The Ehlers Danlos Society

# IMPACT REPORT 2022

JANUARY 1 - DECEMBER 31, 2022

CARE ACCESS RESEARCH EDUCATION

# LETTER FROM THE PRESIDENT & CHAIR OF THE BOARD OF DIRECTORS

Dear Supporters and Contributors,

We are thrilled to present to you the annual impact report for The Ehlers-Danlos Society.

It is with immense gratitude that we share the achievements and progress made in advancing Care, Access, Research, and Education for individuals affected by the Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD), worldwide. None of this would have been possible without your generous support and dedication to our shared mission.

Throughout the year, we have witnessed significant milestones in our efforts to improve the lives of those living with EDS and HSD and their families. We have remained committed to enhancing awareness, supporting the community, collaborating with medical professionals and researchers, and funding groundbreaking research. Each section of this report will provide an overview of the impactful work carried out by our organization in various domains.

We extend our deepest gratitude to the volunteers, medical professionals, researchers, donors, and all those who have contributed their time and resources. Together, we have made a profound difference in the lives of individuals with EDS and HSD, and we look forward to continuing our journey toward a better future.

With sincere appreciation,

Professor Lara Bloom, President and CEO, The Ehlers-Danlos Society

Susan Hawkins, Chair of the Board of Directors, The Ehlers-Danlos Society

The Ehlers Danlos Society

# CARE

## Helpline

Our Helpline has been an invaluable resource for individuals affected by EDS and HSD, providing vital information, support, and guidance.

Over the past year, our dedicated team has answered thousands of emails and calls, offering compassionate assistance to those in need. The Helpline has become a lifeline for community members, caregivers, and healthcare professionals seeking reliable information and emotional support.

We remain committed to expanding and improving our Helpline services, ensuring that no one faces the challenges of EDS and HSD alone.

Our ongoing aim is to provide support and information to best equip people with the knowledge they need to improve quality of life.

Frequently asked questions asked on the helpline include:


"How do I get diagnosed with a type of EDS or HSD?"

"How can I manage pain?"

"How can I manage the symptoms I have?"

"What kind of accommodations are best for school & work?"

"How can I find a doctor?"

"How can I support my family member?"

C A R E

The Ehlers Danlos Society

# Virtual Support Groups

Virtual support groups play a crucial role in supporting individuals living with chronic illnesses such as EDS and HSD.

Accessibility: Virtual support groups break down geographical barriers and make it easier for individuals to access support from the comfort of their own homes. This is particularly beneficial for those with mobility limitations or who live in remote areas with limited access to in-person support groups.

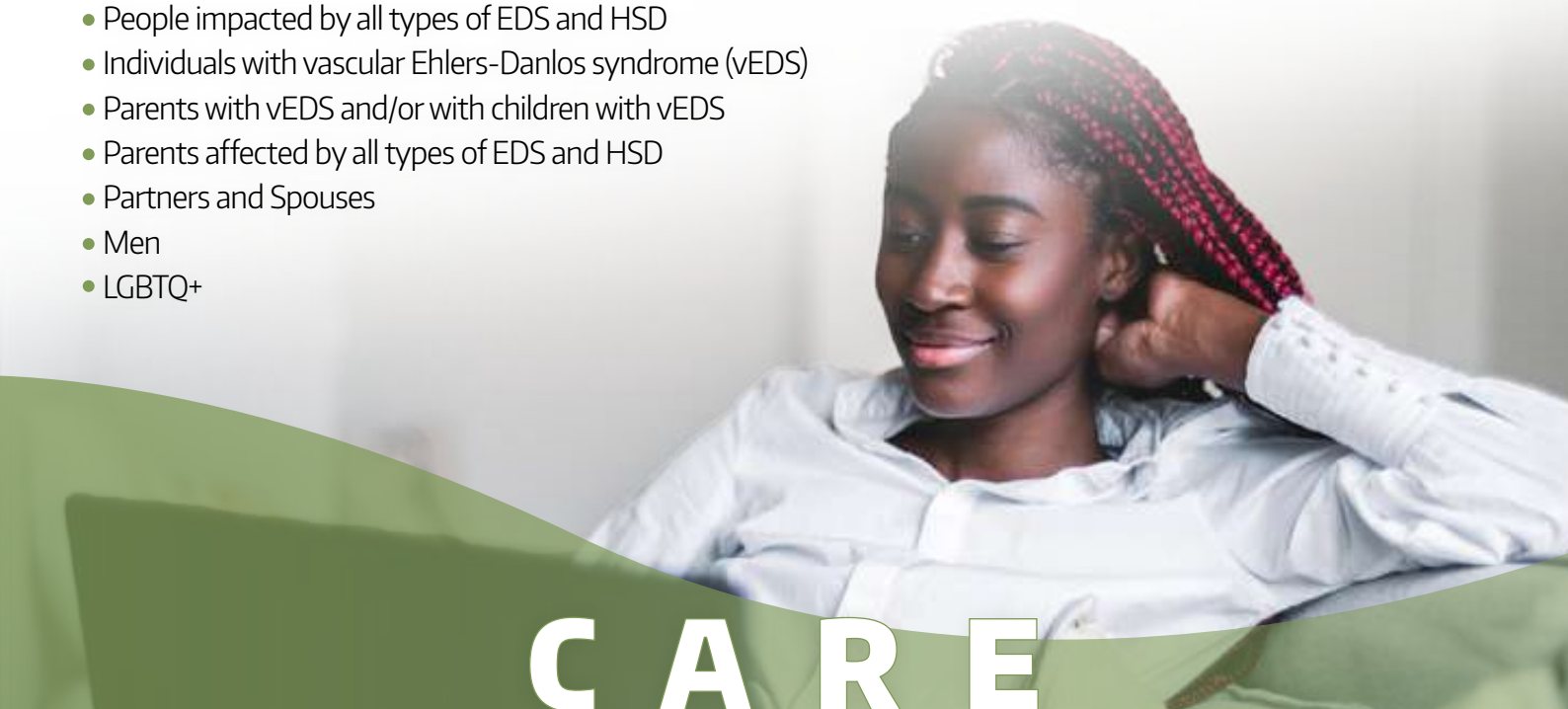
Connection and Understanding: Living with a chronic illness can be isolating, and virtual support groups provide a sense of community and connection. Participants can interact with others who share similar experiences, challenges, and emotions. This understanding and empathy from fellow group members can help reduce feelings of loneliness and provide validation for their struggles.

Emotional Support: Chronic illnesses can take a toll on an individual's mental and emotional well-being. Virtual support groups offer a safe space where participants can express their emotions, vent their frustrations, and seek comfort. Being part of a supportive community that understands the challenges of living with a chronic illness can provide a source of strength, encouragement, and validation.

Virtual support groups provide a valuable avenue for individuals living with chronic illnesses to connect, learn, share, and find solace in a community of understanding peers. The combination of emotional support, access to information, and empowerment can significantly enhance their well-being and ability to navigate the challenges associated with their condition.

In 2022, The Ehlers-Danlos Society increased the number of virtual support group meetings by over 20% to help meet the needs of the community. New groups were held for kids and teens, alongside regular meetings for:

- People impacted by all types of EDS and HSD
- Individuals with vascular Ehlers-Danlos syndrome (vEDS)
- Parents with vEDS and/or with children with vEDS
- Parents affected by all types of EDS and HSD
- Partners and Spouses
- Men
- LGBTQ+



Over **121 meetings** were held throughout 2022, with attendees joining from all around the world including **Colombia**, **Japan**, **Germany**, **South Africa**, **Russia**, **Switzerland**, **Sweden**, **Denmark**, **the UK**, **Canada**, **Turkey**, **Brazil**, **and all over the USA**! Many were meeting someone living with EDS or HSD for the first time.


