new challenges due to COVID-19, mental health pressures such as isolation, and lack of treatment due to delayed or canceled medical appointments.

COVID-19 Resource Hub

The global pandemic greatly impacted those living with EDS and HSD in their access to care, treatments, and the therapies they depend on for quality of life. The community was naturally very concerned about how COVID-19 may affect them with underlying health conditions, and looked to The Society to provide the emerging information as the pandemic progressed.

We built a resource hub to provide up-to-date medical information on COVID-19, EDS, and HSD, including the latest research, comorbidity-specific information from affiliate organizations and healthcare bodies, and vaccines. In addition, we developed resources for people self-isolating or restricted by pandemic regulations put in place by their region or country.

Keeping Moving

We worked with Allied Health Professionals from around the world as part of our Movement Webinar Series, providing weekly webinars and video series to help our community keep moving safely at home during the global pandemic, from Yoga for Kids and Teens to webinars for managing EDS and HSD within a home living space.

"I joined movement therapists and Allied Health Professionals as part of The Ehlers-Danlos Society's Movement Series, providing video resources to help people continue to move safely at home, practice mindful breathing, and promote relaxation, whilst in isolation. Part of the Society's COVID-19 resource hub which has been viewed over 135,000 times, the movement series includes resources for you to adapt your activity program to your home environment and was been created with EDS, HSD, and hypermobility in mind."

Jeannie Di Bon, Movement Therapist

Global Experiences

Community Voices were introduced as part of the virtual events series, enabling community members living with different types of EDS and HSD from different parts of the world to share their experiences, management strategies, and healthcare encounters in their country on video.

COVID-19 Survey

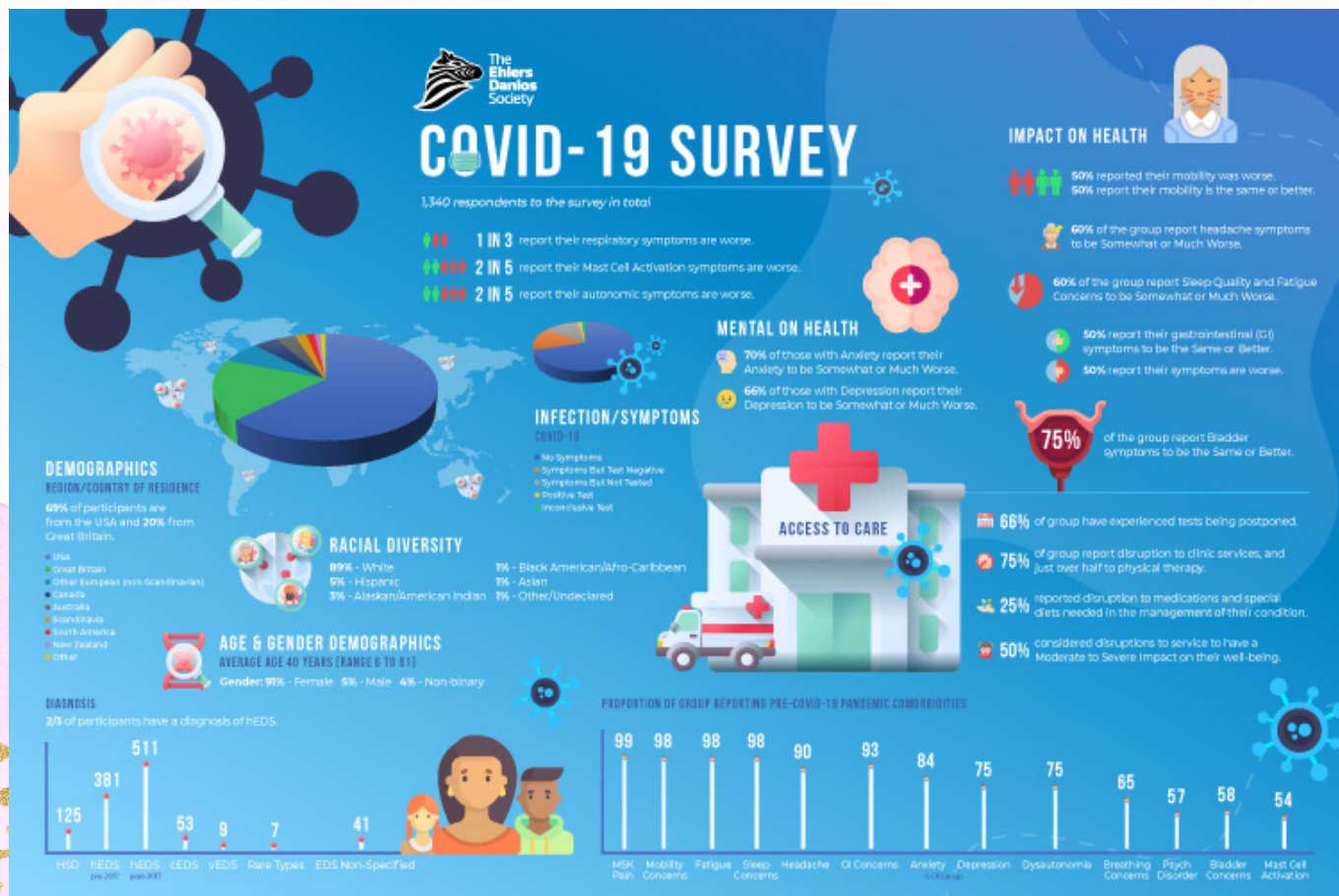
From the onset of the coronavirus (COVID-19) pandemic, The Ehlers-Danlos Society learned from our Helpline and Support Group program that members of the EDS and HSD community were experiencing a deterioration in well-being considered to be a consequence of disruption to normal levels of care and imposed social restrictions.

The Society invited our communities to take part in a formal survey, Self-Reported Changes in Health Status During the Coronavirus Pandemic: A Survey of Individuals With Ehlers-Danlos syndrome and hypermobility spectrum disorder, to assess the impact the COVID-19 pandemic has had on people with EDS and HSD. Whether or not they had COVID-19, or whether or not they felt their health and well-being had been affected by the pandemic, we wanted to hear from as many people with EDS or HSD as possible.

The abstract can be read [here](#), and the survey responses seen in the infographic below.

The second abstract is The Impact of the COVID Pandemic on Dietary Changes and Gastric Symptoms in People With Ehlers-Danlos syndromes. The patient advisory group discussed the impact of the COVID pandemic and the consequences of the pandemic on their community. The group was particularly interested in the disruption of the food supply chain and its ultimate impact on GI symptoms. Because many members have gastric issues that require specialized diets, they were able to identify challenges with accessing food. They were also interested in understanding whether others in their community had similar experiences. The purpose of this research was to measure the impact of the pandemic on food acquisition, dietary changes, and GI symptoms.

The abstract can be read [here](#).



REACHING THE GLOBAL COMMUNITY



FACEBOOK

97,000



TWITTER

17,000



INSTAGRAM

43,000



YOUTUBE

13,000



731,000
Video Views

Loose Connections e-Magazine

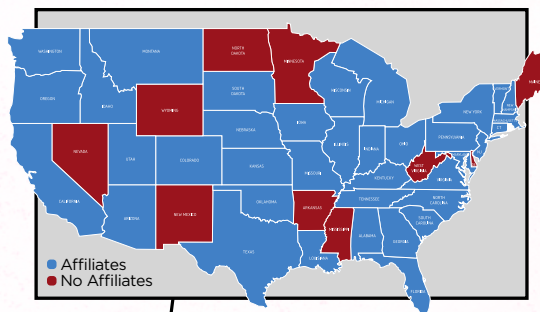
Loose Connections e-Magazine publishes original content about, or created by, those with Ehlers-Danlos syndromes and hypermobility spectrum disorders, including poetry, art, photography, and both non-fiction and creative writing. Started in 1986 under the Ehlers-Danlos National Foundation, Loose Connections was revived in 2020 by The Society with three issues focused on escape, inclusion, and comfort.



