



The
**Ehlers
Danlos**
Society

IMPACT REPORT

2019

-
Our Strength Begins With Hope

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

ONE SOCIETY, A HOME FOR ALL.

With your support of our shared mission, The Ehlers-Danlos Society has made great strides in 2019.

Our goals are world-wide awareness – and a better quality of life for all who suffer from these conditions, and we are closer than ever before to making this a reality.

GLOBAL EDUCATION IN HEALTHCARE

We are thrilled to have so many professionals and patients interested in expanding their knowledge and increasing awareness by joining EDS ECHO, and we are working towards our goal of 1,000 new EDS and HSD experts by 2021.

EDS ECHO seeks to tackle a key issue facing patients with EDS and HSD: lack of knowledgeable clinicians. Too many in our community report that they are forced to travel far and wide to access a physician who knows how to manage their healthcare, often at great personal expense, and often with incredibly long wait times of over two years. EDS ECHO is helping us reach clinicians all over the world, arming them with the tools and knowledge to care for their own patients with EDS and HSD.

RESEARCH FOR OUR FUTURE

Research is at the center of what we do.

We have funded research projects this year to improve our understanding of topics with profound impacts on individuals who live with EDS and HSD: diagnosis, pain, life-threatening vascular complications, and genetic evaluation.

We need as much data as possible to better understand the different sub-types and their varying, multi-systemic impact on patients.

The Ehlers-Danlos Society EDS and HSD Global Registry collects a wide range of data from people living with all types of Ehlers-Danlos syndrome and those living with hypermobility spectrum disorders.

Given the different ways in which the Ehlers-Danlos syndromes and hypermobility spectrum disorders can present, it will also help us to raise awareness and support clinicians to recognise signs and symptoms more effectively. The registry will also provide new opportunities for research – including identifying links between EDS and HSD and other conditions. Without this understanding, patients will continue to be mis- or undiagnosed.

TOGETHER WE DAZZLE

The Ehlers-Danlos Society team works to provide global learning conferences, collaborative research and education initiatives, awareness campaigns, advocacy, community-building, and care for the EDS and HSD (hypermobility spectrum disorders) population around the world.

We strive to give hope to all those whose lives are affected by EDS and HSD. Building our community is therefore vital. We 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.

OUR STRENGTH
BEGINS WITH
HOPE,
OUR HOPE
BEGINS WITH YOU.



Lara Bloom

Lara Bloom
PRESIDENT & CEO



Susan Hawkins

Susan Hawkins
CHAIR, BOARD OF DIRECTORS

OUR GLOBAL 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 the quality of life for those with these conditions, around the world.

We proudly work 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.**

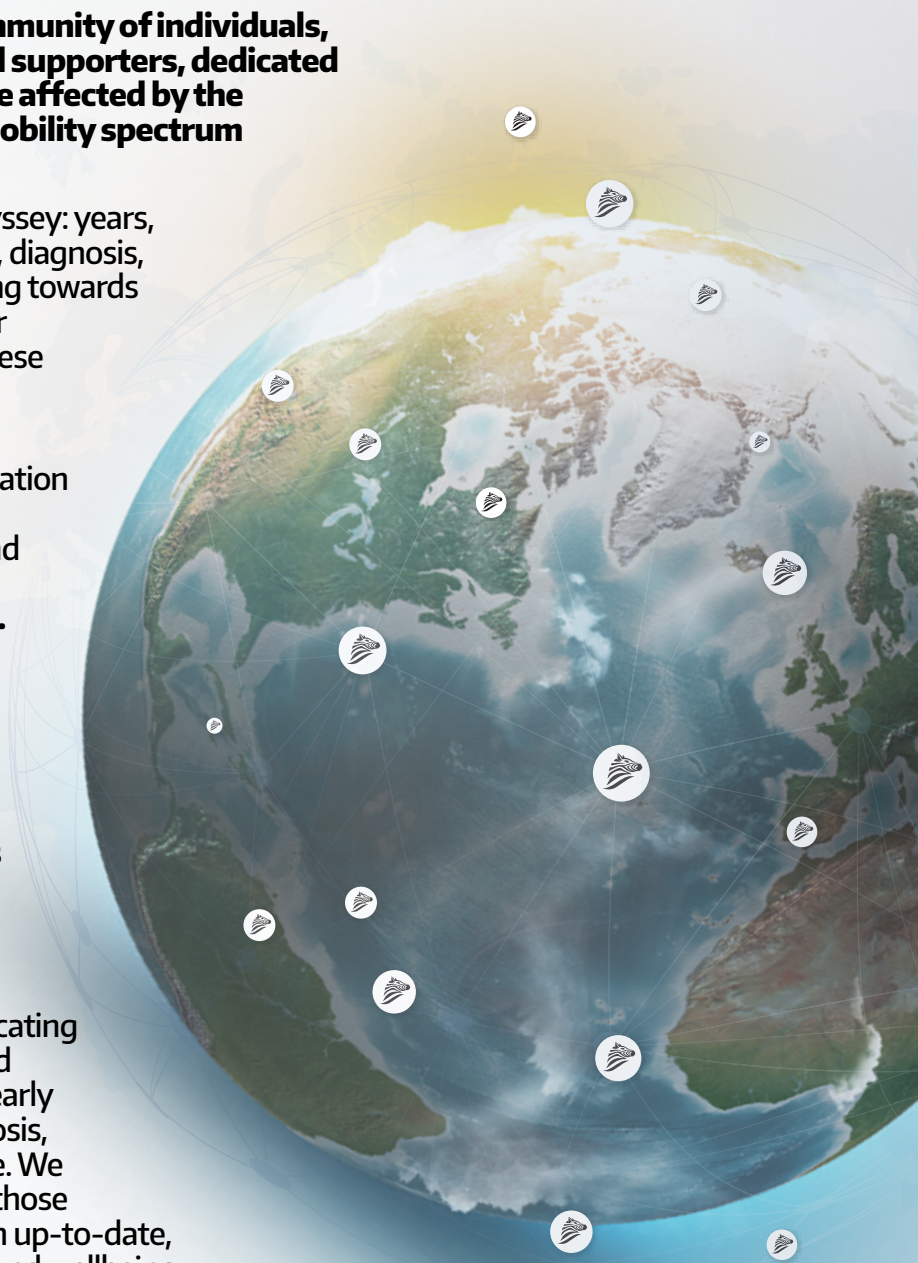
WHAT WE DO

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 wellbeing.