Commonly discussed topics included:

- How to treat pain and symptoms
- How to make family members/friends/schools/ employers understand
- How to have effective doctor appointments
- How to find doctors/seeking recommendations

The Ehlers-Danlos Society's 2023 Global Learning Conference will focus on "Difficult Conversations in EDS and HSD," and leading experts will cover the above topics and more with feedback from the virtual groups informing discussions.

## Connecting With Community

Connection is everything when living with a chronic or rare disease. Some people have never met or spoken to another person living with the same type of EDS or HSD. Some of the rarer types of EDS affect a small number of families around the world. A lack of research and evidenced-based insights means families often wish to connect with others to understand how their conditions have affected them, and how they are coping, and living with quality of life.

The Ehlers-Danlos Society's Inspire messageboard is the most engaged community on the Inspire platform, with **118,000 members from more than 150 countries**.

Conversation and connection are fostered through social media, across Facebook, Instagram, Twitter, LinkedIn, and YouTube.

The Ehlers Danlos Society

## Reaching Out to Our Youth Community

The Ehlers-Danlos syndromes and hypermobility spectrum disorders are genetic disorders, and individuals can be symptomatic from birth. With earlier diagnosis and intervention, and with support networks and a "Zebra Strong" community, our Junior Zebras can thrive!

Many spend years coping alone with symptoms, missing out on social occasions, schooling, or hobbies, and not being able to express the grief and frustration they feel. For children, teens, and young adults affected by rarer types of EDS, there may also be life-limiting complications.

The Ehlers-Danlos Society wants to ensure the Junior Zebras, teens, and young adults in our community feel supported and have the resources, tools, and opportunities they truly deserve.

In 2022, the foundations were laid for a dedicated youth program to deliver support services for children and adolescents with EDS and HSD. Junior Zebra tracks at our global conferences, and support groups for ages 6–12 and 13–17, offered opportunities for connection with others, and to talk about their experiences in a non-medical setting.

The all-new youth program will review access to age-appropriate resources and support services, identifying where we can improve and develop events, support groups, website information, and community-building activities. With your support, we can provide life-changing resources to support children and youth worldwide, in multiple languages, and in engaging and inclusive mediums.

We are also excited to be planning and fundraising to hold family camps. With your support, our goal is to welcome children, adolescents, and families living with all types of EDS and HSD in a safe and secure camp environment.

In 2023 we will host our first fully-funded family camp for individuals and families impacted by vascular Ehlers-Danlos syndrome at Camp Joy, Ohio, USA.

The Ehlers Danlos Society

# ACCESS

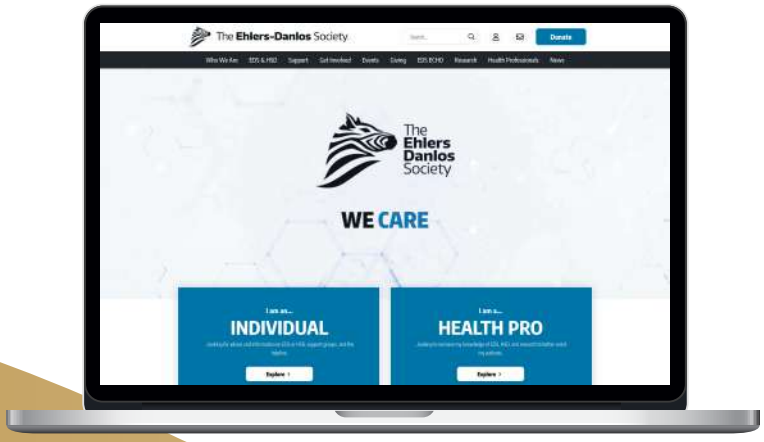

## New Website: www.ehlers-danlos.com

To further our commitment to making information accessible, we introduced new features including:

- A health professionals directory to make it easier to find a doctor or therapist with knowledge on EDS and HSD.
- A local support groups and organizations directory to connect people to local support and our Global Affiliates.
- Website accounts to easily access resources and video recordings.
- Tailored user journeys for health professionals and community members to access information specific to them, quickly and easily.

New website content was introduced specific to each type of EDS and HSD, which will grow and evolve to provide type-specific support and resources. The Ehlers-Danlos Society continues to work with the International Consortium on EDS and HSD, to provide the latest evidenced-based information to the community.

The Medical Professionals Directory has been a crucial resource connecting individuals with knowledgeable and experienced healthcare providers. We have expanded the directory to include a diverse range of medical specialties and regions, ensuring that patients have access to EDS and HSD experts worldwide. By facilitating these connections, we aim to improve diagnostic accuracy, quality of care, and the overall well-being of individuals affected by these disorders.



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## Global Centers and Networks of Excellence Vision: Multi-Disciplinary Team Care Around the World

The Ehlers-Danlos Society is committed to increasing the availability of clinical services for people living with EDS and HSD, decreasing the diagnostic odyssey, and standardizing communication and care for those impacted by EDS and HSD.

Toward those ends, we are developing a global Centers and Networks of Excellence program for EDS and HSD. This will be the first step toward Centers and Networks of Excellence that will assist thousands of people worldwide, and alleviate their pain and symptoms.

## Clinics around the globe

Our goal is to support ten centers initially, and we are looking for donations to support this exciting initiative and make it a reality.

> "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. Our aim is that no matter where you live, you have access to a multidisciplinary team approach," explained Lara Bloom, President and CEO for The Ehlers-Danlos Society.

ACCESS

The Ehlers Danlos Society

## Building a bridge between hope and reality

"We set a goal to learn about how multidisciplinary clinics work around the world, to enable us to use the gathered information as a guideline for developing the EDS Centers of Excellence," said Dr. Clair Francomano, Professor, Medical and Molecular Genetics, Indiana University School of Medicine. "Although only a small number of multidisciplinary clinics exist for EDS and HSD worldwide, we were fortunate to collect invaluable qualitative data from prominent physicians and clinics in Australia, Belgium, Canada, France, Germany, Japan, Sweden, Switzerland, the United Kingdom, and the United States of America."

Alongside the in-person clinic services, telehealth services and a helpline will be integral aspects of the Centers of Excellence. Telehealth systems have proved to be essential during the COVID-19 global pandemic and shown to have the opportunity to greatly increase access to care. Telehealth services within the Center of Excellence clinics will enable patients country-wide and globally to be seen, alongside providing access to care for patients who are seriously ill.

"We want to think past bricks and mortar. We know that in each country and region, centers may look different based on the resources and clinical set-up, and we want this framework to function for all," detailed Lara Bloom.

"Patients might live hundreds of miles away from a Center of Excellence, or for one reason or another, patients may not be able to afford to attend an in-person or on-site appointment. These services will allow physicians to reach out to those who would not receive the medical care they need and deserve because of distance," explained Dr. Isabelle Brock, Visiting Scientist, Medical and Molecular Genetics, Indiana University School of Medicine. "It is crucial to have a helpline, as seen in Switzerland, to which patients can reach out to find clinics around Switzerland as there is not one multidisciplinary clinic."

The Ehlers-Danlos Society's Centers and Networks of Excellence program will ensure critical standards of care with each center required to meet rigorous clinical, research, professional education, and patient care criteria. Geographical, financial, and cultural considerations will advance the highest standards of care to improve the lives of people living with EDS, HSD, and related conditions worldwide.

CENTERS & NETWORKS OF excellence

"We want the goal to be long-term care, for both the physical and the psychological aspects of living with these conditions. Both are essential to ensure that people living with EDS and HSD are offered the best chance at a good quality of life that everyone so richly deserves. We know that is more than diagnosis and tests, it's the language used, it's the tone. It's about someone feeling believed and validated," said Lara Bloom.

