The Ehlers Danlos Society

IMPACT REPORT

January 1 - December 31, 2023

Letter From the President and Chair of the Board of Directors

Dear Friends and Supporters,

As we reflect on the past year, it is with immense pride and gratitude that we share the transformative strides The Ehlers-Danlos Society has made in 2023. This year has truly demonstrated the power of our collective commitment to enhancing the lives of those affected by Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD).

Thanks to your unwavering support, we have expanded our reach and impact across the globe. Our efforts in CARE—Care, Access, Research, and Education—have flourished, allowing us to provide critical support services, advance groundbreaking research, and empower healthcare professionals with the knowledge needed to improve patient care.

One of the most significant milestones this year was the growth of our EDS ECHO program, which now supports a global network of healthcare professionals and advocates. With over 350 new health professionals joining our programs in 2023, we are more equipped than ever to ensure that individuals with EDS and HSD receive the specialized care they deserve.

Our commitment to expanding access to care was further solidified with the introduction of the Centers and Networks of Excellence Program. This initiative, now including 23 centers from eight countries, is a testament to our dedication to reducing diagnostic delays and improving multidisciplinary care for our community.

We are particularly proud of our efforts to support our Junior Zebras, who are often among the most vulnerable in our community. The launch of our fully funded family camps, including the first for vascular Ehlers-Danlos syndrome (vEDS), provided a much-needed space for connection, learning, and support.

Our research endeavors have also reached new heights. The HEDGE study, with participants from 86 countries, continues to break new ground in understanding the genetic underpinnings of hypermobile EDS. This study, alongside generous pledges from the Mike and Sofia Segal Family Foundation and InVitro Cell Research LLC, marks a turning point in our pursuit of earlier diagnoses and better treatment options.

Through it all, our community has remained at the heart of everything we do. Whether through our virtual support groups, which connected participants from across the world, or our dynamic social media campaigns that reached over 21 million people, we have worked tirelessly to ensure that no one faces these challenges alone.

As we look ahead to 2024, we are energized by the progress we have made and the potential that lies before us. With your continued support, we will forge ahead in our mission to create a world where individuals with EDS and HSD can thrive.

Thank you for being the driving force behind our success. Together, we are making an indelible impact.

With gratitude,

Professor Lara Bloom

President and CEO
The Ehlers-Danlos Society

Susan Hawkins

Chair of the Board of Directors
The Ehlers-Danlos Society

Helpline

The Ehlers-Danlos Society's helpline is a vital resource, offering essential support, information, and connection. It significantly enhances the quality of life for those affected by EDS and HSD. As well as serving families, caregivers, and educators, the helpline also provides health professionals with the latest information to assist in delivering optimal care.

Demand for the helpline grew year-on-year, and in 2023 we welcomed Nina Fernandez to the team, joining Rebecca Gluck and Scarlett Eagle. Together, the team answered over 530 calls and 2,600 emails, offering potentially life-changing advice.

The helpline is fundamental to our ability to provide comprehensive support for several key reasons:

Access to Expert Knowledge and Guidance

Given the frequent misunderstandings and misdiagnoses of these conditions, having a dedicated source of accurate information and guidance is invaluable for both patients and health professionals. The helpline offers access to our Healthcare Professionals Directory, where providers with expertise in EDS and HSD can list their services. It is our most accessed resource online. Additionally, the helpline team provides access to our Support Group and Charity Directory, enabling individuals to find local support groups and charities in their area, fostering local support networks.

Emotional Support and Validation

For those living with EDS and HSD, the helpline serves as a source of emotional support. People often face frustration, isolation, and anxiety due to the chronic and often debilitating nature of their conditions. The helpline offers validation and understanding, providing comfort and empowerment.

Resource Navigation

The helpline aids in navigating the complex array of resources available to those with EDS and HSD. This includes information on medical providers, symptom management, support groups, and research. For families and caregivers, understanding where to seek help and what services are available can greatly alleviate the burden of care.

Education and Advocacy

Health professionals can utilize the helpline to educate themselves about EDS and HSD, enhancing their ability to diagnose and manage these conditions. This leads to improved patient outcomes and a higher standard of care. The helpline also plays a crucial role in helping people advocate for themselves, a family member, or patient, ensuring they receive necessary accommodations and support in educational and occupational settings.