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.



THE EHLERS-DANLOS SOCIETY

CONNECTING OUR DAZZLE



MADRID, SPAIN | APR 2019

THE EHLERS-DANLOS SOCIETY HOSTED ITS **FIRST EVER** GLOBAL LEARNING CONFERENCE IN MADRID, SPAIN.

Conference attendees had the opportunity to learn directly from leading world-experts in EDS, HSD, and related symptoms and conditions. Informative presentations were given on topics from mast cell activation syndrome to neurology, and from gastrointestinal complications to gynecological issues, with an invaluable question and answer time with these distinguished professionals.



197

COMMUNITY DAY ATTENDEES

COMPARED TO **83**
(GHENT 2018 COMMUNITY EVENT)

AN INCREASE OF OVER **130%**

Madrid Health Professionals Day

Presentations and workshops focused on helping health professionals who work with EDS/HSD patients provide higher levels of patient care, offering them insight into the latest advances in research, and presenting clinical case studies.

Madrid Community Day

"We learnt about the conference and the work of The Ehlers-Danlos Society through Facebook. We have an organization in Italy, and we want to learn of ways to work with The Ehlers-Danlos Society towards common goals. **The conference has been very good, with great people presenting.** We have learnt a lot of information and have met with medical professionals across all disciplines, which has been fantastic."

TRANSLATED INTO
FIVE
LANGUAGES:



SPANISH



ITALIAN



GERMAN



DUTCH



FRENCH



THE EHLERS-DANLOS SOCIETY

CONNECTING OUR DAZZLE



NASHVILLE, TENNESSEE | AUG 2019

OUR BIGGEST GLOBAL LEARNING CONFERENCE YET!



826 Attendees of Community Day
compared to 641 in 2018



144 Health Professionals Day
Attendees compared to 40 in 2018

The 2019 Global Learning Conference brought together people with Ehlers-Danlos syndromes and hypermobility spectrum disorders, families, caregivers, and health professionals for three days of education and support.

Welcoming new expert speakers and subjects, including our Keynote Speaker Dr. Daniel Clauw speaking on Fibromyalgia. Dr. Chad Shepherd from the UK spoke on "Living with EDS, HSD, and PTSD and Trauma." Other areas covered included bleeding and bruising, bone fragility, child protection, genetic considerations in having children, and red flags in vascular EDS.

Health Professionals Day opened with a Genetic Testing talk led by University of Arizona College of Medicine associate professor Dr. Christina Laukaitis, and closed with a Children and EDS talk led by clinical molecular geneticist Dr. Brad Tinkle.



867 Users

The WHOVA app allowed attendees and those tuning in via live-stream to converse, follow the event, and ask questions to speakers in a live Q&A.

JUNIOR ZEBRAS

The Society's Junior Zebra program experienced continued expansion, growing from 24 attendees in 2018 to 40 in 2019.



For the first time, we made it possible to watch the Global Learning Conference via live-stream, from anywhere in the world. Over **3,200** people signed up to watch the speakers via live-stream from **48 countries!**



THE EHLERS-DANLOS SOCIETY

FEEDBACK



NASHVILLE, TENNESSEE | AUG 2019



"I just wanted to let you guys know that you did **such an amazing job** at the conference I attended in Nashville; you **helped my family and I so much** in learning exercises and outlets. I just wanted to let you know and personally thank you."

McKenna

"The Nashville EDS Learning Conference 2019 was the first conference I had ever attended. To make the most of this opportunity, I wanted to **connect with as many other people with EDS** (I had previously never met another person with EDS), I wanted to learn as much as I could about the syndrome that I have lived with all of my life, and I wanted to have some fun too. What better way to accomplish these goals than to jump in the deep end and volunteer! I loved being able to help an **organization that makes such a difference** in the lives of so many of us."

Jenni Craddick



"It was **fantastic** to be able to sit in my living room here in Denmark and follow the livestream. Thank you!"

"I had an **incredible time at the conference in Nashville**. I learned so much and met so many wonderful people. Thank you for all that you do, and I look forward to the conference next year."

Nina Pharis

NASHVILLE

CONNECTING OUR DAZZLE

 EDINBURGH, SCOTLAND | NOV 2019

Psychological and Emotional Health: Exploring the mind-body connection in EDS and HSD.

Renowned speakers from the UK shared their clinical experience and considered the literature on psychosocial well-being, highlighting the importance of a holistic approach in supporting individuals with EDS and HSD. Patients and carers of people with EDS and HSD shared their experiences of living with these conditions, and the benefits and hurdles of using these tools.



“I believe that when you are diagnosed with any rare, chronic, or invisible condition you should be offered a full **multidisciplinary** team. We must be offered all the physical care and management we need, but also be offered the psychological management needed to be able to take on what we have to deal with every day, for the rest of our lives. Some may not need it but don't think that if you need psychological support, CBT, mindfulness, meditation, counseling, whatever form it comes in, that invalidates your very, very physical, real problem. It is not in your head.”



LARA BLOOM
PRESIDENT & CEO

TOPICS COVERED:



EDS, HSD, & PSYCHOLOGICAL HEALTH
WHAT DO THE STUDIES TELL US?



TRAUMA & POST-TRAUMATIC STRESS DISORDER
WHAT IS IT & COULD IT AFFECT ME?



ADHD, EDS & HSD



DEALING WITH A FAMILY DIAGNOSIS



SUPPORTING CHILDREN & TEENAGERS



COPING WITH A NEW 'NORM'



MEDICATION FOR ANXIETY & DEPRESSION



MINDFULNESS
THE IMPORTANCE FOR HYPERMOBILE INDIVIDUALS



TALKING THERAPIES
PSYCHOLOGICAL APPROACHES TO SUPPORTING
PEOPLE WITH COMPLEX & CHRONIC CONDITIONS

THE EHLERS-DANLOS SOCIETY

SCIENTIFIC MEETING

 TOKYO, JAPAN | NOV 2019

World-leading speakers presented cutting-edge research updates on clinical advances and the molecular and pathogenic mechanisms of EDS, allowing researchers and healthcare professionals to collaborate at The Society's 2019 Scientific Meeting in Tokyo, Japan.