Organizations that are interested in becoming a Center or Network of Excellence can register their interest upon launch in 2023.

## Global Affiliation Program

The Ehlers-Danlos Society strives to increase awareness, improve care, and grow community support for people living with EDS and HSD worldwide. Local support groups and charities are working hard to help those with EDS and HSD in their communities throughout the world.

Through The Ehlers-Danlos Society's Global Affiliate Program we work collaboratively to improve the lives of individuals around the world. By uniting, we aim to provide resources and information where they are needed. Our directory enables people living with EDS or HSD to find support services and groups that are near them, and our aim is to provide translated resources to enable them to find care and management locally.

The Global Affiliation Program has 70 members in 19 countries, dedicated to supporting people affected by these conditions.

TOGETHER
**WE DAZZLE**

**ACCESS**

The Ehlers Danlos Society

# RESEARCH

## Funded Research

The Ehlers-Danlos Society remains dedicated to funding innovative research that deepens our understanding of EDS and HSD and paves the way for improved treatments and therapies. Over the past year, we have supported groundbreaking studies across various aspects of these disorders, including genetic research, pain management strategies, and rehabilitation interventions. Our funded research has the potential to transform the lives of millions affected by EDS and HSD.

In 2022, The Ehlers-Danlos Society funded **$1,073,045** in research for our futures.

## Research Grant Program

The Research Grant Program has continued to support promising researchers and investigators in their pursuit of scientific advancements in EDS and HSD. By providing financial assistance and mentorship, we have fostered a vibrant research community focused on unraveling the complexities of these disorders. The outcomes of these grants contribute to the development of effective interventions, increased awareness, and the improvement of clinical practices.

In 2022, The Ehlers-Danlos Society awarded 23 grants to researchers worldwide:

- Research Support - $330K Grant
- Rarer Types of EDS - $200K Grant
- Microgrants Round 1 - $50K Grant
- Microgrants Round 2 - $50K Grant
- Joint Grant from The Ehlers-Danlos Society and The Mast Cell Disease Society - The Mechanisms Behind Hypermobile Ehlers-Danlos Syndrome, Mast Cell Activation Syndrome, and Dysautonomia Grant - $200K Grant
- Research Support - $70K Grant

The Ehlers Danlos Society


# $300K Grant - Research and Educational Support in EDS

## Awardees:

## $150,000

**Primary Investigator:**

Russell Norris
Medical University of South Carolina
Charleston, South Carolina, USA

The funds from this gift/grant will be used to explore new gene candidates for hEDS. By taking the genetic variants that we identified in hEDS patients, we can validate whether these potential mutations (or variants of unknown significance) are relevant to causing hEDS. Through these studies, new models will be generated that will allow us to test how genotype can correlate with phenotype and various co-morbidities found in the patients.

RESEARCH

The Ehlers Danlos Society


# $300K Grant - Research and Educational Support in EDS

## Awardees:

## $150,000

**Primary Investigator:**
Hal Dietz
John Hopkins University
Baltimore, Maryland, USA

Our lab uses mouse models of vascular Ehlers-Danlos syndrome (vEDS) to try to understand the underlying mechanism that drives vascular fragility and rupture. In this manner, we hope to develop new treatment strategies for vEDS.

While substantial progress has been made in defining a list of abnormalities that occur in the walls of arteries in models of vEDS, we lack the ability to assign these abnormalities to specific cell types, or an understanding of how cells send abnormal signals to each other.

We have now launched a comprehensive program to address these issues using state-of-the-art genetic technologies that allow identification of all the genes that are turned on or turned off in thousands of individual cells in the aorta, and to look at how these gene signatures vary based upon the specific location of a given cell, including consideration of what cell types are immediately next door.

This profiling will be performed in vEDS mice that are either vulnerable to having a vascular event or protected based upon manipulation (such as use of a medication). In this manner we hope to identify new drug targets, predict at-risk vascular segments for more frequent imaging or surgical intervention, and identify a protein in the bloodstream (a so-called biomarker) that can help to monitor disease progression or an individual's response to treatment.

We are very excited about this research direction and thankful to
The Ehlers-Danlos Society for the opportunity to perform this work.

RESEARCH

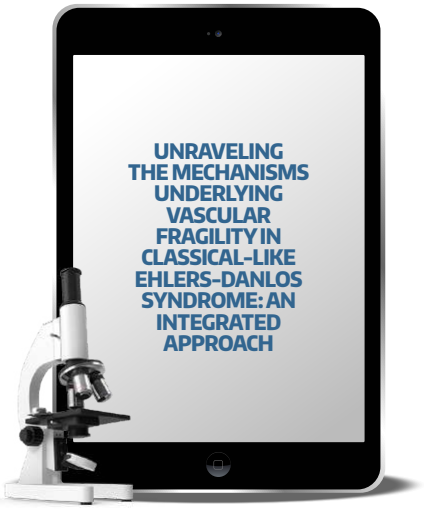
The Ehlers Danlos Society


## $300K Grant - Research and Educational Support in EDS

### Awardees:

**$30,000**

**Primary Investigator:**
Rebecca Bascom
The Pennsylvania State University
Pennsylvania, USA




## $200K Grant - Rarer Types of EDS

### Awardees:

**$80,000**

**Primary Investigator:**
Ulrich Valcourt
University Lyon
Lyon, France

Unraveling the Mechanisms Underlying Vascular Fragility in Classical-like Ehlers-Danlos Syndrome: An Integrated Approach.


**$120,000**

**Primary Investigator:**
Frederico Forneris
University of Pavia
Pavia, Italy

Dissecting the Significance and the Impact of Missense PLOD1 Mutations Causing Kyphoscholiotic Ehlers-Danlos Syndrome.

# RESEARCH

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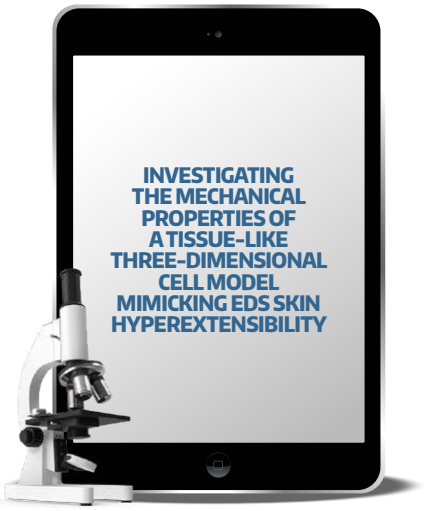


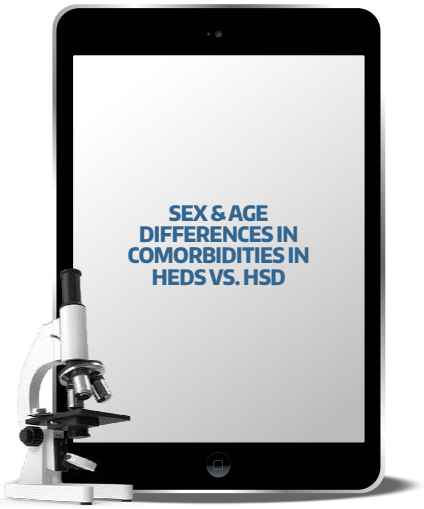

## $50K Grant - Microgrants Round 1

## Awardees:

### $5,000

**Primary Investigator:**
Catherine Bui
Université de Lorraine
France, Nancy

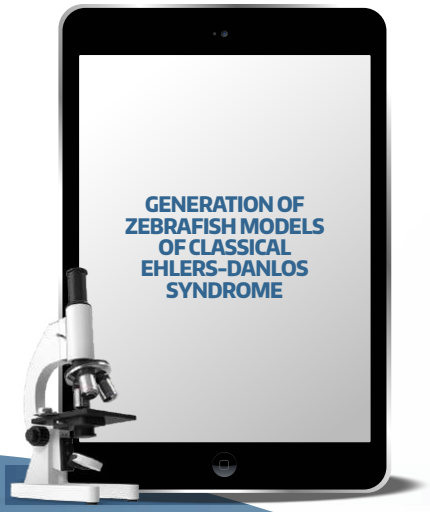
Investigating the Mechanical Properties of a Tissue-Like Three-Dimensional Cell Model Mimicking EDS Skin Hyperextensibility.