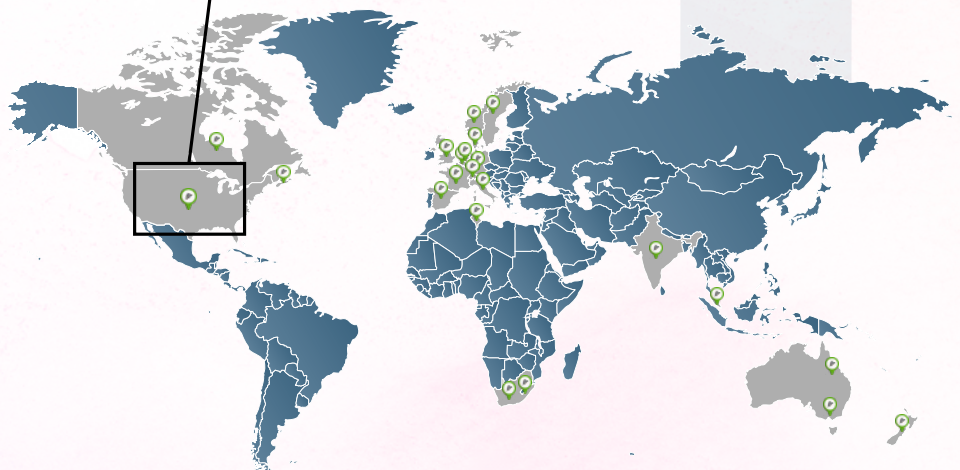
Global Affiliate Network

The Global Affiliate Network provides outreach and programming through collaboration with regional and local support groups, charities, and societies. The network grew to nearly seventy members across thirteen countries.

In 2020 The Ehlers-Danlos Society attended or presented virtually at over twenty-five medical and patient conferences, events, and government policy meetings across the globe to educate healthcare professionals, government representatives, and the general public about EDS and HSD, to advocate for those with these conditions, and to foster collaboration and promote networking for education and research initiatives.



Affiliate
THE EHLERS-DANLOS SOCIETY



GOING VIRTUAL: THE 2020 SUMMER CONFERENCE

The challenges of COVID-19 drove The Society's first Virtual Conference, which saw presentations from 40 health professionals delivered to over 1,600 community members/households in 41 countries, live translated into four languages over three days!

The first day of the event was dedicated to the rarer types of Ehlers-Danlos syndromes and featured a new Community Voices segment. Camille Schrier, Miss America 2020, joined for a special Q&A, and our community showcase went virtual with Zebras Got Talent. A dedicated event app, Whova, enabled attendees to follow the event, make connections with other attendees, and pose questions to speakers for the live Q&As.

Making conferences and resources more accessible worldwide is a long-term goal, and three of the 2021 events will be translated live into four additional languages, including French, German, Spanish, Italian, Portuguese, and Japanese.



1,300

Individuals from
the EDS and HSD
community



40

Health professionals
and leading experts



41

Countries that
were present



LIVE TRANSLATIONS

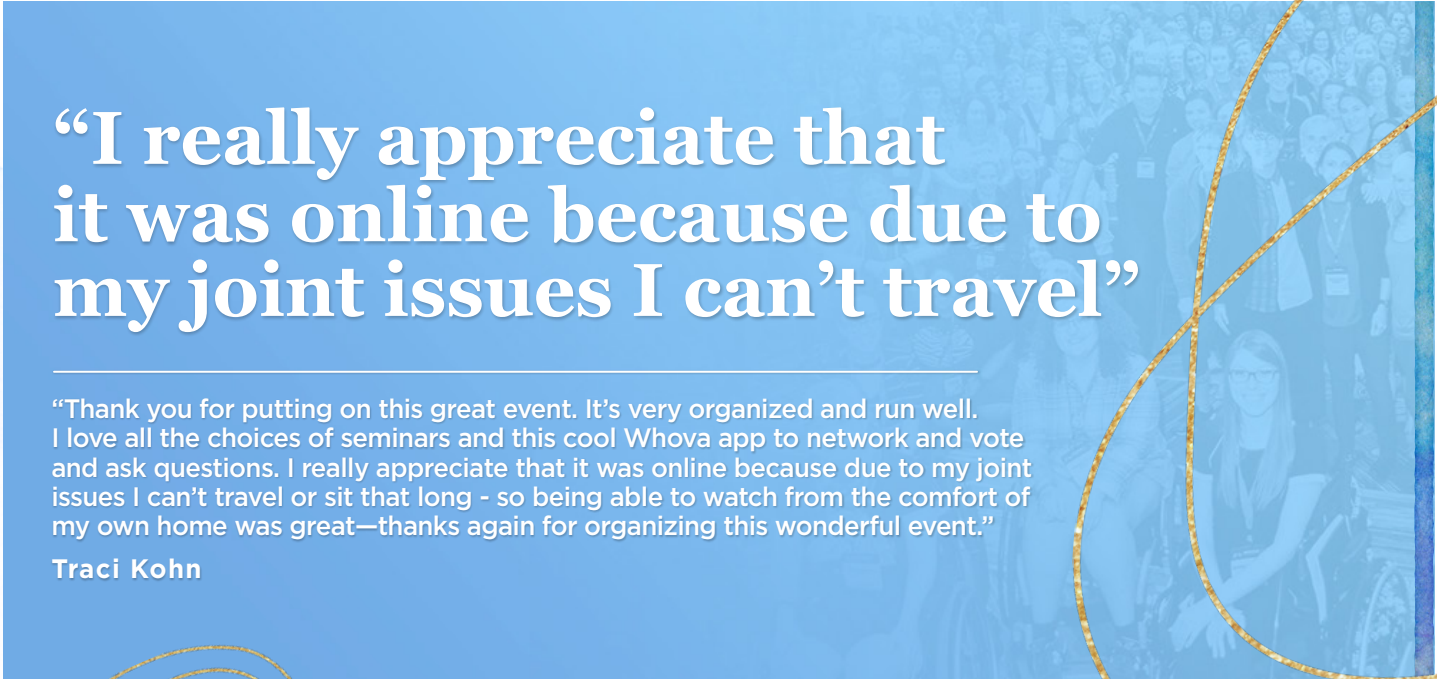
French, Spanish,
German and Arabic



1,490

Questions submitted
in the live Q&A





“I really appreciate that it was online because due to my joint issues I can’t travel”

“Thank you for putting on this great event. It’s very organized and run well. I love all the choices of seminars and this cool Whova app to network and vote and ask questions. I really appreciate that it was online because due to my joint issues I can’t travel or sit that long - so being able to watch from the comfort of my own home was great—thanks again for organizing this wonderful event.”

Traci Kohn



“A very informative conference”

“I would really like to thank the organizers and all the contributing specialists for making this a very informative conference. Currently stuck in a hospital room with my adult daughter (hEDS) who has been here for nine months.”

Erica Wareham



“For the first time in 45 years, I felt seen”

“Last summer, I was just a few months into my “new normal” - having recently been diagnosed with hypermobile Ehlers-Danlos syndrome (hEDS). Attending The Ehlers-Danlos Society global patient education conference last summer in Nashville allowed me to meet other patients (literally the first time in my entire life I’d met someone “like me”) and to learn from the best doctors and scientists in the world about what to expect, how to manage my symptoms and how to live my best life. For the first time in 45 years, I felt seen and I felt like I had a roadmap. Because of the pandemic, this summer’s EDS Society conference has been canceled, but I jumped for joy when I learned they were offering two days of sessions (this weekend) virtually. I made an extra donation to express my gratitude.”

Kate Colbert



The Ehlers-Danlos Society celebrated one year of the EDS ECHO program in 2020.

EDS ECHO supports clinicians by increasing their knowledge; helps clinicians network with each other to discuss care; improves access to care by increasing the number of experienced clinicians; and supports community advocates in raising awareness of EDS and HSD. This free, virtual program also enables participants to claim CME/CPD credits.

By the end of 2020 EDS ECHO had trained over 500 healthcare professionals and 200 community advocates from nearly 25 nations to date, and is on track to meet the goal of 1000 participants joining our programs and network by the end of 2021.

In 2020 EDS ECHO added a vEDS ECHO; an Allied Health Professionals ECHO from three hubs around the world; a Nurses ECHO; and a Pediatrics ECHO.

In 2021 The Society will introduce EDS ECHO Clinicians Drop-In Clinics once per month. This invitation will be extended to all clinicians who have participated in any EDS ECHO program. Each session will be co-facilitated by Dr. Alan Hakim and Dr. Clair Francomano. The aim of the sessions is to allow colleagues to bring current clinical concerns about their patients to the group for advice.

The EDS ECHO Summit

The Ehlers-Danlos Society in October hosted our first EDS ECHO Summit: A Virtual Scientific Meeting on EDS, HSD, and Comorbidities, sharing the latest research and knowledge with health professionals globally, through the traditional Project ECHO® all-teach, all-learn format.