State of the art presentations highlighting the latest medical and scientific achievements were discussed including arthrochalasis, dermatosparaxis, kyphoscoliotic, classical, classical-like, cardiac-valvular, spondylodysplastic, musculocontractural, myopathic, vascular, and periodontal EDS.

Host, Tomoki Kosho opened The Society's first conference in Asia, discussing the rarer types of the Ehlers-Danlos syndromes. Dr. Clair Francomano started the first session discussing classical EDS (cEDS), its presentation, and treatment and management guidance. Marlies Colman presented historical background and findings from a large clinical patient cohort of 277 individuals with cEDS.

Tomomi Yamaguchi updated the group on clinical sequencing for vascular Ehlers-Danlos syndrome using panel-based next-generation sequencing in Japan.

HEALTH PROFESSIONALS & RESEARCHERS ATTENDED FROM ACROSS THE GLOBE:



JAPAN



BELGIUM

UNITED
KINGDOM

AUSTRALIA

NEW
ZEALAND

CHILE



PAKISTAN

UNITED STATES
OF AMERICA

FRANCE



NORWAY



FIJI



THE EHLERS-DANLOS SOCIETY

WEBINARS

WEBINARS ARE AN IMPORTANT RESOURCE FOR OUR COMMUNITY, OFFERING ACCESS TO THE LATEST **RESEARCH, EVIDENCE, & CLINICAL DATA** ON THE COMPLEXITIES OF EDS & HSD.

The Ehlers-Danlos Society produced webinars presented by medical professionals from around the globe, which each include a Q&A portion for the attendees to pose questions on the specific topic being discussed.

Past webinars are available on The Society's YouTube channel, and we are currently working on our long-term goal to transcribe, translate, and caption these videos to be fully accessible to all.

WATCHED OVER
123,000
TIMES

WEBINARS

THE EHLERS-DANLOS SOCIETY

EDS ECHO



ALL TEACH & ALL LEARN TO ENSURE DIAGNOSIS & **CARE FOR ALL**

Education is essential to advance early diagnosis and intervention, and after diagnosis, patients urgently need support and guidance. For these reasons in 2019 The Ehlers-Danlos Society was excited to launch EDS ECHO – a program to educate healthcare professionals across all disciplines, by moving knowledge, not patients.

**270 PROFESSIONALS EDUCATED****FROM 25 COUNTRIES****THIRD HUB ADDED IN AUSTRALIA**

The EDS ECHO Advocacy program was also introduced, a seven-week program dedicated to providing the tools one needs to advocate effectively for individuals living with EDS and HSD.

The Society aims to educate 1,000 new experts by 2021. Share the downloadable flier from our website with your healthcare team to help educate more experts in your community!

New EDS ECHO® Programs for 2020:

- ✓ Vascular EDS (vEDS)
- ✓ Orthopedic Management
- ✓ Nurses
- ✓ Allied Health Professionals
- ✓ Pediatric



ADVOCACY

WORLD ORPHAN DRUG CONGRESS

The World Orphan Drug Congress is the meeting place for the rare disease community, which took place in April attended by The Ehlers-Danlos Society Community and Advocacy Director.

"This is truly an exciting and hopeful time for genetic disorders! I participated in discussions about Rare Disease research, how to recruit more doctors and researchers to the Rare Disease space for earlier diagnosis and treatment, and how to get insurance to cover gene therapy and orphan drugs."

The Ehlers-Danlos Society met with EURODIS (The Voice of Rare Disease Patients in Europe) and NORD (National Organization for Rare Diseases) and was filmed by checkrare.com for a rare disease research fundraising campaign sent to their database of tens-of-thousands of doctors, discussing the Ehlers-Danlos syndromes and the work of The Ehlers-Danlos Society. The Society also met with the Head of the Organization for Rare Diseases India, which represents 93 million people throughout their organization.

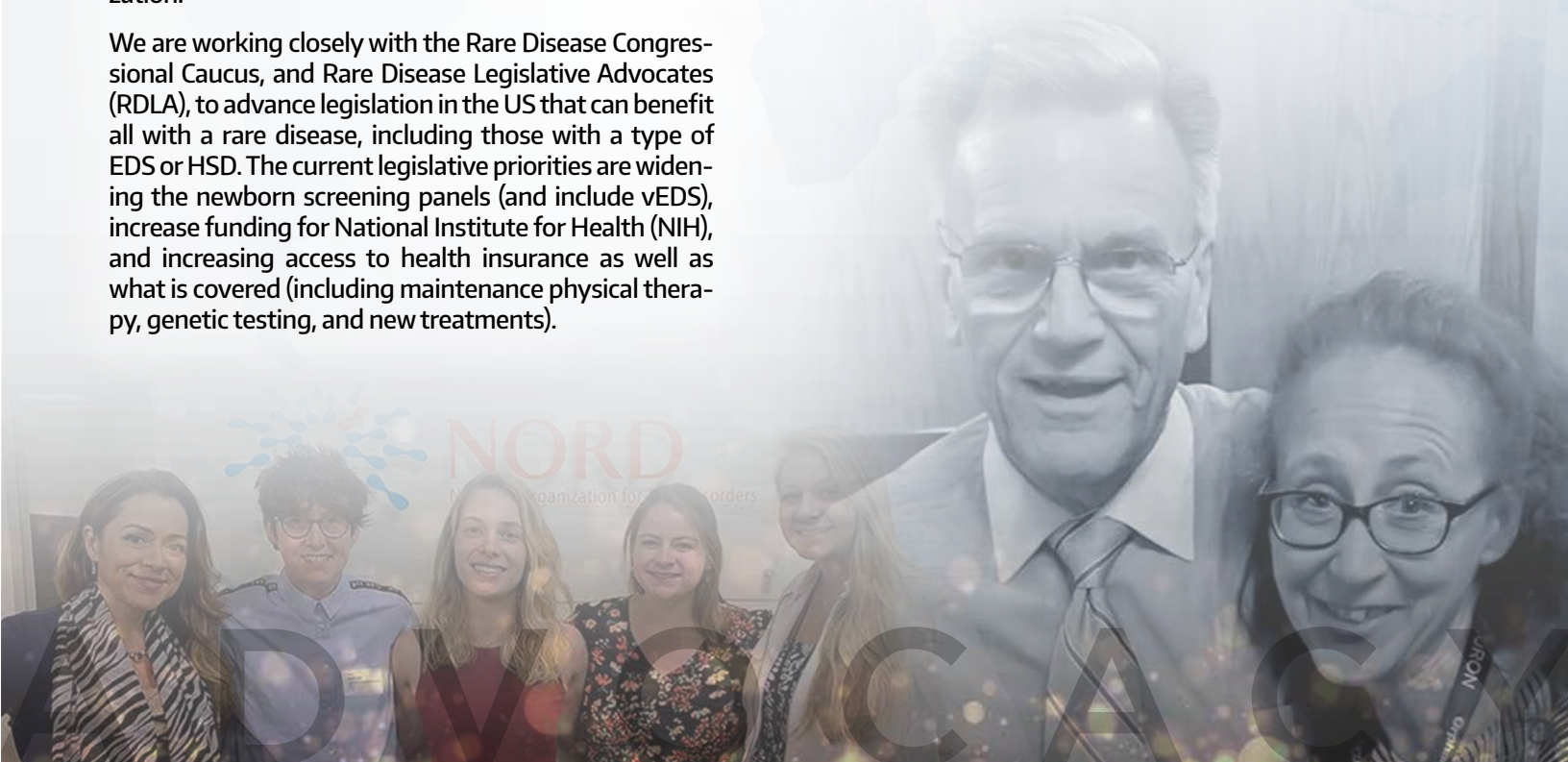
We are working closely with the Rare Disease Congressional Caucus, and Rare Disease Legislative Advocates (RDLA), to advance legislation in the US that can benefit all with a rare disease, including those with a type of EDS or HSD. The current legislative priorities are widening the newborn screening panels (and include vEDS), increase funding for National Institute for Health (NIH), and increasing access to health insurance as well as what is covered (including maintenance physical therapy, genetic testing, and new treatments).