Ongoing Research and Updates

The helpline provides updates on the latest research, clinical trials, and advancements in understanding and treating EDS and HSD. Research insights can be complex for individuals to navigate and understand how it affects them directly, or what it can mean for their care. Staying informed about these developments offers hope and direction for individuals seeking to manage their conditions more effectively.

"I just wanted to say **THANK YOU for this thoughtful and detailed response!** I was able to use the information provided to secure an appointment with our hospital's pediatric physical medicine team to work on getting a wheelchair for longer outings. We are also using some of the resources provided to craft better accommodations for my daughter's school day. Really appreciate the support and community while we work to figure out what's happening with our daughter."

"**Thank you for your comprehensive and very helpful response** to my query about EDS and HSD. It will help me and my daughter find the best care for her. Your help is greatly appreciated."

"Thank you so much! **This is the most helpful response I have ever received specific to Ehlers-Danlos syndrome**."

Those wishing to contact the helpline team can call, request a callback, or email. Further information on this service can be found here.

Virtual Support Groups

Let's Chat: Virtual Support Groups, hosted on the Zoom platform, play an essential role in supporting individuals affected by EDS and HSD.

These support groups eliminate geographical barriers, making it easier for people to access support from the comfort of their own homes. This is especially beneficial for those with mobility issues or those living in remote areas where in-person support groups are not available.

Living with a chronic illness can be isolating, and virtual support groups offer a sense of community and connection. Participants can engage with others who share similar experiences, challenges, and emotions. The understanding and empathy from fellow group members help reduce feelings of loneliness and provide validation for their struggles. Many participants meet someone else living with EDS or HSD for the first time through these groups.

Meetings are scheduled at various times to accommodate as many time zones as possible, catering to the needs of our diverse global community. Regular meetings are held for:

- Individuals impacted by all types of EDS and HSD
- Adults who have vascular Ehlers-Danlos syndrome (vEDS) and/or those who have a child with vEDS
- Parents with EDS or HSD or parents of children with EDS or HSD
- Partners and spouses
- Men
- LGBTQIA+ individuals
- Teens

Throughout 2023, 82 meetings were held with participants joining from around the world, including Colombia, Japan, Germany, South Africa, Russia, Switzerland, Sweden, Denmark, the UK, Canada, and all over the USA!

Commonly discussed topics included:

- Managing pain and symptoms
- Dealing with the reactions of family, friends, schools, and employers
- The emotional burden of chronic illness
- Maximizing the effectiveness of doctor appointments
- Finding doctors and seeking recommendations

"I gathered **so much good information** and **so many good resources** at this meeting that I haven't even had time to go through all of them yet. Thank you for hosting this community resource."

Community Connections

Connection is crucial when living with a chronic or rare disease. Many individuals have never met or spoken to someone else with the same type of EDS or HSD. Some of the rarer types of EDS affect only a small number of families globally. Families impacted by EDS or HSD often seek to connect with others to understand how they are managing their conditions, coping, and maintaining their quality of life.

The Ehlers-Danlos Society's Inspire message board is the most active community on the Inspire platform, with over **131,630** members from more than **150 countries**. On Inspire, members can search conversations by keyword or topic, or create their own thread asking peers for recommendations around healthcare providers or management strategies for example, and others' personal experiences. Members can also contact each other directly through the platform and search for members in their local communities.

Conversation and connection are also promoted through The Ehlers-Danlos Society's social media channels, including Facebook, Instagram, Twitter, LinkedIn, and YouTube, where community voices are lifted, educational content is shared, and awareness is raised through campaigns. The social media communities now include over **280,000 supporters**, and in 2023 **over 21 million** people saw our posts across the different platforms!

> "Hello, My name is Kristan and I am from Salt Lake City, Utah. I just wanted to say that finding your page has brought me a sense of comfort because I have felt very alone and a bit helpless."

> "Thank you for sharing the recent post about dysautonomia. It was a light bulb moment for me and makes perfect sense as I've experienced all of these and have a diagnosis of hypermobile EDS (hEDS). It's been particularly significant today as I'm having a flare up of symptoms."

Supporting Our Junior Zebras

EDS and HSD can cause symptoms from birth. Many individuals spend years managing symptoms alone, missing out on social occasions, schooling, or hobbies, and often struggling to express their grief and frustration. For children, teens, and young adults with rarer types of EDS, there may also be life-limiting complications.