This Summit was so successful that the American College of Medical Genetics approved a Special Issue Part C publication of the reviews and original research presented which will be published in December 2021.

The Summit explored the most up-to-date knowledge of, and research into, the association, causation, and management of comorbidities seen in EDS and HSD, and was The Society's most-attended event for health and social care practitioners. Project ECHO® enabled participating physicians to claim continuing education credits. EDS ECHO Summits will be held each year between the in-person International Symposiums.

316
MEDICAL PROFESSIONALS
FROM 23 COUNTRIES
(UP FROM 45 ATTENDING IN TOKYO 2019)



IU Health

A Center for Change

In October 2019, thanks to the generosity of our donors, The Ehlers-Danlos Society pledged \$500,000 over five years to support the opening of the Indiana University Health Center for Ehlers-Danlos syndromes: a clinic committed to advancing research, education, and patient care for those living with the Ehlers-Danlos syndromes (EDS), hypermobility spectrum disorders (HSD), and associated symptoms and conditions. IU Health Foundation committed to a partially-matched donation following the pledge.

We know that around the world what is desperately needed is early diagnosis, validation, and effective multidisciplinary care. We look forward to making this a reality at this center, researching effectively so that this can be rolled out around the world—so that no matter where you live, you have access to a multidisciplinary team approach.

“Helping people with all types of Ehlers-Danlos syndromes and hypermobility spectrum disorders to more effectively manage their disorders and live with less pain and greater functionality.”

The Center for Ehlers-Danlos syndromes, led by Dr. Clair Francomano, will provide comprehensive, multidisciplinary care to people with EDS, HSD, and related conditions, and work on three key areas: clinical care, research, and education.



Indiana University Health

2020 IU Health Updates:

Clinical Care

The center continued to be open for in-person appointments with Dr. Francomano, limited due to the COVID-19 pandemic or adapted to virtual appointments.

Dr. Francomano and the IU Health team continued to work towards establishing a multidisciplinary clinic, working with healthcare specialists in pain, dysautonomia, physical medicine, and rehabilitation, and working to establish partners in gastroenterology, urogynecology, neurology, and neurosurgery.

Research

The team worked on a retrospective study to examine patient-reported outcomes for craniocervical fusions among patients of the Metropolitan Neurosurgery Group. The objective is to examine patient-reported outcomes in patients with Ehlers-Danlos syndrome and hypermobility spectrum disorder with craniocervical instability.

A Neurosurgical Outcomes Team was developed, including Dr. Fraser Henderson, Dr. Malini Narayanon, and Dr. Peter Rowe, with Dr. Jane Schubart, a surgical outcomes researcher from Penn State University College of Medicine, joining the team. The Neurosurgical Outcomes Team began a collaboration with the Bobby Jones Chiari and Syringomyelia Foundation to initiate planning for a multi-center study on craniocervical and C1-2 fusions in persons with the Ehlers-Danlos syndromes.

Dr. Francomano is also collaborating with Dr. Rebecca Bascom and Dr. Jane Schubart from Penn State University College of Medicine. An ongoing study includes an in-depth analysis of clinical care utilization by persons with the Ehlers-Danlos syndromes from Market Scan, a large database of medical claims from private insurers around the United States. Their project on the use of drugs for gastrointestinal co-morbidities was presented at the EDS ECHO Summit by Dr. Radha Dhingra.



Education

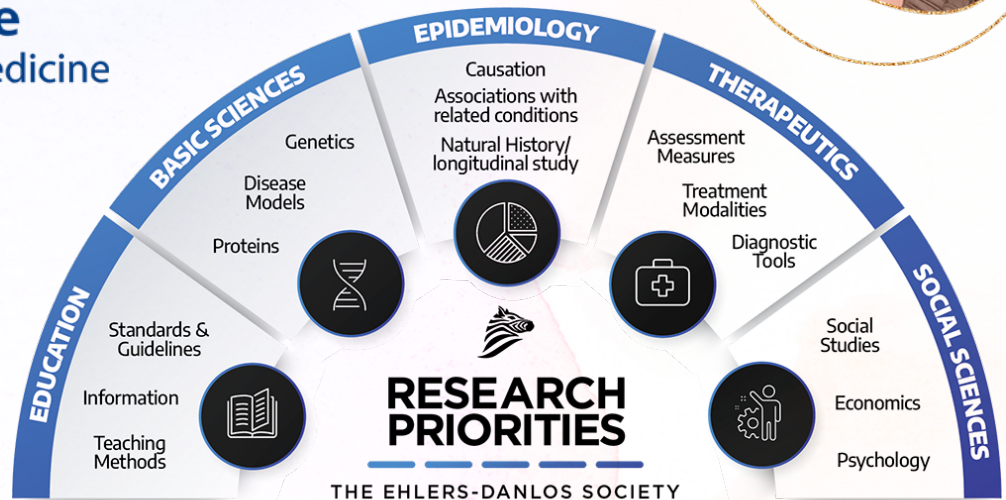
Dr. Francomano takes part twice a month in the Penn State STRETCH ECHO/COVID Enhancement: Clinical Discussions of the impact of the COVID-19 pandemic on persons with EDS and HSD.

We are delighted that a symposium proposal to the American College of Medical Genetics has been accepted for presentation in April 2021, The Ehlers-Danlos syndromes Circa 2021, to be presented by Dr. Clair Francomano, Dr. Ellen Elias, Dr. Joel Hirshhorn, and Dr. Alan Hakim.



PennState
College of Medicine

RESEARCH



Research Grant Program

Research is at the center of what we do so that one day we will have a cure. Our goal is to ensure consistent and groundbreaking research to help individuals worldwide who live with EDS and HSD.

The Ehlers-Danlos syndromes and hypermobility spectrum disorders are complex conditions. There remain many unanswered questions. These questions include our understanding of the basic sciences at a genetic and protein level and their interactions with the environment; the functional changes in disease (pathophysiology) that arise from related disorders and their true relationships with EDS and HSD; the best ways to measure and treat symptoms related to EDS and HSD; the social impact of ill-health; and the best ways to educate and share information.

The Ehlers-Danlos Society has established a [roadmap](#) to develop and convey its research priorities, in collaboration with The International Consortium on EDS and HSD. Our aim is to inform researchers and funders of areas of interest that they may wish to explore or support.

These priorities have been based initially on the 2019 opinion of the members of The Consortium and The Society also seeks opinions from other sources to ensure that the portfolio remains live, up to date and encourages views from our whole community.

Our portfolio recognizes that there are a variety of disciplines within research. In cataloging the priorities, we have considered these in the context of:

Basic Sciences (genetics, molecular protein studies, disease models, i.e., how the disease develops and testing potential treatment approaches);

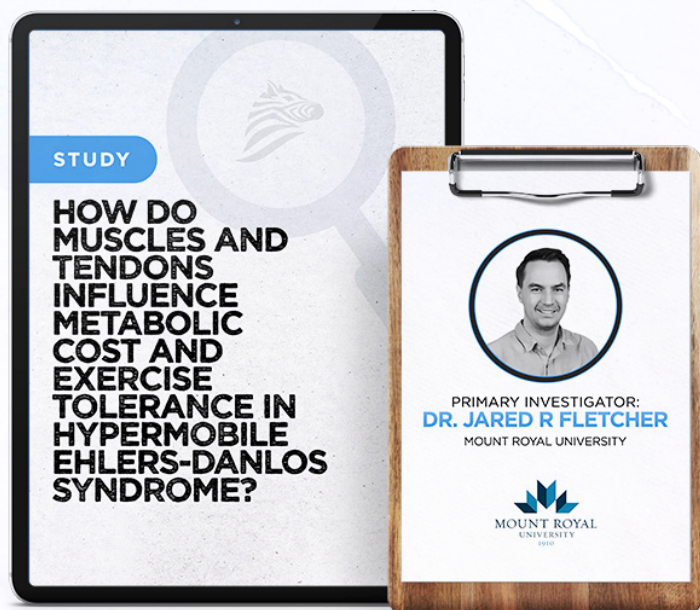
- ▶ Epidemiology (study of the incidence and prevalence of diseases, association between conditions, causes of illness, natural history of illness);
- ▶ Therapeutics (tools for diagnosis, tools for measuring the effects of treatment, treatments);
- ▶ Social Sciences (social studies, health economics, the psychology of illness); and
- ▶ Education (teaching methods, information, Standards and Guideline engagement).