DIAGNOSIS & MANAGEMENT OF SYNDROMES OF THE CRANIOCERVICAL JUNCTION & ROUNDTABLE DISCUSSION

The situation around the world for those living with Chiari malformation and cervical instability has been extremely challenging, with delays in diagnosis, lack of access to MRI imaging, treatment and care, and many needing to self-fundraise to travel abroad for surgery.

The Ehlers-Danlos Society was delighted to partner with the Bobby Jones Chiari & Syringomyelia Foundation to bring together a day of global experts, to talk about the current knowledge and understanding in surgical and conservative management recommendations for hypermobile patients with these issues. The aim of the roundtable was to encourage a way forward for individuals living with these conditions around the world, that treatment, management, and care, could be an option.

Both organizations have been working internationally to improve the care and management in these areas and were excited to bring their experience to London at The Royal Society of Medicine on September 13, 2019, with health professionals, medical students, and key organizations in attendance.



THE EHLERS-DANLOS SOCIETY

ADVOCACY

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC. (NORD)

Rare Diseases and Orphan Products Breakthrough Summit.

Social determinants of health in rare diseases, exploring some of the current inequities and bias in access to diagnosis and care, and how they are being addressed were key on the agenda of the NORD Summit in October 2019. President and CEO for The Ehlers-Danlos Society introduced EDS ECHO to key stakeholders: a revolutionary program that seeks to support health professionals around the world in caring for patients with Ehlers-Danlos syndromes and hypermobility spectrum disorders.

VOLUNTEERS OF THE EHLERS-DANLOS SOCIETY REPRESENT THE COMMUNITY AT THE CIPM POLICY CONGRESS

The Ehlers-Danlos Society remains committed to reducing the pain of our community.

Towards this goal, volunteers of The Ehlers-Danlos Society have been participating in the Comprehensive Integrative Pain Management Policy Congress.

This engagement with other organizations is particularly important to ensure that the unique pain management concerns of people with the Ehlers-Danlos syndromes, and hypermobility spectrum disorders, are represented as comprehensive integrative pain management (CIPM) guidelines are considered.

The CIPM Policy Congress recognizes chronic pain as a complex illness, often co-existing with other conditions such as sleep and mood disorders, and requiring treatment that is multi-modal, patient-centered, individualized, and team-based. Ample evidence demonstrates CIPM's effectiveness in reducing pain and improving function, but the work of the CIPM Policy Congress is critical to making CIPM accessible to zebras everywhere.



ADVOCACY

THANK YOU CELEBRITIES

REACHING NEW HEIGHTS OF AWARENESS

Throughout 2019 several celebrities shared that they have EDS, and we are so grateful for their bravery sharing their stories which elevated the public's awareness of these conditions.

Thanks to Sia, Jameela Jamil, Baroness Nicola Blackwood, Lena Dunham, Yvie Oddly, and Sophie Hulme for proudly joining our Zebra Dazzle and spreading EDS and HSD awareness with their fans and media outlets around the world.

The Ehlers-Danlos Society was thrilled to present actress and activist, Jameela Jamil, with the Patient Advocate of The Year.

"I am sorry it took me so long to speak publicly about my condition. I think I was afraid of being discriminated against, and I think I feel, I felt, discouraged by how little information there is about it publicly."

"So many people have it, and so many more people than we realize as they don't know the symptoms because the symptoms aren't being discussed on mass. I hope to do my part to raise awareness and encourage more research, and more science, around discovering how we can support people of this community."

British fashion designer Sophie Hulme closed down her namesake handbag label in December 2019 due to health reasons.

"My conditions are rare and very few people understand them. Some people suffer far more than me and many remain undiagnosed. I can't imagine how isolating that must be. I hope that, in some way, by raising awareness we can help them."

The Sophie Hulme company donated 10% of the proceeds, from sales of her final collection, to The Ehlers-Danlos Society and Kleine Levin Syndrome Support.

Sophie also partnered with luxury e-tailer THE OUTNET to retail a curated selection of past season styles, with THE OUTNET donating 10% of their proceeds to the same two charities.



SUPPORT

GOING GLOBAL SUPPORTING OUR DAZZLE ALL OVER THE WORLD

Supporting our communities worldwide, and educating health professionals to diagnose, care for, and treat them is at the heart of what we do, and, in 2019 our community grew substantially.