### $5,000

**Primary Investigator:**
Dacre Knight
Mayo Clinic
Florida, United States

Sex and Age Differences in Comorbidities in hEDS vs. HSD.




### $5,000

**Primary Investigator:**
Delfien Syx
Ghent University
Ghent, Belgium

Generation of Zebrafish Models of Classical Ehlers-Danlos Syndrome.



# RESEARCH

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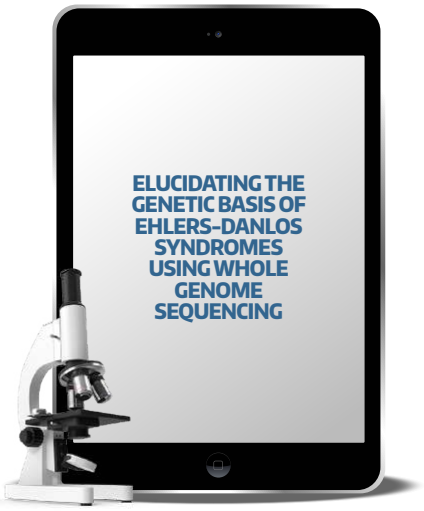



## $50K Grant - Microgrants Round 1

## Awardees:

### $5,000

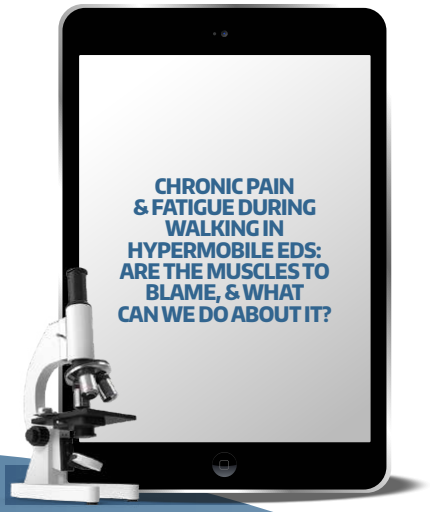
**Primary Investigator:**
Fransiska Malfait
Ghent University
Ghent, Belgium

Elucidating the Genetic Basis of Ehlers-Danlos Syndromes Using Whole Genome Sequencing.


### $5,000

**Primary Investigator:**
Jane Schubart
Penn State College of Medicine
Pennsylvania, United States

Cost of Illness for Ehlers-Danlos Syndromes in the United States: Patient and Family Perspectives.




### $5,000

**Primary Investigator:**
Jared R. Fletcher
Mount Royal University
Calgary, Canada

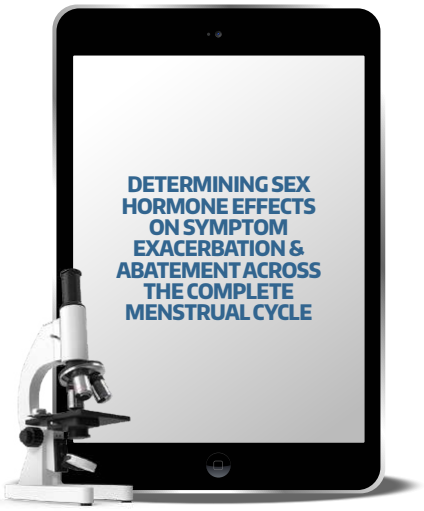
Chronic Pain and Fatigue During Walking in Hypermobile EDS: Are the Muscles to Blame, and What Can We Do About It?

# RESEARCH

The Ehlers Danlos Society

# $50K Grant - Microgrants Round 1

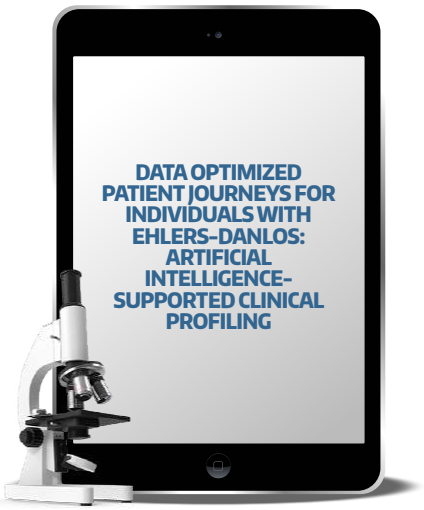
## Awardees:




### $5,000

**Primary Investigator:**
Jennifer Andrews
University of Arizona
Arizona, United States

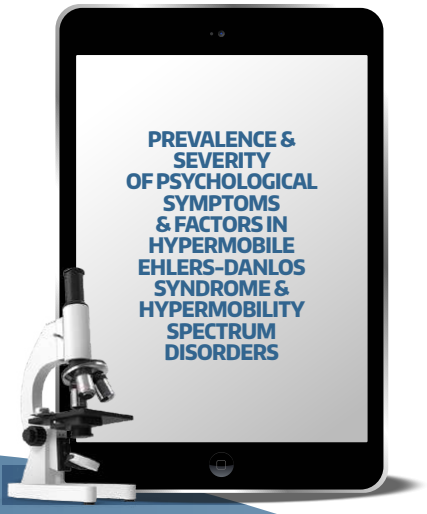
Determining Sex Hormone Effects on Symptom Exacerbation and Abatement Across the Complete Menstrual Cycle.




### $5,000

**Primary Investigator:**
M.C Scheper
Hogeschool Rotterdam
Rotterdam, Netherlands

Data Optimized Patient Journeys for Individuals With Ehlers-Danlos: Artificial Intelligence-Supported Clinical Profiling.




### $5,000

**Primary Investigator:**
Ranita Manocha
University of Calgary
Calgary, Canada

Prevalence and Severity of Psychological Symptoms and Factors in Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders.

RESEARCH

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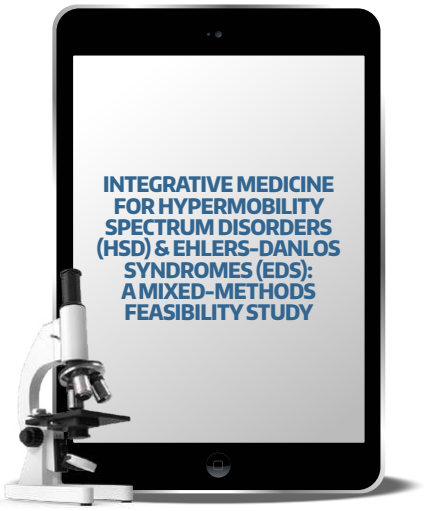
## $50K Grant - Microgrants Round 1



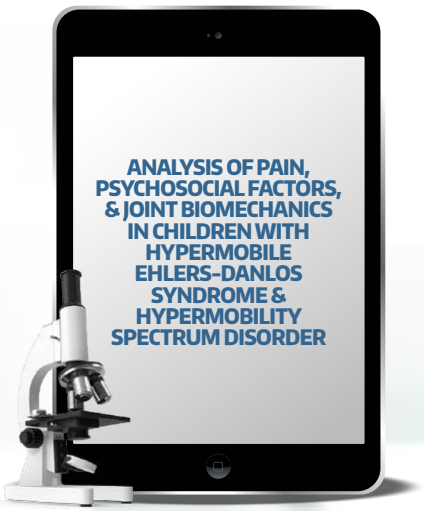

### Awardees:

**$5,000**

**Primary Investigator:**
Sara Guedry
National University of Natural Medicine
Portland, Oregon, United States

Integrative Medicine for Hypermobility Spectrum Disorders (HSD) and Ehlers-Danlos Syndromes (EDS): A Mixed-Methods Feasibility Study.