We aspire to offer grants annually, with calls for clinical research proposals early in the year and for basic science later in the year. We also offer grants of varying value to reflect the different nature of researcher requirements. These include microgrants and support for two to three-year projects.

In 2020, The Ehlers-Danlos Society announced our largest Research Grant Program to date.

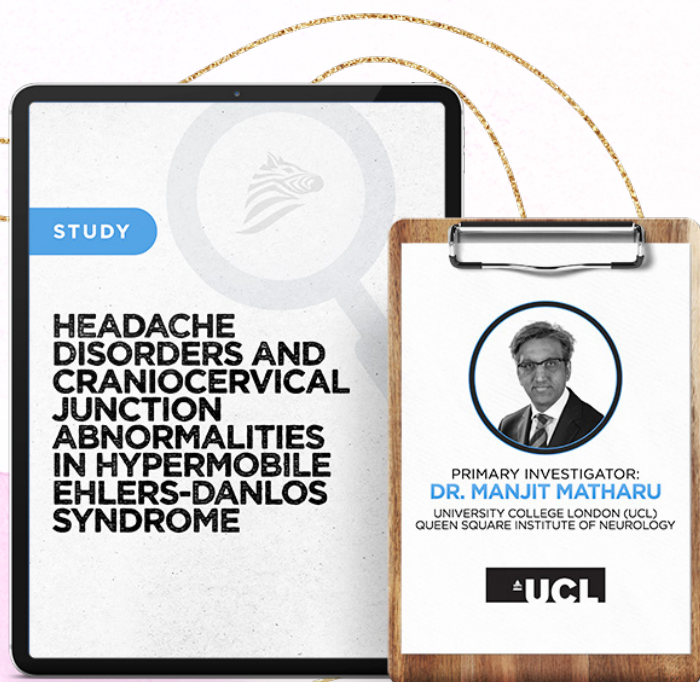
Funded research in 2020 includes:

Clinical Research Major Grants 2020



Research Grant Awarded: **\$148,348.10**

Chronic pain and fatigue/exercise intolerance is a major complaint in individuals living with hypermobile EDS (hEDS) and may have a severe impact on quality of life and activities of daily living. There is a need for better understanding the impact of hEDS on activities of daily living, including walking, an easy and accessible mode of exercise for individuals with hEDS. A clearer understanding of the mechanisms of subjective fatigue, exercise tolerance and energy expenditure is needed. This investigation proposes to compare muscle-tendon properties of hEDS and healthy-controls and evaluate the impact of these properties on energy expenditure, subjective pain, fatigue, and exercise (in)tolerance. We further propose to investigate the impact of exercise training on these properties. This information will help to inform treatment plans for individuals living with hEDS to reduce fatigue, safely engage in physical activity and improve their quality of life.



Research Grant Awarded: **\$149,698.13**

People with hypermobile Ehlers-Danlos syndrome (hEDS) frequently suffer from headaches, neck pain and other neurological symptoms. However, the cause of these symptoms is poorly understood. hypermobility of the craniocervical junction (joints between the skull and top of the spine) has been proposed as a major cause of these symptoms by causing pressure or stretch related injury to the brainstem, nerves and blood vessels in the neck. This has been termed the cervicomedullary syndrome (CMS).

We anticipate that describing the burden of headache disorders and neurological symptoms in hEDS will increase awareness of these symptoms to healthcare providers, and better inform appropriate investigation and management. The main hypothesis of this study is that craniocervical hypermobility in patients with hEDS would cause structural brainstem or spinal cord damage. If our results were in line with this hypothesis, then we would provide evidence supporting larger surgical trials that will help to deliver improved care to highly disabled patients. Alternatively, we would provide data against potentially unnecessary invasive and expensive neurosurgical treatment.

Health and Social Care Grants



Research Grant Awarded: **\$99,159**

Information is sparse with regard to the oral health of patients affected by Ehlers-Danlos syndromes (EDS). Systematic clinical oral investigations are missing for most of the 14 EDS types, and if available, study cohorts were small due to the rarity of the syndromes. The lack of evidence has led to various incorrect assumptions.

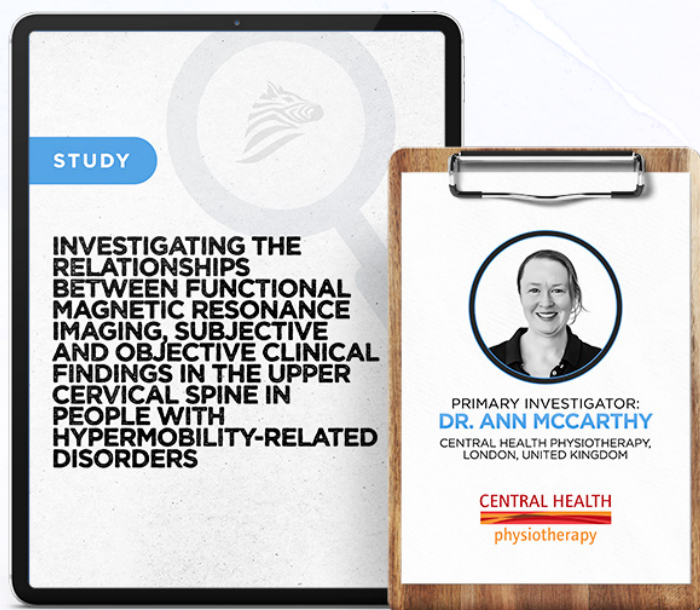
We aim to recruit at least 50 individuals per EDS type for clinical dental investigations in six European centers. This seems realistic for hypermobile EDS, classical EDS, vascular EDS, and periodontal EDS. Based on clinical studies we will assess oral health in people with different EDS types and develop and disseminate oral treatment strategies. Finally, patient leaflets and fact sheets for dental professionals will be designed, which will have an immediate impact on oral health-related quality of life of EDS patients.

Research Grant Awarded: **\$164,393.53**

Symptoms such as headache, neck pain, nerve pain in the arms and legs, and disturbances of heart rate and blood pressure, thought to be derived from the upper cervical spine (upper neck) and craniocervical junction (the junction of the neck with the base of the skull) can be frightening and debilitating. It is suggested that these symptoms can result from instability of these joints and subsequent pressure on the spinal cord and nerve roots as they pass from the cord out to the body. Clinically, both from physical examination and from radiological imaging, it is difficult to establish if this is truly the case.

Whilst upright dynamic magnetic resonance imaging (MRI) is used to investigate such symptoms, there is a lack of evidence as to which measurements on MRI, if any, are truly linked to the presenting symptoms. It is also not clear if any of these measurements are commonly found in hypermobile people without symptoms. If the latter is true, then the MRI results could be unhelpful or misleading for people with symptoms. It is also not clear which tests and measures taken in clinic by doctors and physiotherapists are most useful to help guide decisions on how to help people manage their symptoms. Nor is it known if or how these clinical tests and measures relate to MRI findings.

This study aims to answer these questions by comparing upright dynamic MRI of the cervical spine and craniocervical junction in two groups of people with confirmed generalized joint hypermobility. The first group is those who have symptoms that could be coming from the upper cervical spine. The second group is those with hypermobility who do not have neck problems. Everyone in both groups will be asked a series of questions and will undergo a clinical examination for head and neck, and shoulder and arm concerns that might arise. The study will use currently accepted standards of clinical assessment and validated questionnaires. The usefulness of two new questionnaires will also be assessed. The MRI and clinical results from the two groups will be compared. Statistical techniques will be used to determine if MRI and/or clinical signs consistently identify people with neck symptoms compared to those without. Clinicians around the world can use this information in their clinics to help guide their practice, helping to improve the experience of people with these truly awful symptoms.