Inspire SM | OVER
75,000
MEMBERS



OVER
2,700
HELPLINE EMAILS ANSWERED



FREEPHONE INTERNATIONAL
HELPLINE NUMBERS IN
28 COUNTRIES



RECEIVED OVER
440 HELPLINE CALLS IN 2019



10-15% OF HELPLINE CALLS
ARE FROM MEDICAL PROFESSIONALS
SEEKING ADVICE & RESOURCES FOR
PATIENTS

“

“Thank you so much, for your response! I have an appointment scheduled with a geneticist regarding another issue in the coming months so this should be a good opportunity to also ask about EDS. I will also look at the links to the support groups and local providers to help with more direction. Your explanation of tackling the pain from a holistic approach is really helpful.”

“The resources you provided seem to cover the issue from multiple perspectives and I look forward to delving into them. I am so appreciative of your thorough response and for helping people find relief, resources, and answers to their difficulties related to this condition!”

“With Kindest Regards,
Michelle”

”

In an effort to bring support to everyone, The Society also launched several virtual online support groups in 2019 that meet monthly and quarterly to provide support to our virtual and global community.

FUNDED RESEARCH

RESEARCH IS AT THE CENTER OF WHAT WE DO.

In 2019 we funded \$344,020 in research grants to improve our understanding of topics with profound impacts on those with EDS and HSD: diagnosis, pain, life-threatening vascular complications, and genetic evaluation.

DR. SHERENE SHALHUB & DR. PETER BYERS

University of Washington | Seattle, Washington, USA

Outcomes of aortic and arterial surgical interventions in individuals with Vascular Ehlers-Danlos Syndrome.

\$75,000

Dr. Sherene Shalhub and Dr. Peter Byers were awarded \$75,000 for their project, "Outcomes of aortic and arterial surgical interventions in individuals with Vascular Ehlers-Danlos Syndrome." The two will lead a team of researchers conducting a thorough review of 1,000 vascular EDS patient medical records from multiple clinicians to assess the effectiveness of a variety of approaches used to help vEDS patients prevent, survive, and recover from life-threatening vascular events.

DR. MARINA COLOMBI

University of Brescia | Brescia, Italy

Proteome profiling for hypermobile Ehlers-Danlos syndrome/hypermobility spectrum disorders to unravel pathogenetic mechanisms and identify potential biomarkers supporting clinical diagnosis.

\$50,000

Dr. Marina Colombi's team received \$50,000 for "Proteome profiling for hypermobile Ehlers-Danlos syndrome/hypermobility spectrum disorders to unravel pathogenetic mechanisms and identify potential biomarkers supporting clinical diagnosis," which will examine skin samples from individuals with hypermobile Ehlers-Danlos syndrome (hEDS) and HSD in an effort to better understand how hEDS and HSD alter connective tissues, with the goal of identifying recognizable differences that can help definitively diagnose individuals with these conditions as well as point towards potential treatment and intervention strategies.

PROF. FRANSISKA MALFAIT

University of Ghent | Ghent, Belgium

Exploring Causal Pathways for Chronic Musculoskeletal Pain in the Ehlers-Danlos syndromes.

\$75,000

Prof. Fransiska Malfait was granted \$75,000 to lead her team in "Exploring Causal Pathways for Chronic Musculoskeletal Pain in the Ehlers-Danlos syndromes," which will investigate both humans with hEDS and cEDS, as well as mice with cEDS, in a two-pronged approach to better understand how pain manifests in these conditions on a molecular level and determine if these findings might be able to inform new diagnostic or treatment approaches.

DR. RAYMOND DALGLEISH

University of Leicester | Leicester, UK

Refine and improve the Ehlers-Danlos Syndrome Variant Database.

\$75,000

Dr. Raymond Dalgeish was awarded \$75,000 to refine and improve the Ehlers-Danlos Syndrome Variant Database, which has been collecting sequencing data from Ehlers-Danlos syndromes research for over 30 years. This collaborative database is widely used worldwide by both clinicians and researchers but has limited use in its current, outdated form.

DR. CHRISTINA M. LAUKAITIS

UAHS Center for Applied Genetics and Genomic Medicine

Examining global gene expression in skin biopsies from people with hypermobile EDS

\$69,020

Hypermobility Ehlers Danlos Syndrome (hEDS) is the most common of the 13 EDS subtypes. It is also the only subtype without identified causative genes. This study supports analysis of gene expression (RNAseq) in people with hEDS compared with normal controls. The goal is to identify genes that are differentially expressed in hEDS, thus pointing to relevant pathogenic processes and supporting candidate genes found in whole genome sequencing.

 **\$344,020**

IN FUNDED RESEARCH GRANTS IN 2019

 **\$2,000,000**

PLEDGED FOR THE HEDGE STUDY

RESEARCH

COLLABORATIVE

INTERNATIONAL RESEARCH

The Ehlers-Danlos Society is bringing together medical professionals from all over the world to work on ground-breaking management and care.

We need to understand the true prevalence of the Ehlers-Danlos syndromes and hypermobility spectrum disorders worldwide. We need as much data as possible to better understand the different sub-types and their varying, multi-systemic impact on patients.

The Ehlers-Danlos Society EDS and HSD Global Registry is a collection of standardized health information provided by thousands of patients with all forms of EDS and hypermobility spectrum disorders (HSD), allowing researchers to compare and analyze patient data on a much larger scale than possible in individual

THE EHLERS-DANLOS SOCIETY EDS & HSD GLOBAL REGISTRY

research studies alone. The Registry has the potential to unlock countless discoveries about all forms of EDS and HSD and lays the groundwork for large-scale research efforts. Given the different ways in which the Ehlers-Danlos syndromes and hypermobility spectrum disorders can present, it will also help us to raise awareness and support clinicians to recognize signs and symptoms more effectively.

The registry will also provide new opportunities for research, including identifying links between EDS and HSD and other conditions. Without this understanding, patients will continue to be mistakenly diagnosed or undiagnosed.

The Ehlers-Danlos Society launched the EDS and HSD Global Registry in late summer 2018, and it grew to nearly 8,500 participants from 78 countries in 2019. This is the first time that there will be the information in one place to help researchers throughout the world to map the experiences of those living with EDS and related disorders, to enable the gene search for hEDS and HSD, to facilitate research into the frequency of related symptoms and conditions, and to discover new forms of EDS and HSD. Participation is free to all, with global access available — no matter where you live — and more languages will be available soon.

A huge thank you to every participant who will help researchers to advance our understanding of EDS, HSD, and related symptoms and conditions.