## $50K Grant - Microgrants Round 2




### Awardees:

**$5,000**

**Primary Investigator:**
Hyo Jung Jeong
University of Wisconsin
Milwaukee, Wisconsin, United States

Analysis of Pain, Psychosocial Factors, and Joint Biomechanics in Children With Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorder.



# RESEARCH

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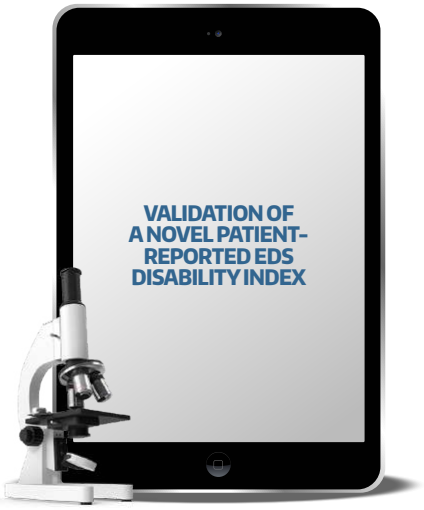
# $50K Grant - Microgrants Round 2

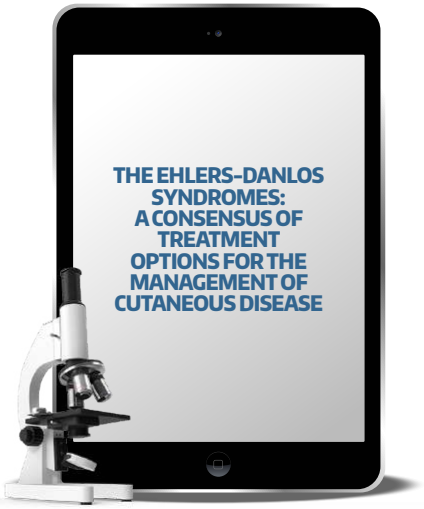
## Awardees:




**$5,000**

**Primary Investigator:**
Emily Rosario
Casa Colina Hospital and Centers for Healthcare
Pomona, California, United States

Validation of a Novel Patient-Reported EDS Disability Index.




**$5,000**

**Primary Investigator:**
Brent Doolan
Cambridge University Hospitals
Cambridge, United Kingdom

The Ehlers-Danlos Syndromes:
A Consensus of Treatment Options
for the Management of Cutaneous
Disease.



RESEARCH

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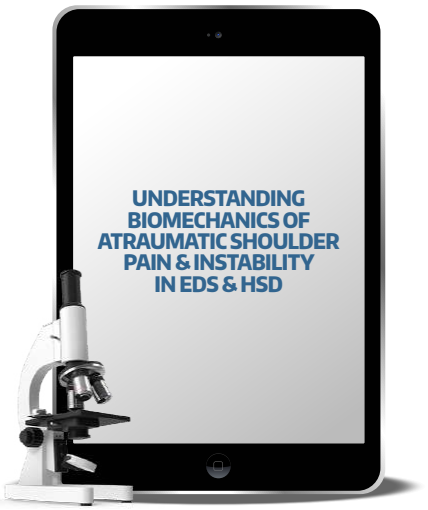
# $50K Grant - Microgrants Round 2

## Awardees:


### $5,000

**Primary Investigator:**
Veronique Vitart
University of Edinburgh
Edinburgh, United Kingdom

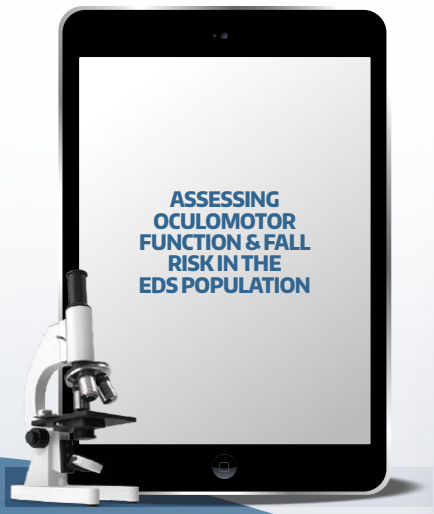
Investigating Bone Fragility in a Mouse Model of Brittle Cornea Syndrome Caused by Mutation in ZFP469.




### $5,000

**Primary Investigator:**
Marta Jokiel
Poznan University of Medical Sciences
Poznan, Poland

Understanding Biomechanics of Atraumatic Shoulder Pain and Instability in EDS and HSD.




### $5,000

**Primary Investigator:**
Laurie Jahnke
Boro Medical Clinic
Murfreesboro, Tennessee, United States

Assessing Oculomotor Function and Fall Risk in the EDS Population.



# RESEARCH

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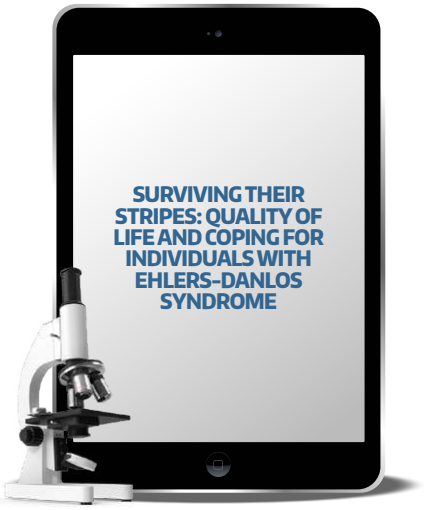
# $50K Grant - Microgrants Round 2

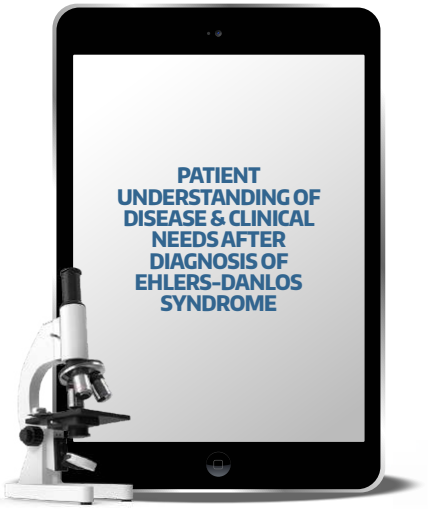
## Awardees:




**$5,000**

**Primary Investigator:**
Julie Hill
Auburn University
Auburn, Alabama, United States

Surviving Their Stripes: Quality of Life and Coping for Individuals With Ehlers-Danlos syndrome.




**$5,000**

**Primary Investigator:**
Jordan Jones
Children's Mercy Kansas City
Kansas City, Missouri, United States

Patient Understanding of Disease and Clinical Needs After Diagnosis of Ehlers-Danlos syndrome.

RESEARCH

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# HEDGE Study

The Ehlers-Danlos Society's groundbreaking HEDGE (Hypermobile Ehlers-Danlos Genetic Evaluation) study is a large-scale research project aiming to unravel the genetic and epidemiological factors underlying hypermobile EDS. Through collaborative efforts, this study has the potential to revolutionize our understanding of this condition, leading to earlier diagnosis, personalized treatments, and improved patient outcomes.