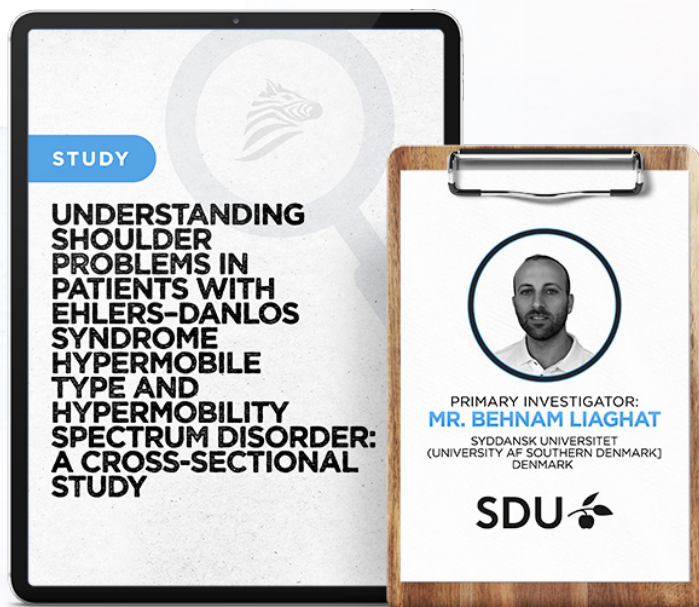


Research Grant Awarded: **\$5,000**

Hypermobility spectrum disorder (HSD) is a recently defined group of conditions related to the symptomatic manifestation of generalized joint hypermobility (GJH), and is characterized among others by symptoms in the shoulder joint including and not limited to shoulder strength deficits, shoulder instability, and shoulder pain. This condition has negative consequences in daily living for these people, but currently, there is no optimal treatment for this population.

In an ongoing randomized controlled trial (RCT) (ClinicalTrials.gov identifier NCT03869307), we are investigating the effectiveness of a 16-week heavy strengthening exercise program in people with HSD and persistent shoulder complaints/problems. This study will use data collected in the RCT to obtain knowledge about associations between pain trajectories, exercise-induced pain flares, and exercised load in this population. In an exercise diary, the participants report pain before and after each exercise session, which makes it possible to analyze if pain decreases, increases, stays the same, and how it varies during the strengthening exercise program. In addition, associations between pain and the applied load in the specific exercise session will be studied. This information may guide healthcare professionals responsible for effective and safe treatment, in predicting response to heavy strength training, and inform a deeper understanding of possible pain patterns during exercise for this population.



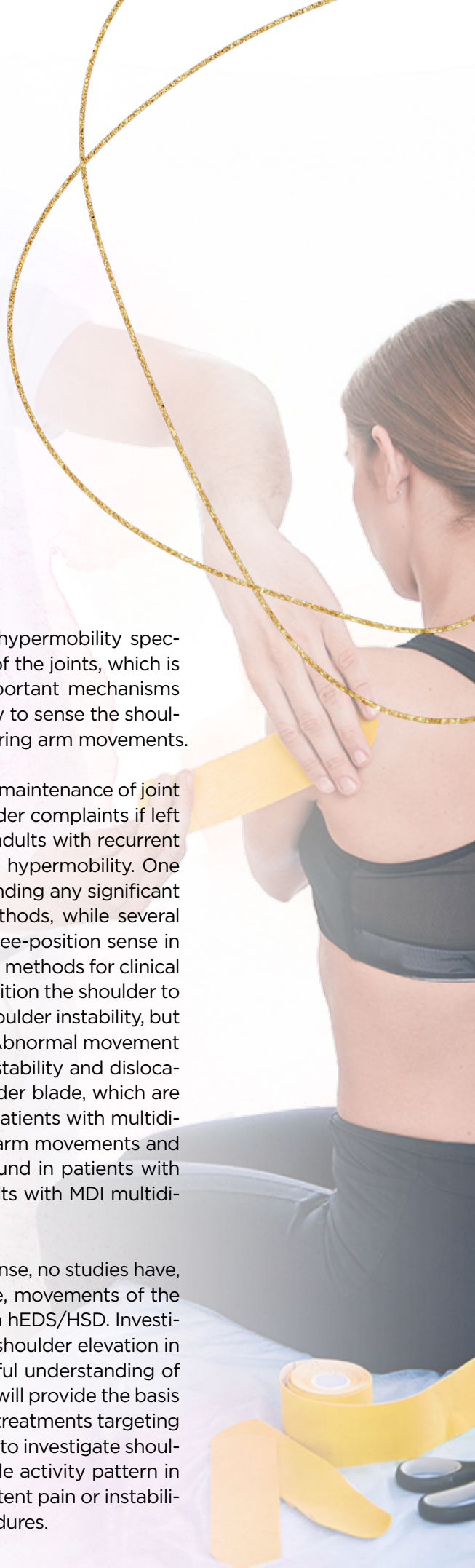


Research Grant Awarded: **\$5,000**

Patients with hypermobile Ehlers-Danlos syndrome (hEDS) and hypermobility spectrum disorder (HSD) typically present with hypermobility in most of the joints, which is frequently associated with recurrent joint dislocations. Some important mechanisms that are thought to play a role in shoulder dislocation are the ability to sense the shoulder joint, muscle function, and movement of the shoulder blade during arm movements.

The ability to sense the shoulder joint plays an important role in the maintenance of joint control during all arm movements, which may lead to severe shoulder complaints if left undiscovered. Poor shoulder position sense has been reported in adults with recurrent anterior shoulder instability, but not in adolescent swimmers with hypermobility. One study has investigated dynamic shoulder-position sense without finding any significant deficits in patients with hEDS using advanced measurement methods, while several previous studies have consistently reported deficits of dynamic knee-position sense in this patient group compared with healthy people. Feasible dynamic methods for clinical use, e.g. active joint reposition, which measures the ability to re-position the shoulder to a previous position, have shown deficits in patients with anterior shoulder instability, but this method has not yet been used in patients with HSD or hEDS. Abnormal movement of the shoulder blade has been found in patients with shoulder instability and dislocations. Less upward rotation and more inward rotation of the shoulder blade, which are indicative of poor movement, have consistently been reported in patients with multidirectional instability during arm elevation, which may compromise arm movements and impair shoulder control. Also, altered muscle activity has been found in patients with shoulder laxity, adolescent swimmers with hypermobility, and adults with MDI multidirectional instability.

While there is limited and inconclusive research on joint-position sense, no studies have, to our knowledge, simultaneously investigated joint-position sense, movements of the shoulder blade, and muscle activity of the shoulder in patients with hEDS/HSD. Investigation of these parameters during functional movements, such as shoulder elevation in different directions with and without resistance will provide a useful understanding of shoulder complaints in patients with hEDS or HSD. This knowledge will provide the basis for further investigating the effect of more specific exercise-based treatments targeting these shoulder deficits in this patient group. The aim of this study is to investigate shoulder reposition sense, movements of the shoulder blade, and muscle activity pattern in patients with hEDS or HSD with shoulder complaints such as persistent pain or instability compared to healthy controls using standardized feasible procedures.

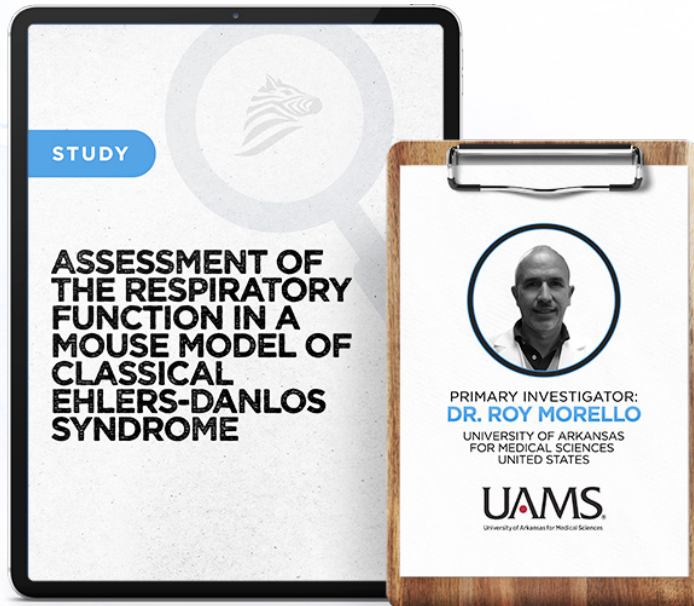




Research Grant Awarded: **\$5,000**

Osteoarthritis or joint wear is the deterioration in quality of one or more joints. The two main features of osteoarthritis are pain and movement restriction. At the beginning, pain occurs when loading the joint, e.g. during sports or even when walking. In a more advanced stage, there is also pain at rest that can interfere with sleep. Joint stiffness can also occur. Two types of osteoarthritis can be distinguished. On the one hand, osteoarthritis can develop in a normal joint, due to aging. It usually starts from the age of 50 and is most common in the knees, hips and hands. This can happen to everyone. On the other hand, osteoarthritis can develop due to an illness or injury. This develops at a younger age, usually between the ages of 35 and 50, and is therefore called osteoarthritis at early-onset or premature osteoarthritis. It has been suggested that because of the hypermobility in the joints and the frequent dislocations ([sub]luxations) and sprains, patients with Ehlers-Danlos syndrome (EDS) are prone to develop early osteoarthritis. However, no studies have been published that determine whether patients with EDS actually have early osteoarthritis and how severe it is.