The Ehlers-Danlos Society is committed to ensuring that the kids and teens in our community feel supported and have access to the resources, tools, and opportunities they deserve. With early diagnosis and intervention, coupled with support networks, our Junior Zebras can thrive.

Our vision is to provide life-changing resources to support children and youth worldwide, in multiple languages, and through engaging and inclusive mediums. We work with the Pediatric Working Group of the International Consortium on EDS and HSD to advocate for families and children, with the aim of reducing time to diagnosis and improving care.

"I have a student in my classroom this year, 10-years-old and he has received a diagnosis of hEDS, he has a care team, he has support and interventions in place, his family have answers and an avenue for information and support. It's a huge shift from me who'd never heard of EDS and wasn't diagnosed until I'd deteriorated to a point where I could barely function. Despite years of tests and specialist and text-book anecdotes from throughout childhood and my teenage years, I wasn't diagnosed until 25 (and that was considered fast). I just wanted to Thank The Ehlers-Danlos Society and Lara Bloom for the incredible work that you have done, and continue to do, educating, advocating and raising awareness for this condition. It's wonderful to see the systemic changes you are bringing about."

Let's Chat: Teens Support Groups

Every month we host a Let's Chat: Teens group on Zoom. The group is a safe space for teens aged 13-18 to share their experiences and make friends with people who are the same age and know what it is like to be affected by EDS and HSD.

"What a great teen's group today! We talked about getting ring splints, accommodations in high school and college, how to talk to friends and teachers about EDS and HSD, dynamic disabilities, and maintaining friendships when you don't have the energy to hang out."

Junior Zebras Program

The Junior Zebras programs at our Global Learning Conferences are an incredible opportunity for connection with others and for our younger community members to talk about their experiences in a non-medical setting. The program is led by the incredible team from Camp Joy and offers two tracks for kids ages 6-12 and teens ages 13-17.

The 2023 Global Learning Conference was held in Dublin, Ireland, for the first time, and we welcomed junior zebras from all around the world. With a packed schedule of crafts, games, music, and talks from health professionals on managing EDS and HSD, a fun-filled time was had by all!

We had incredible feedback from those attending whose children felt validated and made lifelong friends.

Q. What did your junior zebra enjoy most about the program?

"Validation of what they were feeling, and that they're not alone. Definitely a worthwhile event and a big thank you to the organizers."

Family Camps

Thanks to the generosity of our donors, in July 2023 we hosted our first fully funded family camp for individuals and families affected by vascular Ehlers-Danlos syndrome (vEDS). Organized by The Ehlers-Danlos Society in collaboration with The VEDS Movement, at Camp Joy in Ohio, USA.

Vascular Ehlers-Danlos syndrome (vEDS) is a heritable connective tissue disorder that makes the connective tissue very fragile, particularly in the blood vessels and hollow organs. vEDS can cause life-threatening complications, such as aneurysm, dissection, and rupture of the arteries and rupture of organs. Recognizing the importance of community and connection for individuals affected by vEDS , the camp provided an invaluable opportunity to meet others with the same diagnosis. These individuals understood the challenges and uncertainties associated with vEDS.

Camp Joy Ohio served as the venue for this three-day event, made possible by generous donations covering registration fees, accommodations, camp activities, and meals for participating families. For many attendees, this was their first time meeting someone else living with vEDS. The camp provided an environment for building relationships, with children and parents spending quality time together.

Throughout the weekend, the community engaged in various activities such as basketball, rock painting, hiking, abseiling, swimming, and the timeless tradition of enjoying s'mores. These experiences made long-lasting memories and friendships.

People with vEDS often need to make lifestyle adjustments to minimize the risk of injury. As a result, they may have limited opportunities to participate in sports and activities, potentially missing out on social experiences with their peers. The camp was designed with safety and enjoyment in mind, enabling families to relax and partake in an unforgettable experience.

CAMP JOY

Family Camps

"We had an amazing experience at Camp Joy! The nature surroundings were beautiful, the activities fun for the whole family, and the staff are great! Our kids particularly enjoyed making s'mores by the campfire and watching the fireflies in the evening."