In 2022, The Ehlers-Danlos Society announce the study had completed enrollment. The Broad Institute in Boston is performing whole-genome sequencing of the DNA samples and when all the samples have been sequenced, two teams will begin the data evaluation phase, which is expected to require two years.

Joel Hirschhorn, MD, PhD, Concordia Professor of Pediatrics and Professor of Genetics, Harvard Medical School, will lead the team in Boston, Massachusetts. Christina Laukaitis, MD, PhD, Associate Professor at the University of Illinois, and the Carle Illinois College of Medicine, will lead a team based in Illinois. Dr. Clair Francomano, Professor of Genetics at Indiana University and HEDGE Co-Principal Investigator, commented, "We are excited to see HEDGE enrollment completed after a lengthy process delayed by COVID and are looking forward to the start of data analysis."

HEDGE is the first and only population study in hypermobile Ehlers-Danlos syndrome to sequence 1,000 people. HEDGE is designed to provide information about causative genetic variants in the hEDS population by using statistical methods to identify variants that occur more commonly in hEDS. Studies in specific families have uncovered variants that appear to cause hEDS findings in a family, but no studies to date have yet shown findings that are thought to affect more than about 2% of people with hEDS. HEDGE is directed at understanding the remaining 98%.

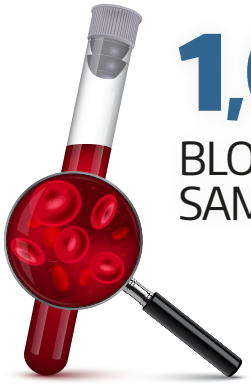
"We believe hypermobile Ehlers-Danlos syndrome will most likely turn out to be a group of distinct genetic conditions that give rise to similar findings," Dr. Francomano explained. Geneticists refer to the manifestations of a genetic condition as the "phenotype." Dr. Francomano went on to say, "The hEDS phenotype could be due to many distinct genetic conditions; alternatively, a single genetic cause that has heretofore eluded identification may account for most cases — we just don't know yet. HEDGE, by relying on whole-genome sequencing in a large population, offers the possibility of providing information regardless of which scenario is true."

RESEARCH

The Ehlers Danlos Society

## HEDGE Study

The Ehlers-Danlos Society extends its sincere thanks and gratitude to all of the individuals living with hEDS who applied for the study, and to those who donated their time and their blood samples to change the future of this condition.



**1,000**
BLOOD SAMPLES

PARTICIPANTS FROM
**86 COUNTRIES**

## Global Registry

Over **13,000 individuals from 16 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!


# RESEARCH

# EDUCATION

## EDS ECHO

EDS ECHO is a series of programs and courses for healthcare professionals across all disciplines who want to improve their ability to care for people with Ehlers-Danlos Syndromes (EDS), hypermobility spectrum disorders (HSD) and associated symptoms and conditions. Enhancing care for people with all types of EDS and HSD through case-based discussions, sharing knowledge, and expert updates is at the heart of what we do.

EDS ECHO also runs programs on advocacy and for community leaders and educators, exploring ways participants can better teach and support those living with EDS or HSD.
Participants in our programs are able to share their cases and questions in the sessions and are guided to further educational materials and support.

After taking part in a healthcare professional program, participants are invited to join us at any future EDS ECHO sessions and continue to take advantage of and support our ever-growing network of knowledgeable clinicians.

### HEALTHCARE PROFESSIONALS

**EDS** ECHO welcomed **377** new healthcare professionals from around the world in 2022, with **1,100** now having taken part in **EDS** ECHO, a commitment to supporting their patients who have a type of EDS or HSD.

### ADVOCACY

Advocacy programs welcomed **119** new community members to **EDS** ECHO in 2022, with **381** now having taken the Community and Advocacy **EDS** ECHO program sessions.

### EDS ECHO PROGRAMS

Across the twelve **EDS** ECHO programs ran in 2022, **169** sessions and a total of **250** hours of learning/teaching took place. A total of **182** Continuing Educational credits were available to attendees across the programs.

**1,700**
PARTICIPANTS HAVE ALREADY JOINED **EDS** ECHO

### **EDS** ECHO PROGRAMS:

- Clinicians
- Fundamentals of the Integral Movement Method (IMM)
- Advocacy
- Allied Health Professionals
- Pediatrics
- Genetics & Genomics
- Vascular Ehlers-Danlos Syndrome (vEDS)
- Nutrition

EDUCATION

The Ehlers Danlos Society

## Attendee feedback:

> The interdisciplinary model of EDS ECHO has allowed me to build a massive network to help my patients and to learn more about each specific system involved in the healthcare of my patients with Ehlers-Danlos syndromes.

> I can give the patient a lot more advice on strategies to cope with the condition and a graded rehab program which suits the patient's lifestyle, fatigue levels and goals.

> Thank you again for such a great series! As a physiotherapist I feel more empowered and less intimidated by medical professionals (GPs and specialists) when I advocate for a client's or my own needs.

> This program gave me more information so that I may know when to refer a client out for cardiovascular care. It has given me language that I can teach to my clients for their use when speaking with their PCP or other caregivers.

Late 2022 saw the launch of the first non-English language EDS ECHO program, a Spanish program hosted in New Mexico, EDS ECHO Clínico en Español. As we close 2022, **49 health professionals** have joined the Spanish language program from **Mexico**, **Spain**, **Chile**, **Peru**, **Columbia**, **Costa Rica**, **Ecuador**, **USA**, and **Venezuela**.

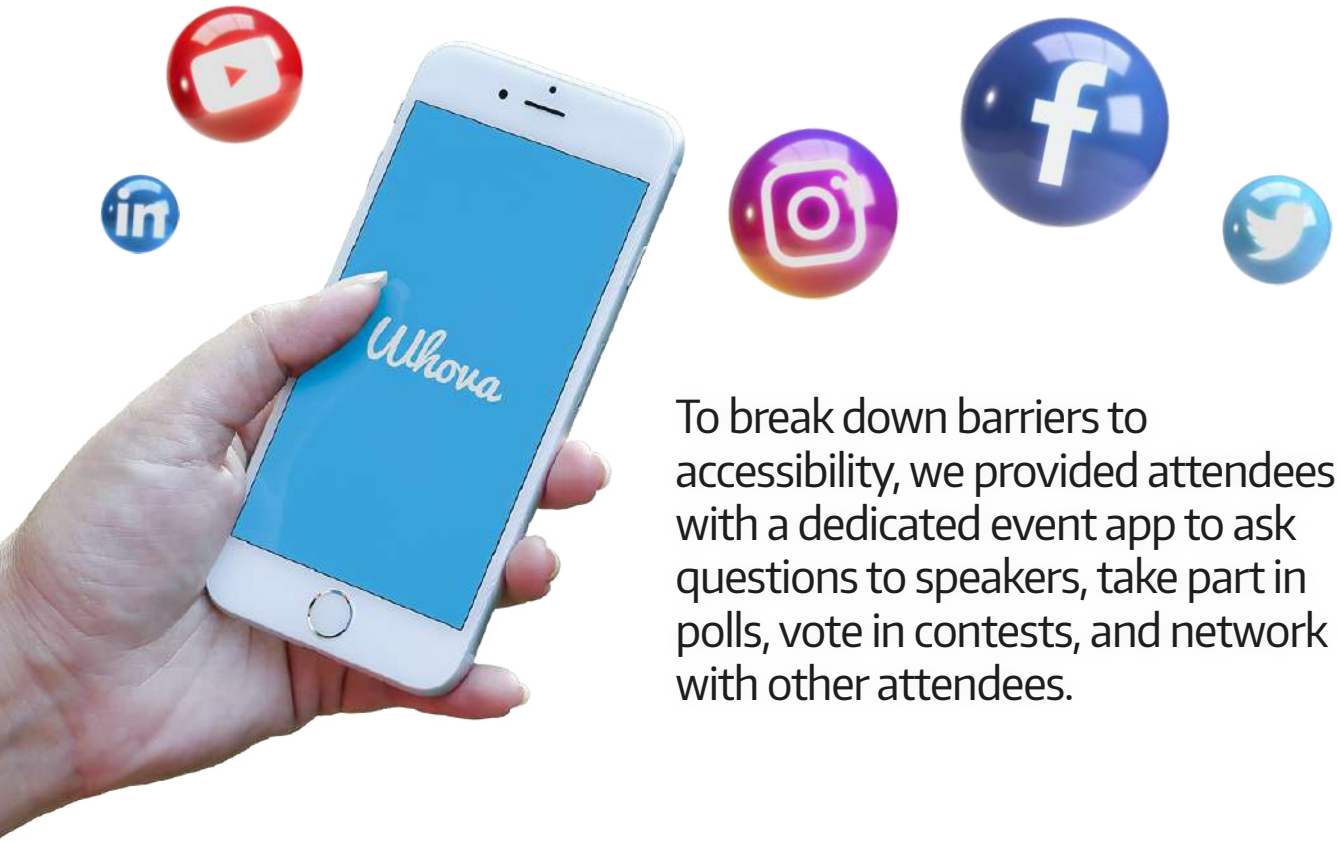
Everything we do at EDS ECHO supports people suffering today and helps prevent their symptoms from progressing tomorrow, ensuring a better future for every child and adult diagnosed with these conditions.