It is important to investigate the occurrence of early-onset osteoarthritis in EDS patients because it can help to better understand the types of pain and pain mechanisms in EDS and because it can help to improve and specify the treatment of EDS patients regarding physiotherapy and pain medication. Therefore, we set up a research study to investigate with radiography (X-rays) whether patients with classical EDS, classical-like EDS, and hypermobile EDS, between 35 and 50 years old, have early-onset osteoarthritis in the hands, knees and hips and whether this is different between these types of EDS and compared to healthy persons. Also, mobility of the joints is measured to investigate whether there is a relationship between the degree of (hyper)mobility in a joint and the presence of early-onset osteoarthritis in that joint in EDS patients.



Research Grant Awarded: **\$5,000**

Diseases of the connective tissue, including EDS, are systemic and negatively affect multiple tissues and organ/systems. In fact, although EDS is characterized by various skin features (including hyper-extensibility, fragility, softness, bruising, abnormal scarring) and joint hypermobility, it often causes joint and muscle pain in addition to a variety of other symptoms. These, including symptoms affecting the respiratory system, are less studied but can significantly reduce the quality of life of EDS patients. A few, sparse studies have reported an increased number of respiratory symptoms (wheezing, coughing, chest pain, breathing difficulties), lung diseases and even asthma in patients with EDS. However, data on the prevalence and/or incidence of these cases are not available and no in-depth studies on the respiratory system of EDS patients have been performed. We recently characterized the respiratory phenotype in a mouse model of recessive osteogenesis imperfecta (OI), a disease that causes severe bone fragility but also skin alterations, with some overlapping features with EDS. OI is most often caused by alterations in type I collagen, the most abundant protein in our body and an essential structural component of our connective tissues. Our study showed that type I collagen expressed in the lung tissue presents similar defects to those seen in bone and skin; moreover, we demonstrated that OI mice have both morphological and functional respiratory defects with important implications for patients with this disease. Indeed, previous theories suggested that the respiratory function is impaired because of the musculoskeletal issues caused by OI. Instead, our study indicated that collagen defects directly impact lung structure and function. Therefore, our working hypothesis is that collagen alterations such as those impacting type I collagen in OI or type V or III collagen in EDS also primarily affect the respiratory system with deleterious pathophysiologic consequences that could help explain the symptoms observed in these patients.

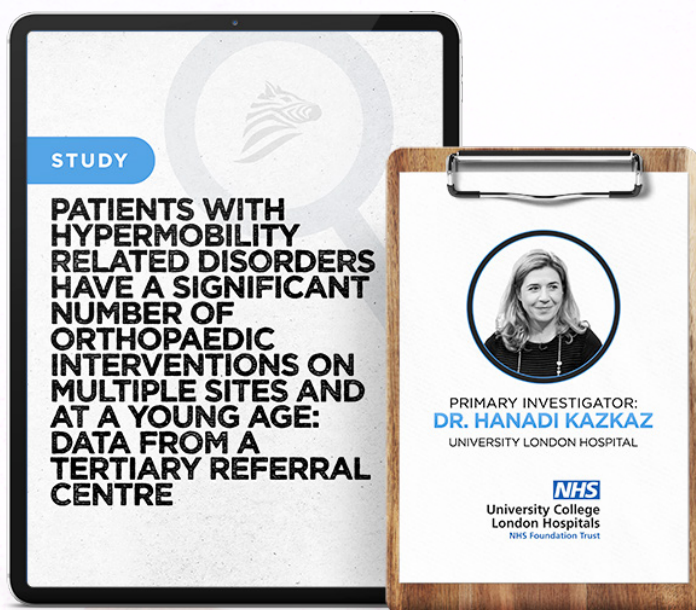
We believe it is critical to begin to study these important aspects of the disease. We thus propose to utilize a well-described mouse model of classic EDS (carrying mutations in the *Col5a1* gene) and determine potential alteration in its respiratory function and respiratory mechanics using the forced oscillation technique, a powerful tool permitting the experimental assessment of lung function in a comprehensive, detailed, precise and reproducible manner. Our pilot study provides an opportunity to explore these aspects in a mouse model with the ultimate goal to translate the new knowledge into improvements in the respiratory management and care of EDS patients.





Research Grant Awarded: \$5,000

Mutations in a protein called FKBP22 cause kyphoscoliotic EDS (kEDS). Individuals with kEDS have a broad spectrum of phenotypes, such as the curved spine, excess joint flexibility, poor muscle tone, stretchy skin, hearing loss, and breakable aorta. The mechanism by which reduced or abnormal FKBP22 leads to kEDS is unknown and represents a critical gap in our knowledge. I have recently discovered that the FKBP22 protein binds to some of the 28 different collagens but not others. Understanding how and where FKBP22 differentially binds collagens has never been explored. Determining the nature of these interactions would contribute to a fundamental understanding of kEDS disease mechanisms and contribute to the development of novel therapeutic interventions.



Research Grant Awarded: \$5,000

Hypermobility is a common body type and it is estimated to affect 20% of the population. Only 10% of people with hypermobility are symptomatic which often causes a confusion regarding the nature of pain in these patients. Furthermore there is an anecdotal impression among some doctors that patient with rare forms of EDS, such as classical or vascular type, do not suffer with pain or significant musculoskeletal issues. We have observed an increase in the rate of orthopaedic surgical procedures undertaken in patients attending the hypermobility clinics compared to those attending the general rheumatology and chronic pain clinics. This indicates that mechanical pathology rather than pain oversensitivity plays an important role in their symptoms. We have performed a retrospective review of medical records of 350 patients attending a hypermobility clinic at our tertiary referral centre, University College London Hospital, between January 2018 and December 2018.

This study was accepted as an oral presentation at EULAR (the main European rheumatology meeting) in June 2020 and received a very good feedback. We would like to apply to this grant to perform subgroup analysis and get a professional statistical advise to be able to publish this in one of the main rheumatology journals.



Research Grant Awarded: **\$5,000**

The Spider: Mapping your symptoms

Patients with joint hypermobility report joint pain as their main symptom. However, their lives are often affected by many other problems situated outside the muscles and joints as well. Fatigue, feeling unwell after exercise, feeling faint in an upright position, abdominal pain, slow bowel transit, diarrhea, and urinary incontinence are examples of additional 'non-musculoskeletal' symptoms.

Since 2017, these bothersome symptoms have been acknowledged by the international EDS consortium and are referred to as the comorbidities of hypermobility. Unfortunately, when seeking treatment, many patients feel as if these symptoms are neglected at first because they are not taken into consideration when diagnosing HSD and EDS. The reason is that diagnosis of EDS is based on more structural symptoms, such as abnormal scarring and fragility of soft tissues.

Although the functional symptoms do not have a central place in the diagnostic procedure, researchers found that they lower quality of life importantly. In fact, the impact of symptoms like fatigue, difficulty regulating blood pressure, and stomach and bowel problems is often as large as the impact of pain. Furthermore, evidence is growing that subgroups exist in patient with HSD and in hEDS and that these may need different treatment strategies. For instance, a Dutch-Australian research team evaluated 101 children with hEDS/HSD and detected three subgroups. The most severely affected subgroup reported a larger number of non-musculoskeletal symptoms and was more likely to have a worse disease trajectory growing up. A similar finding was described in adults by Belgian researchers. To register the non-musculoskeletal symptoms (comorbidities) of joint hypermobility in a standardized way, the "Spider" was developed.

The end result of this questionnaire is a graph shaped like a spider web, that shows healthcare professionals which issues require further assessment and should be treated as a priority. For instance, if patients have severe digestive problems or symptoms related to blood pressure regulation, these should be addressed first before starting intensive physiotherapy or physical training. In addition, the spider can be used to track how a patient's health is evolving over time and to monitor the effects of treatment.

Finally, researchers will also be able to use the spider, since it provides insight into the prevalence of non-musculoskeletal symptoms in HSD and EDS, and reveals whether differences exist between patient groups with HSD, hEDS, and other EDS-types. In many countries, patients with EDS diagnoses are more likely to receive acknowledgment, assistance and reimbursement for treatment than patients with HSD. The faulty assumption that hEDS is more severe than HSD could be confuted by symptom registration on a large scale. Because little is known about the genetic background of HSD and hEDS, the spider could be an interesting tool to shed light on the differences and similarities between both pathologies. Finally, the spider could be helpful to detect groups of similar patients within large populations with the same diagnosis. Researchers hope to understand whether patient subgroups with different symptoms also have a different genetic background.