HEDGE

\$2,000,000 PLEDGED FOR THE HEDGE STUDY

In 2018, the groundbreaking Hypermobile Ehlers-Danlos Genetic Evaluation (HEDGE) was launched. Never before has there been a worldwide collaborative effort of this magnitude devoted to finding the underlying genetic markers for hypermobile EDS (hEDS).

Since the announcement of the extraordinary “Moon-shot” pledge in early 2018, which was then followed by another generous pledge in early 2019, The Ehlers-Danlos Society brought together a highly experienced international group of physicians, geneticists, and technical volunteers to form the **Hypermobile EDS Genetic Research Network**, (HEDGE) dedicated to finding the genetic cause, or causes of hEDS.

Of the 14 subtypes of the group of connective tissue disorders known collectively as the Ehlers-Danlos syndromes (EDS), only the hypermobile type does not yet have identified genetic markers.

“To find preventions and treatments for hEDS, we have to understand the cause. Genetic studies like this one provide a path towards that goal,”

said Joel Hirschhorn, MD, PhD, Concordia Professor of Pediatrics and Professor of Genetics at Boston Children’s Hospital/Harvard Medical School, and a member of the Hypermobile Genetic Research Network.

Starting in 2019, the HEDGE study has been recruiting, screening, and undertaking genetic sequencing tests on 1,000 individuals who have been diagnosed with hypermobile EDS by the most recent clinical criteria established in 2017.

The HEDGE study would not be possible without The Ehlers-Danlos Society EDS and HSD Global Registry. All potential study participants must first join The Ehlers-Danlos Society EDS and HSD Global Registry.

THE EHLERS-DANLOS SOCIETY EDS & HSD GLOBAL REGISTRY



413

participants enrolled
into HEDGE in 2019
towards a goal of 1,000



THE EHLERS-DANLOS SOCIETY

EDS & HSD RESEARCH ROADMAP

THE EHLERS-DANLOS SOCIETY RECEIVES **\$1,000,000** DONATION TO ADVANCE RESEARCH

In November 2019, The Ehlers-Danlos Society was delighted to announce an anonymous gift of \$1,000,000 to advance research within EDS, HSD, hypermobility spectrum disorders (HSD), and associated symptoms and conditions.

This generous donation set the foundation for vital research and enabled The Ehlers-Danlos Society, in conjunction with The EDS and HSD International Consortium, to establish and build the foundations and focus for future research priorities, proposals, and investments. The research roadmap presents a long-term action plan for the prioritization of EDS and HSD as focal points for research, worldwide, providing opportunities to enhance the speed and effectiveness of research.

We aspire to offer grants annually, with calls for clinical research proposals early in the year and for basic science later in the year.

“People living with EDS and HSD, need and deserve research: the advancement of research and ultimately patient care, is so vitally needed. We are so pleased that this donation can lay the foundations for this research program, and we hope this enables others to work with The Ehlers-Danlos Society to drive this forward.”

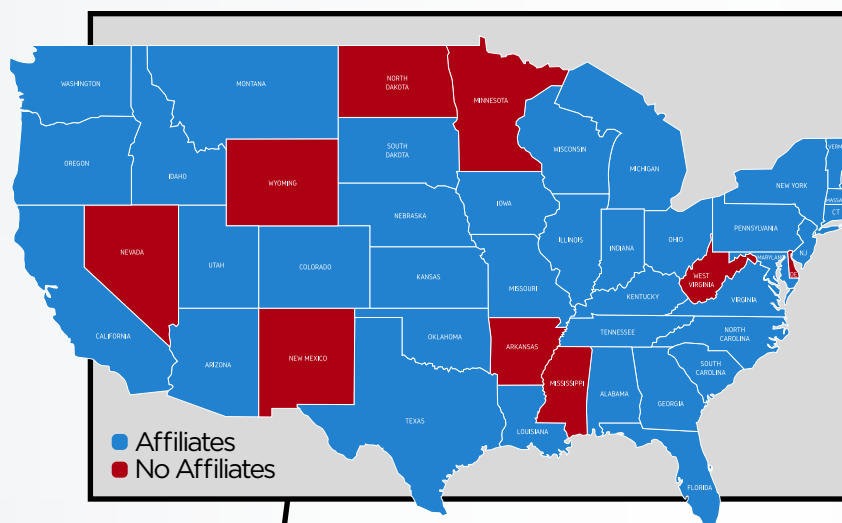
- anonymous donor

THE EHLERS-DANLOS SOCIETY

GLOBAL AFFILIATE PROGRAM

The Ehlers-Danlos Society collaborates through its Global Affiliation Network to expand outreach, programming, and collaborative efforts with outstanding regional and local support groups, charities, and societies.

These affiliates work toward a future where everyone living with EDS, HSD, and related disorders can receive the care and support they need through wider awareness in the medical and general communities, expanded research efforts, and improved medical care.



Affiliate
THE EHLERS-DANLOS SOCIETY

2019
57 Affiliates
2018
28 Affiliates



THE EDS & HSD

COMORBIDITY COALITION



The Comorbidity Coalition brings together clinicians and researchers from:

- Chiari and Syringomyelia Foundation
- Dysautonomia International
- International Consortium on EDS & HSD
- Mastocytosis Society
- ME Action
- Penn State University
- Spinal CSF Leak Foundation
- The Coalition Against Pediatric Pain
- The Kennedy Forum
- The Pain Community

Their research priorities for people with EDS and HSD are:

- The effectiveness of local anesthetic
- The impact sex hormones have on symptoms in HSD & EDS
- Vagus nerve stimulation for gastrointestinal function

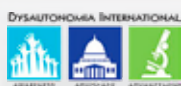


Dr. Satish Raj, University of Calgary, Canada, and a member of the coalition began a study looking at the response to different local anesthetics in individuals with EDS. The study started at the Ehlers-Danlos Society Global Learning Conference, Nashville 2019, and is looking for additional funding to recruit more people to the study.

Groups outside the Consortium have commenced looking at vagal nerve stimulation.



DEFY FOUNDATION



COMORBIDITY COALITION



The Coalition focus beginning in 2019 was the development of information guides on 12 priority areas.