# EDUCATION

## Events

The Ehlers-Danlos Society events program serves as a platform for education, community building, and raising awareness about EDS and HSD.

We continued to provide fully hybrid events in 2022, returning back to in-person events but ensuring continued engagement and participation through a comprehensive virtual attendance option.




To break down barriers to accessibility, we provided attendees with a dedicated event app to ask questions to speakers, take part in polls, vote in contests, and network with other attendees.

Six events were held in 2022, bringing together renowned experts for interactive discussions, presentations, and Q&As. Our events have offered invaluable insights, shared experiences, and much-needed support to over **4,000** patients, caregivers, and medical professionals. Over **56%** of the medical professionals were first time attendees to a Society event!

The Ehlers Danlos Society

# Global Learning Conference 2022, Arizona, USA.

Due to the pandemic, our Global Learning Conferences had been virtual in 2020 and 2021, but with travel restrictions lifted, we were delighted that we could join together in person again. It was wonderful to be in Scottsdale, Arizona, USA, and to welcome people joining virtually from around the world.

Over three and a half days we heard from a variety of global speakers who gave talks under the umbrella of this year's conference theme, "Living with EDS and HSD Through a Lifetime," featuring expert presentations, case studies, and panel discussions about the different stages of life with the Ehlers-Danlos syndromes and hypermobility spectrum disorders. An exciting, all-new agenda included topics and tracks covering pregnancy and childbirth, children and teenagers, sex and intimacy, and aging.

Throughout the conference, we were joined by attendees in **35 countries**: **Argentina**, **Australia**, **Austria**, **Belgium**, **Brazil**, **Canada**, **Chile**, **Colombia**, **Costa Rica**, **Denmark**, **Ecuador**, **France**, **Georgia**, **Germany**, **India**, **Ireland**, **Israel**, **Italy**, **Jordan**, **Latvia**, **Mexico**, **the Netherlands**, **New Zealand**, **Norway**, **Panama**, **Poland**, **Portugal**, **Singapore**, **South Africa**, **Spain**, **Sweden**, **Switzerland**, **the United Kingdom**, **the United States**, and **Venezuela**. Of those, 59% were attending an Ehlers-Danlos Society conference for the first time.

We welcomed **27 Junior Zebras** to a special track for kids and teens led by Camp Joy Ohio, and **63 participants** enjoyed a 1:1 visit with an EDS or HSD expert to address a symptom that had been challenging them.

> "As a newly diagnosed hypermobile Ehlers-Danlos syndrome (hEDS) patient, I learned so much, especially about OB/GYN and ortho! **I feel like I have a handle on my condition now**."

> "As a pediatrician, I am able to recognize when to assess for EDS and how to approach treatment and care for patients and their parents. As a parent of two individuals diagnosed with hEDS in their adulthoods, **I am better able to understand my children and their condition**."

> "**I really like that the conference incorporated the topics to include psychiatry and psychology** to address the mental health aspects of the diagnostic odyssey, living with, coping with, and being diagnosed with a rare disorder."

# EDUCATION

The Ehlers Danlos Society

## Virtual EDS ECHO Summits

The EDS ECHO Summits are virtual events that share the latest research and knowledge with community members and health professionals globally, through the traditional Project ECHO® all-teach, all-learn format, and are CME-accredited.

Dedicated EDS ECHO Summits covered Classical Ehlers-Danlos Syndrome, Allergy and Immunology Complications, and Pediatric and Adolescent Concerns in EDS and HSD.

The EDS ECHO Summits welcomed **2,023** attendees (1,648 Community members and 375 healthcare professionals) in over **46 countries** including: **Australia**, **Austria**, **Belgium**, **Brazil**, **Canada**, **Colombia**, **Czech Republic**, **Denmark**, **Ecuador**, **France**, **Germany**, **Greece**, **Iceland**, **India**, **Indonesia**, **Ireland**, **Israel**, **Italy**, **Japan**, **Latvia**, **Malaysia**, **Malta**, **Mexico**, **Netherlands**, **Nepal**, **New Zealand**, **Norway**, **Peru**, **Puerto Rico**, **Poland**, **Portugal**, **the Philippines**, **Saint Lucia**, **Singapore**, **South Africa**, **Spain**, **Sweden**, **Switzerland**, **Taiwan**, **the Netherlands**, **the United Kingdom**, **Turkey**, **United States Minor Outlying Islands**, **United States of America**, **Venezuela**, and **Zambia**.

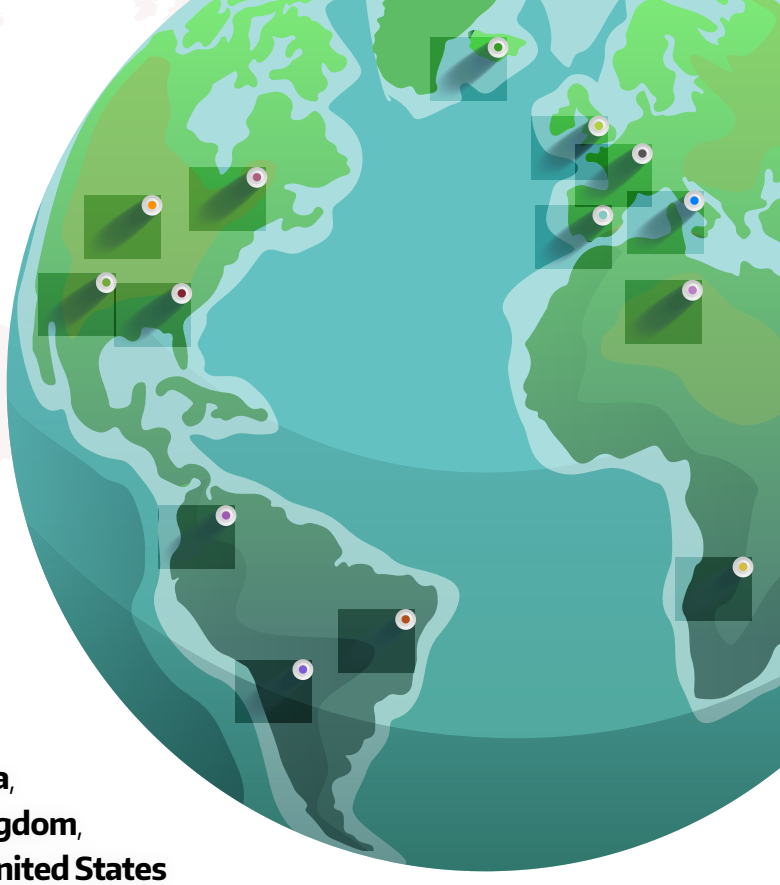
## International Scientific Symposium 2022, Rome, Italy.