STUDY

IN-DEPTH THREE-DIMENSIONAL STUDY OF DERMAL CONNECTIVE TISSUE ULTRASTRUCTURE IN DIFFERENT EHLERS-DANLOS SYNDROME SUBTYPES AND HYPERMOBILITY SPECTRUM DISORDERS



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NHS Foundation Trust

Research Grant Awarded: **\$5,000**

For diagnosis and research it is very useful to be able to look at the skin of patients with Ehlers-Danlos syndrome and hypermobility spectrum disorders using a transmission electron microscope.

To be able to do this, a small sample of skin is processed and a very thin slice is taken and put in the microscope. Using this type of microscope, it is possible to look at a cross section through the cells and collagen of the dermis (skin layers) at very high magnification, to see if they are normal or not. By comparison, with a scanning electron microscope it is possible to see the surface of tissues at high magnification in three dimensions. Scanning electron microscopy gives interesting results, but for the study of the dermis, is less useful. Even when both of these types of microscope are used, it is still very difficult to tell what is happening in the skin in three dimensions.

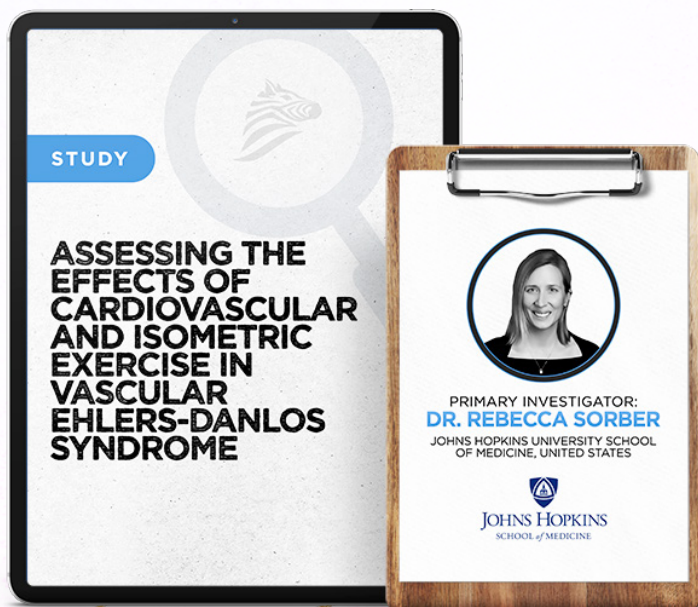
However, a microscope was recently developed where, in an automated fashion, slice after slice is taken from a biopsy and the cut surface is photographed after each slice has been taken. This makes it possible to build up a three-dimensional picture of the cells, collagen strands and elastic fibres. Using multiple slices and a computer to build up a three-dimensional image is called computer tomography which is what x-ray, CT and magnetic resonance imaging body scanners do - which is especially useful when looking at organs. However, when wishing to look at cells and collagen at the microscopic level, electron tomography is required. It is our expectation that by looking at skin biopsies from patients suffering with Ehlers-Danlos syndromes and hypermobility spectrum disorders using this new piece of equipment (Serial Block Face Scanning Electron Microscope) it will help scientists understand more about the molecular biology of these conditions. Only a few research institutions in the UK own these new microscopes. This grant application, in large part, is to pay for the services of one of these universities, with interpretation in large part being the job of those applying for this microgrant. The institution we have approached is the University of Manchester Wellcome centre of Cell-Matrix research.



Research Grant Awarded: **\$148,348.10**

Chronic pain is present in the majority of patients suffering from Ehlers-Danlos syndromes and hypermobility spectrum disorders and is a major reason to seek medical help. It has a detrimental effect on the quality of life and psychosocial well-being of EDS/HSD patients.

This proposal is part of a large, ongoing and collaborative research line at the Center for Medical Genetics Ghent (Belgium), aiming to better understand the molecular and cellular pathways and mechanisms that contribute to pain in EDS, with the ultimate goal to identify targets for safer, more efficient and (potentially) disease-tailored approaches for pain relief.



Research Grant Awarded: **\$149,698.13**

The issue of what type and how much exercise is safe for patients with vEDS is of high concern among patients who want to do whatever they can to prevent spontaneous rupture. The most conservative answer in terms of reducing stress on the blood vessels is to avoid all exertional activity, but this robs the patient of the many health benefits of exercise. The best available exercise recommendations in vEDS are derived from those for other connective tissue related vascular diseases, such as Marfan syndrome and Loeys-Dietz syndrome. However, these syndromes are defined by a reliable pattern of aneurysm formation, followed by dissection and rupture and do not mimic the unpredictable vascular ruptures seen in vEDS.

Financial support from an EDS Society microgrant will allow us to further investigate some preliminary findings from a mouse model, and determine a mechanism for these observed differences that will inform further research in and future recommendations on exercise for patients living with vEDS.



HEDGE

A grant of \$2 million has been pledged to support the Hypermobile Ehlers-Danlos Genetic Evaluation (HEDGE Study).

HEDGE is an ongoing study that will obtain whole-genome sequences for 1000 people with hypermobile EDS (hEDS) under the 2017 criteria, and seek to establish underlying genetic causation. Of the 14 types of EDS, only the hypermobile type does not yet have identified genetic markers. If we are successful in identifying the underlying genes for hEDS, we can create vital opportunities for earlier diagnosis, and more comprehensive treatment and care.

To break down geographical barriers in research participation and to adapt to limitations on travel, The Ehlers-Danlos Society announced a new screening and enrollment process for HEDGE in July 2020.

The exciting newly-established process will make it possible for individuals with hEDS to enroll in the groundbreaking study, without traveling to an in-person event. Invitees can now have blood drawn at home or at other locations.



Global Registry

Almost 11,000 individuals from 82 countries around the world have joined the EDS and HSD Global Registry. Participation is free to all, with global access available—and more languages available soon!

Comorbidity Coalition

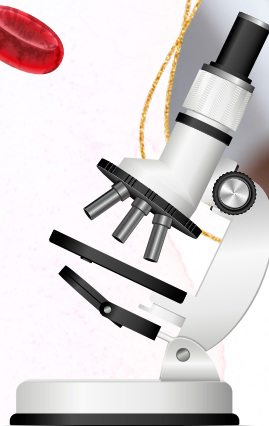
Collaborative international advocacy and research are vital parts of our mission, ensuring we have representation from different organizations and community voices to support and help our global community.

The Comorbidity Coalition consists of stakeholder groups of patients and professionals, allowing international collaboration to increase the quality of life for individuals living with these conditions. The Coalition was originally launched in 2017 with a one-year “Pipeline to Proposal” grant awarded by the Patient-Centered Outcomes Research Institute.

Despite the global COVID-19 pandemic changing some targets and objectives for the Coalition in 2020/2021, we continue to meet to discuss needs as they arise. In 2020 the Coalition worked as a focus group, meeting to discuss the migration of the EDS and HSD Global Registry from the Peer platform to LunaDNA, and the launch of the new Global EDS and HSD Registry and Repository for research for our community's future.

TWELVE IN-PERSON SCREENING EVENTS

have taken place around the world to date and enrolled 413 individuals with hEDS into the study towards the 1,000 participant goal.



FUNDRAISING

May Awareness Month 2020

Advocacy and Acts of Awareness GO VIRTUAL!

The Ehlers-Danlos Society strives to increase awareness of EDS, HSD, and related conditions all around the world. As part of May Awareness Month, Acts of Awareness were carried out all around the world, as the community came together, virtually, to create change.

Local advocates submitted more Awareness Proclamations in 58 states, countries, and cities around the world, nearly double from 2019. Supporters went online with fundraisers, hosting gaming streams, virtual quiz nights, and social media events, surpassing 2019 with over \$100,000 raised by the community. From our global, virtual Walk 'n' Roll to photo-a-day competitions, we saw over 140,000 Acts of Awareness by 376 participants in 21 countries!



“I have *secured a promise* from the mayor...”

“Thrilled to say that I have secured a promise from the mayor of my little city to issue a proclamation for May 2020 as EDS and HSD Awareness month here! They just need to have a City Council meeting to make it happen.