Work has begun on the first five topics:



**EMERGENCY ROOM
ATTENDANCE**



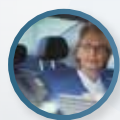
FATIGUE



HEADACHE



PAIN MANAGEMENT



TRAVEL

In addition, the Coalition has identified several areas where there is a need to publish formal peer-reviewed "Accredited Guidelines" that would be recognized by professionals and professional organizations internationally. The first three of these that The Ehlers-Danlos Society is leading on are:

- Diagnostic Pathways for Ehlers-Danlos syndromes
- Pregnancy in EDS and HSD
- Gastrointestinal disorders in EDS and HSD



THE EDS & HSD
Comorbidity Coalition



FUNDRAISING

EDS & HSD MAY AWARENESS MONTH

An incredible number of people from the community joined The Ehlers-Danlos Society in celebrating May as “EDS & HSD Awareness Month!”

Our May Awareness campaign, #myEDSChallenge / #myHSDchallenge, asked people to spread awareness by completing a challenge (or as many as they could!) during the month of May.

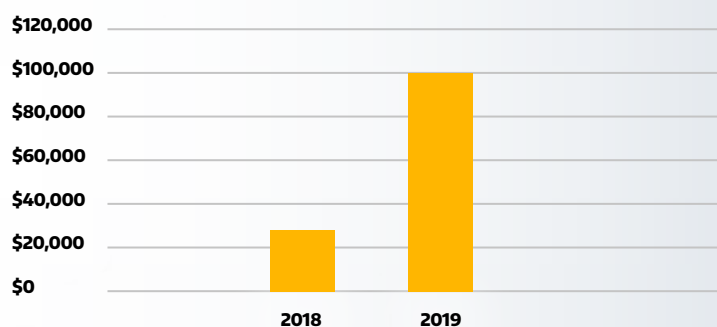
A variety of individual and group challenges were suggested to suit different hobbies, interests, and abilities, as well as tools and resources to make it fun and easy to spread EDS and HSD awareness to friends, family, and local communities. Individuals who raised \$40 or completed/won Daily Challenge Competitions earned a limited edition T-shirt!

“At our performing arts studio we explained to every student and their parents, how EDS affects two of our staff members. We also gave everyone the homework of researching EDS/HSD, and the next time they see us (the following week) they had to explain what they had learnt! We asked them to explain what they have learnt to their friends at school too!”

“We covered our dance studio in posters about EDS/HSD and put print outs of zebras in random spots around the whole building so people would ask ‘why are there zebras around?’”

OVER
450
ONLINE FUNDRAISERS

COMMUNITY DONATIONS



/heds_tales

Many restaurants (both chains and local), as well as local shop vendors, like to participate in charity days. Thank you to Chrystal Nichols who held a fundraiser at her local pizza parlor with a portion of proceeds going to The Ehlers-Danlos Society.

"My son Erhan, age 14, was diagnosed with hEDS and PoTS in 2018. He chose to challenge himself walking over Up at The O2 in London and he smashed his fundraising goal! We were so proud as his knees were a problem."

"We had SUCH a great time and amazing turn out for Zenendipity's Painting for a Purpose event! Stripes were painted, and money was raised for The Ehlers-Danlos Society to further research and awareness about Ehlers-Danlos syndrome and HSD!"

FUNDRAISING

EDS & HSD MAY AWARENESS MONTH

A proclamation is a formal public statement and an official announcement of EDS and HSD Awareness Month in your local area.

38 individuals around the world made May officially EDS and HSD Awareness Month in their state, city, or other local government by taking part in the Proclamation Challenge!

"I care so much about being an advocate for EDS and HSD, and for individuals with these conditions.

"My focus as an advocate is going to be on complex issues-chronic illness and pain, high-risk pregnancies, end-of-life planning, hospice and helping people navigate preparing for Social Security disability."

Ashton Nesmith-Kochera



FUNDRAISING

CARNIVAL SUNRISE

RAISING AWARENESS ON LAND & AT SEA!

In May 2019 Carnival Cruise Lines honored The Ehlers-Danlos Society at their annual naming ceremony.

The Ehlers-Danlos Society is honored to have been in attendance at the launch of the Carnival Cruise Line's newly renovated Carnival Sunrise. The ship's new godmother, Kelly Arison, daughter of Carnival Corporation Chairman Micky Arison and his wife Madeleine, chose to raise awareness for The Ehlers-Danlos Society at this event.

Kelly Arison is a strong advocate of the Ehlers-Danlos syndromes and hypermobility spectrum disorders, awarding The Ehlers-Danlos Society with a check for \$50,000 in a presentation ceremony.



"We are blown away by the generosity of Carnival Cruise Line for choosing The Ehlers-Danlos Society for this incredible honor and for an amazing donation of \$50,000 to help us in our global mission," stated Lara Bloom, President and CEO of The Ehlers-Danlos Society. **"Spotlighting the Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD) at the Carnival Sunrise's naming ceremony helps us sail farther on our journey towards worldwide awareness, and better quality of life for all who live with these conditions. We can't thank Kelly and the Arison family enough for their support."**



FUNDRAISING

END OF YEAR CAMPAIGN

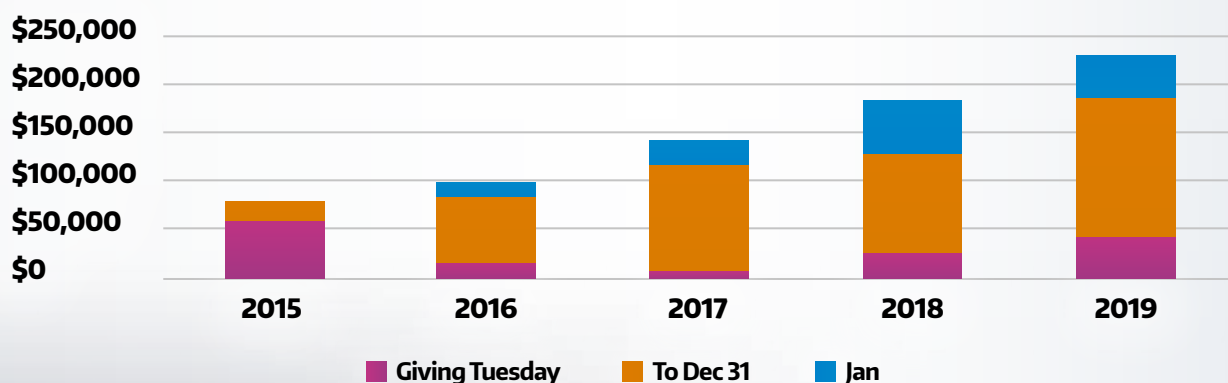
THANK YOU FOR A
DAZZLING
YEAR

The End of Year campaign provided a platform to thank our community and provide updates on the great strides made in 2019 toward our shared mission.