"We enjoyed hearing about everyone's stories and sharing tips about everyday life with vEDS. It was really nice meeting the doctors and getting their input. They are both knowledgeable and compassionate about the struggles of living with vEDS. Overall, we come out of this experience with a heightened sense of connectedness and community. Thank you for making this experience possible for all of us!"

"For us, it was the first time meeting people with vEDS outside of our own family. We found it really comforting to see that other families share some of our experiences with vEDS and to see that even if we live with a rare condition we are not alone."

The Ehlers-Danlos Society is thrilled to be planning and fundraising for upcoming family camps. In 2024 we will host a camp for families with hEDS and HSD, and a camp for families impacted by the rarer types of EDS.

CARE

Expanding Access to Information, Care, and Resources

In 2023, The Ehlers-Danlos Society's website was accessed by over 1.9 million users around the world. The website serves as a vital hub, connecting individuals with EDS and HSD, their caregivers, healthcare professionals, and researchers to essential resources and information tailored to their needs.

"Thank you for all that you do for our community. I was diagnosed before The Ehlers-Danlos Society was founded and I have seen such a difference in care options, doctor's awareness, and so on since then. Your page with doctors by specialty and location changed my life. I see a dietician from your list and she has saved my life in a huge way. Thank you so much. I am truly grateful for all that you do for us."

Access to Essential Information

The Ehlers-Danlos Society is committed to advancing education about EDS and HSD by making information about these conditions widely accessible. During 2023, we published web pages and brochures with general information about EDS and HSD. We also published a webpage on genetics and inheritance, addressing common questions about diagnosis and genetic testing. Responding to the latest research, our team developed a guide to the 2023 Diagnostic Framework for Pediatric Joint Hypermobility, ensuring this information was available shortly after publication.

We made major advancements in our type-specific content by publishing web pages about every type of EDS in 2023. These web pages include general information about the causes, inheritance, prevalence, key signs and symptoms, diagnosis, and management of each type. We will continue to expand these pages to offer comprehensive information and resources related to each type of EDS.

Recognizing the diverse challenges faced by our community, we also developed resources on managing dysautonomia, sleep, and fatigue in 2023. We continue to work with experts on the International Consortium on EDS and HSD to provide our community with the latest information about managing different aspects of these conditions.

In 2024 we will continue to ensure increased accessibility of the website and its content, introducing accessiBe, a web accessibility solution.

"I want to thank you for your website and information. I am a registered nurse at a GP practice. We have started focusing on something each month, and this month we did EDS awareness month. We put flyers from your webpage out in our waiting room and have already had one patient thank us and say 'wow, I think this is what's going on with me.'"

ACCESS

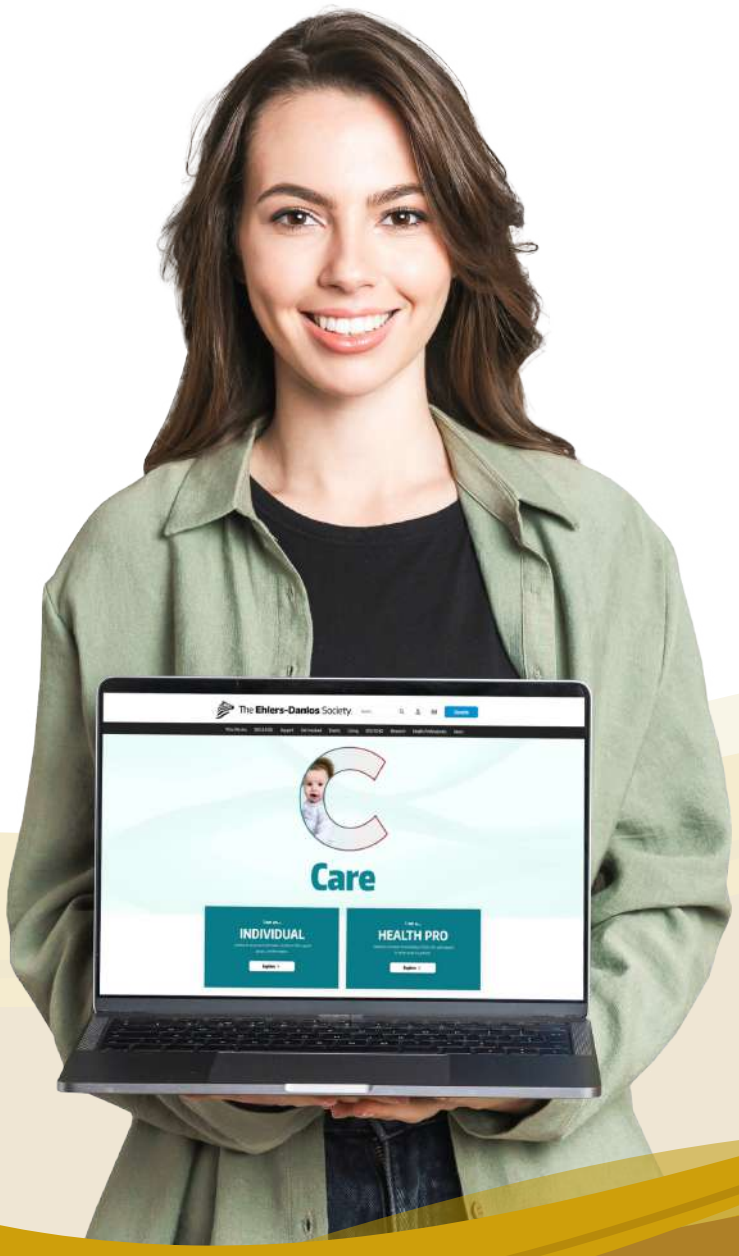
Expanding Access to Information, Care, and Resources