“Someone already had the state wrapped up (YAY) so I thought I'd work a little closer to home. Trying to put together a weekly Q&A for my FB friends as well.” - Judy Sullivan

“Awareness is a *huge step towards* recognition...”

“Awareness is a huge step towards recognition in various fields, such as the medical field leading to diagnoses and the social field enabling integration in society and support. That is why I decided that I would devote my Bachelor's thesis, which I am currently working on, to raising awareness of rare diseases.

“While working on my thesis, during the month of May, I also took part in some of the activities initiated by The Ehlers-Danlos Society. I raised 616 Acts of Awareness in total, mainly through participation in the Walk 'n' Roll Challenge and through a fundraiser I created in honor of my birthday falling on the last day of the awareness month for EDS and HSD.” - Isabella, Finland

END OF YEAR CAMPAIGN

Thanks to the generosity of our donors,
we raised an incredible

\$247,231.00

in our 2020 End of Year Campaign,
celebrating the achievements and
contributions of community members.

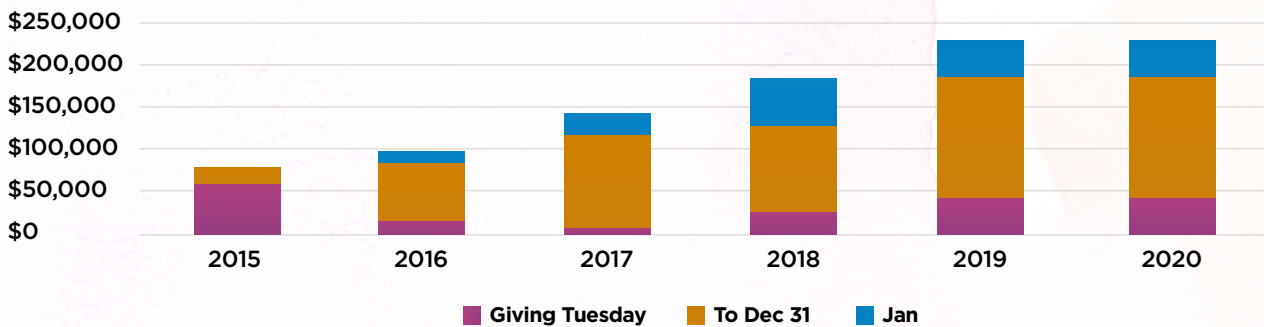
TOGETHER WE DAZZLE

GIVING TUESDAY

DECEMBER 1, 2020



EOY CAMPAIGN HISTORY



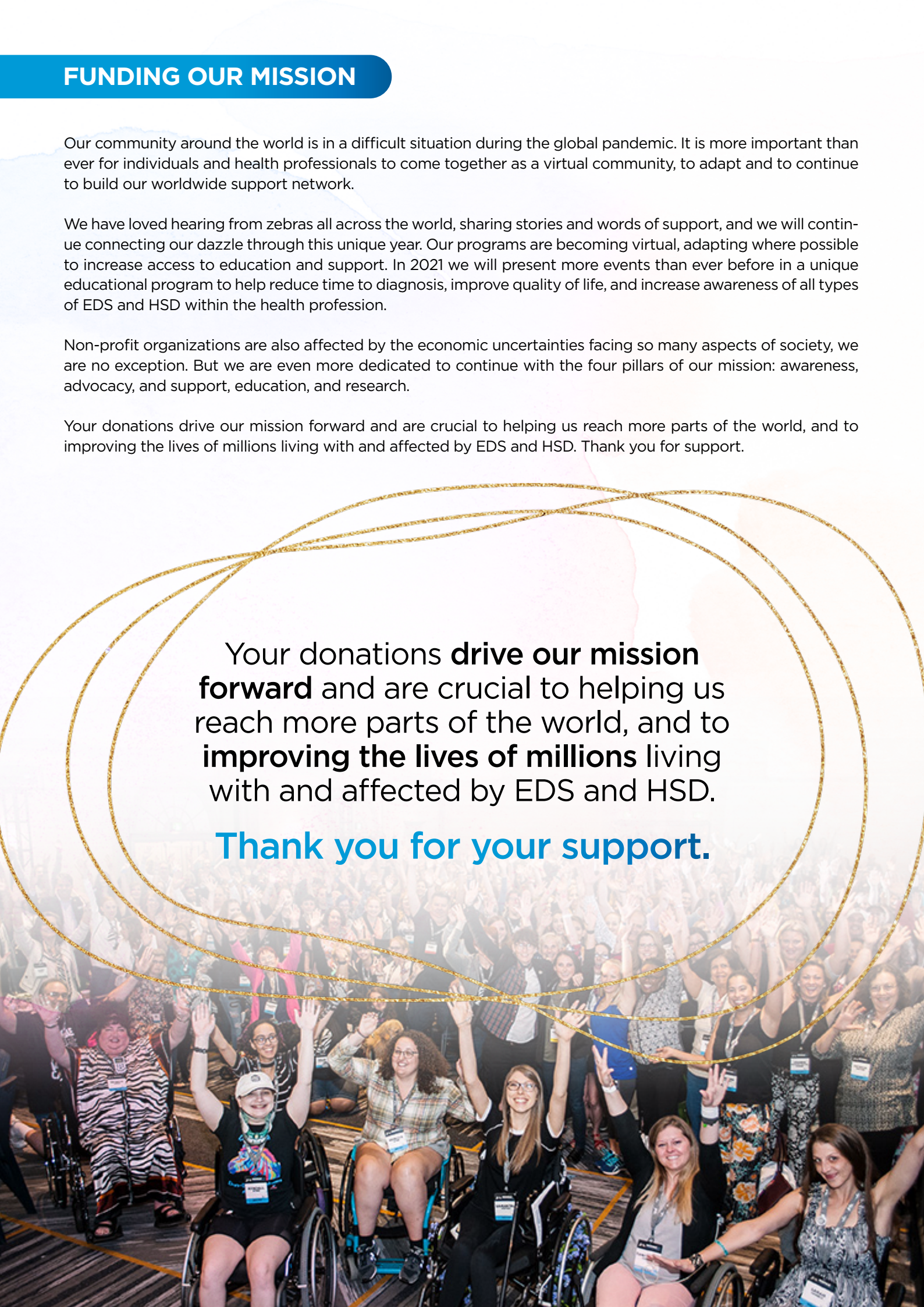
FUNDING OUR MISSION

Our community around the world is in a difficult situation during the global pandemic. It is more important than ever for individuals and health professionals to come together as a virtual community, to adapt and to continue to build our worldwide support network.

We have loved hearing from zebras all across the world, sharing stories and words of support, and we will continue connecting our dazzle through this unique year. Our programs are becoming virtual, adapting where possible to increase access to education and support. In 2021 we will present more events than ever before in a unique educational program to help reduce time to diagnosis, improve quality of life, and increase awareness of all types of EDS and HSD within the health profession.

Non-profit organizations are also affected by the economic uncertainties facing so many aspects of society, we are no exception. But we are even more dedicated to continue with the four pillars of our mission: awareness, advocacy, and support, education, and research.

Your donations drive our mission forward and are crucial to helping us reach more parts of the world, and to improving the lives of millions living with and affected by EDS and HSD. Thank you for support.



Your donations **drive our mission forward** and are crucial to helping us reach more parts of the world, and to **improving the lives of millions** living with and affected by EDS and HSD.

Thank you for your support.

REVENUES & EXPENSES

REVENUES

INCOME TYPE	SUM OF TOTAL	PERCENTAGE
Corporate Donations	\$383,333	16%
Dividend Income	\$110	0%
Grants	\$0	0%
Individual Donations	\$1,948,247	80%
Special Events	\$109,207	4%
GRAND TOTAL	\$2,205,001	

EXPENSES

INCOME TYPE	SUM OF TOTAL	PERCENTAGE
Administration (Mgt & Gen)	\$402,295	22%
Fundraising	\$193,026	12%
ECHO	\$134,500	7%
Education & Awareness	\$234,529	12%
Helpline	\$81,222	4%
Center for Clinical Care	\$5,176	0%
Classical EDS	\$5,021	0%
Comorbidity Coalition	\$20,158	1%
EDS Rarer Types	\$492,604	25%
General Research	\$54,204	3%
Hedge	\$116,230	6%
Registry	\$11,375	1%
Scientific & Research - Other	\$7,863	0%
Vascular EDS	\$5,047	0%
Events	\$123,876	6%
TOTAL	\$2,005,482	

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