Giving Tuesday is a global day dedicated to giving back, and uniting our community for our common goal.

Thanks to the generosity of our donors, we raised an incredible **\$42,349** to advance research, education, awareness, and support of those living with EDS and HSD – and the myriad related symptoms and conditions they face each day.

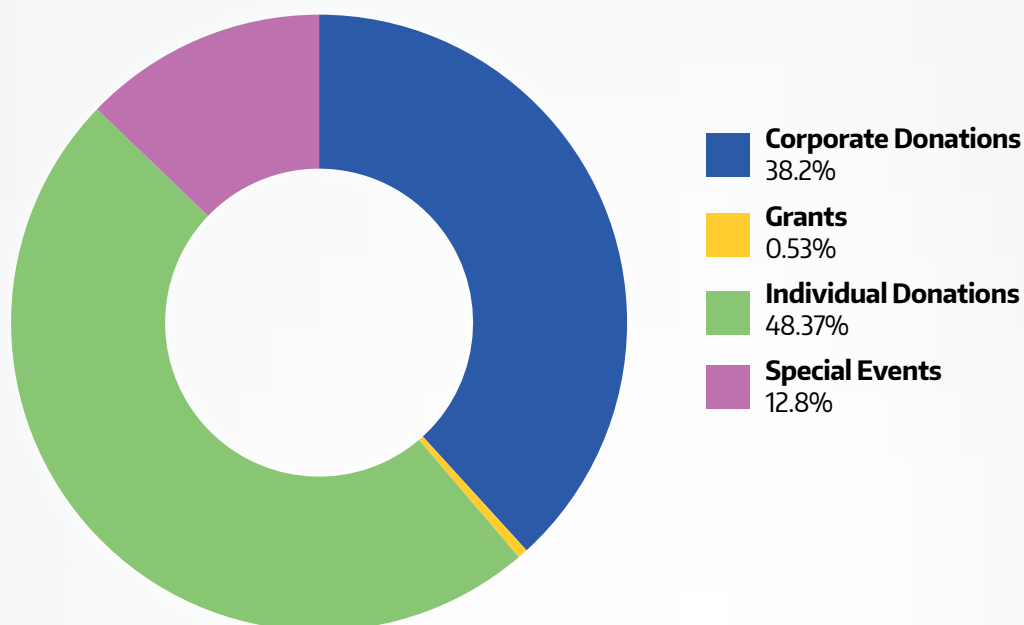
EOY CAMPAIGN HISTORY



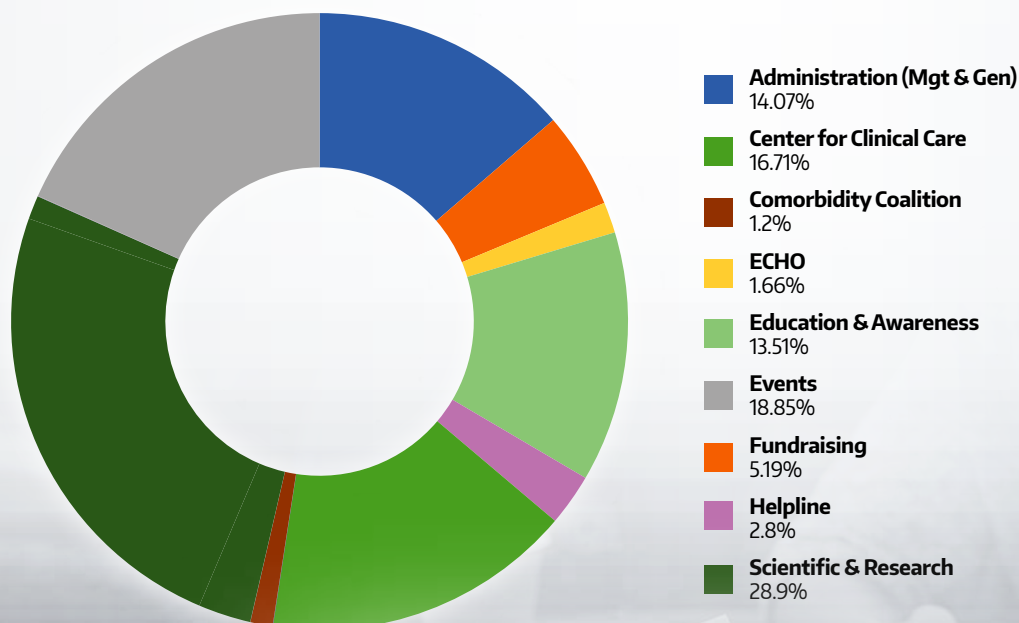
THE EHLERS-DANLOS SOCIETY

REVENUES & EXPENSES

INCOME



EXPENSES



These financial reports are for The Ehlers-Danlos Society US in the year ending December 31, 2019 based on GAAP accrual accounting standards, and have not yet been audited.

STATEMENT

THE EHLERS-DANLOS SOCIETY

FUNDING OUR MISSION

LOOKING
FORWARD TO A
**POSITIVE
FUTURE**
FOR OUR COMMUNITY...

Each gift strengthens research, education, advocacy, awareness, and support – worldwide.

The new decade will bring more global events, translated materials into multiple languages, a brand new accessible website, more research grants than ever before, more educational efforts with EDS ECHO, more virtual support in the form of webinars and support groups and live streaming – all taking us closer than ever before to a time when geography and wealth no longer determine your quality of life.

A time when diagnosis comes when symptoms begin, not decades later. Our community deserves so much, and The Society is here to ensure they get it. **This cannot be done without you, and we are so grateful for your support in making this possible.**

Together, we can continue to advance **research**, **awareness**, **education**, and **support** for all those living with EDS, HSD, and related conditions everywhere around the world.



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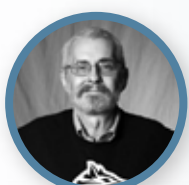
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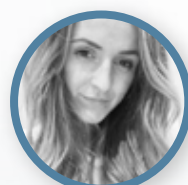
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