Due to the pandemic, the triennial International Scientific Symposium on EDS and HSD had been delayed from 2020. Now that travel restrictions have eased, we were delighted to welcome clinicians and basic and clinical researchers from around the world to Rome, Italy, for a four-day, state-of-the-art meeting in which new research on clinical advances and the molecular and pathogenic mechanisms underlying EDS and related syndromes were discussed.

The International Consortium on EDS and HSD brought together leading experts, clinicians, and scientists in the field of EDS and HSD for a high-quality, scientific program with a focus on "Translational Medicine in EDS and HSD – From Basic Science to Community."

Live simultaneous translations allowed participants to listen to the talks in Italian, French, and Spanish.

The Ehlers Danlos Society



Throughout the conference, we were joined by 255 in-person attendees and 654 virtual attendees in **42 countries** around the world: **Argentina**, **Australia**, **Austria**, **Belgium**, **Brazil**, **Canada**, **Chile**, **China**, **Colombia**, **Denmark**, **Finland**, **France**, **Georgia**, **Germany**, **Greece**, **Hungary**, **Iceland**, **Ireland**, **Israel**, **Italy**, **Japan**, **Kuwait**, **Latvia**, **Malaysia**, **Mexico**, **New Zealand**, **Norway**, **Panama**, **Poland**, **Portugal**, **Republic of Korea**, **Russia**, **Saudi Arabia**, **Singapore**, **Spain**, **Sweden**, **Switzerland**, **South Africa**, **the Netherlands**, **Turkey**, **Venezuela**, **the United Kingdom**, **the United States Minor Outlying Islands**, and **the United States of America**.

The event featured the latest research with **30 oral abstracts** and **87 poster abstracts**.

"The interdisciplinary participation was the best part of this event for me - researchers + clinicians + PTs/rehab + mental health professionals + patients."

"Amazing subject matter, experts, researchers, medical professionals sharing their discoveries and experience, and patients sharing their experiences. Amazing interactions with other conference attendees, access to papers and research studies on EDS research and treatment, and networking. I am just getting started on my education in EDS and this conference and the Arizona conference have been GOLD - thank you!"

The next International Scientific Symposium will take place in Canada in 2025. Events in 2023 will include:

- EDS ECHO Summit: Hypermobility Spectrum Disorders
- Global Learning Conference in Dublin, Ireland
- Genetically Defined EDS: Strategies & Solutions for Unmet Needs in Ghent, Belgium
- EDS ECHO Summit: Fatigue, Causes and Management
- Externally Led Patient-Focused Drug Development Meeting

# EDUCATION

The Ehlers Danlos Society

## May Awareness Month Campaign

During May Awareness Month, we launched a comprehensive campaign to raise public awareness about EDS and HSD, and engage our incredible community around the world!

Through the Acts of Awareness social media campaign, educational resources, and community events, we engaged individuals around the world, shining a light on the challenges faced by those living with these disorders.

The campaign fostered empathy, dispelled myths, and inspired action, bringing us closer to a society that understands and supports individuals with EDS and HSD.

Supporters raised an incredible **$51,230.80** to support our global mission! Buildings were lit up across the USA, the UK, and Australia; proclamations were requested to governors across the US; and the community shared the campaign across social media from all corners of the world.

Clara @rollinfunky joined the social media challenge from the UK, sharing her experiences with EDS.


> "I have Ehlers-Danlos syndrome. I am active, I like to push the boundaries, and live life to the max. I am also in constant excruciating pain, have joint dislocations, bruising, chronic fatigue, plus much more, and it is the reason I am a wheelchair user."

> "Living with EDS takes a lot of organization and pacing to help manage my condition and pain. Although, I am smiling in most of my photos, please remember these images are highlights of reality. However, I am zebra strong and will always be wild!"

# EDUCATION

Clover and Charlie climbed Sugarloaf Mountain in Ireland, raising an incredible **€4,637** to support our shared mission!

Alison joined the Acts of Awareness Challenge from the UK, and Nordic walked on the Walk 'N' Roll Challenge. Alison raised **£190.00**!

> Despite my EDS challenges, I was able to qualify and work as an occupational therapist. My children have hypermobile EDS, a diagnosis I was given alongside them. Late diagnosis is very common indeed with parents being diagnosed alongside their children. This is why **I am keen to help spread awareness for others who may be experiencing pain, fatigue, bruising, subluxations, sensory processing disorder, and other symptoms so that they can be helped**. Nordic walking is a sport I am able to do in addition to my online physiotherapy.

Over 14 family and friends from Zolas Zebras participated in the Walk'n'Roll Challenge from Medina, Ohio, USA!

> Thank you to the friends and family that joined us! **Your support means a lot to not only us but zebras all over the world!**. Arzola is 5 years and a kindergartener at Medina Christian Academy. She loves school! Cheerleading is her biggest joy, and she dances kinder ballet and kinder jazz. Though she recently had to quit gymnastics, she will always be a gymnast at heart.

> **Every kilometer counted as an Act of Awareness today towards the worldwide goal of 120,000!** Together we covered 31.5 km and then our friend, Gabby biked 9 more! Bringing Zola's Zebras Walk'n'Roll Challenge total to 40 Acts of Awareness. Diagnosis was only the beginning of this journey and we're so grateful for those following and supporting our girl.

# EDUCATION

The Ehlers Danlos Society

## End-of-Year Campaign

Our End-of-Year Campaign provided an opportunity for our community to come together and support our mission during the holiday season. Through a variety of fundraising initiatives, we successfully raised critical funds to sustain and expand our programs.

The generosity shown during this campaign reinforces our shared commitment to improving the lives of individuals with EDS and HSD. Thanks to the generosity of our donors, we raised an incredible **$323,119.39** in our 2022 End-of-Year Campaign, celebrating the achievements and contributions of community members!

We are grateful for the generosity of our donors and supporters who have contributed to our fundraising campaigns throughout the year. Their donations have enabled us to carry out our vital programs, advance research, and expand our outreach efforts.

## Help Us Fund Our Shared Mission

As we reflect on the accomplishments of the past year, we recognize that there is still much work to be done. We invite you to join us in our mission to advance care, access, research, and education for individuals with EDS and HSD.

Your support, whether through donations, volunteerism, or spreading awareness, will contribute to our collective efforts to transform lives and create a brighter future for those affected by these disorders.

**Together, let us continue to make a difference.**
**Together, we dazzle.**


Donate today at:
**ehlers-danlos.com/donate**

EDUCATION

# REVENUE & EXPENSES

| Income | Amount |
|---|---|
| Corporate | $227,591 |
| Grants | $17,094 |
| Individual Donations | $3,997,948 |
| Events | $583,121 |
| **TOTAL** | **$4,825,754** |

| Expenses | Amount |
|---|---|
| Admin | $492,482 |
| Fundraising | $380,942 |
| ECHO | $256,370 |
| Education | $574,279 |
| Classical EDS | $13,689 |
| General Research | $904,486 |
| HEDGE | $1,050,574 |
| Research Studies | $85,128 |
| Events | $650,527 |
| **TOTAL** | **$4,408,477** |

The Ehlers Danlos Society

# STAFF

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