Access to Expert Care
Healthcare Professionals Directory

The Healthcare Professionals Directory is the most frequently accessed resource on our website, helping people all over the world connect with knowledgeable and experienced healthcare providers. We continue to expand our Healthcare Professionals Directory to include a wide range of specialties and regions, with the goal of reducing diagnostic delays and improving quality of care for people affected by EDS and HSD.

"Thank you for all that you do for our community. I was diagnosed before The Ehlers-Danlos Society was founded and I have seen such a difference in care options, doctors awareness, and so on since then. Your page with doctors by specialty and location changed my life. I see a dietician from your list and she has saved my life in a huge way. Thank you so much. I am truly grateful for all that you do for us."

"The way I cried in the waiting room when I saw this - thanks to all of you and your resources online I've finally found someone who's knowledgeable about hEDS. Should have my confirmation diagnosis in 2 weeks now - thank you from the bottom of my heart."



ACCESS

Global Centers and Networks of Excellence: Multidisciplinary Team Care Around the World

CENTERS & NETWORKS OF eXcellence

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.

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.

Towards this goal, The Ehlers-Danlos Society announced its first and second cohorts of the Centers and Networks of Excellence Program in 2023. The program aims to ensure critical standards of care with each center and network required to meet rigorous clinical, research, professional education, and patient care criteria. Geographical, financial, and cultural considerations are an important aspect of the program, to advance the highest standards of care.

The cohorts include **23 Centers and Networks (CNEs)** from **8 countries** (Australia, Canada, France, Germany, Italy, Kuwait, United Kingdom, United States) comprising 30 total institutions and more than 30 areas of expertise:

Australia
The Sports Physio Clinic Narrabeen, West Pymble & Pymble LC [cohort 1]
Western Kids Health [cohort 1]
Zebras Australia [cohort 2]

Canada
SickKids Foundation [cohort 2]

France
Ellasanté [cohort 1]
Neuropôle Cauderan HSD/SEDh [cohort 1]
L'AP-HP (Assistance Publique - Hôpitaux de Paris) [cohort 2]

Germany
Universität zu Köln [cohort 1]

Italy
Casa Sollievo della Sofferenza [cohort 1]

Kuwait
Alsiri Hypermobility Clinic [cohort 2]

United Kingdom
Kent Community Health NHS Foundation Trust Community Chronic Pain Service [cohort 1]
The London Hypermobility Clinic [cohort 1]

USA
IU Health [cohort 1]
Children's Mercy [cohort 1]
Mayo Clinic Jacksonville, FL [cohort 1]
Children's Hospital Colorado [cohort 1]
CT Center for CranioSacral Therapy [cohort 1]
Forefront Therapy [cohort 1]
Muscle & Joint Clinic [cohort 1]
Mount Sinai South Nassau [cohort 1]
Bethesda Physiocare [cohort 2]
Yellow Brick Clinic: Integrative ADHD, Autism, Developmental Behavioral Health [cohort 1]

Dr. Johanna Theron,
Strategic Clinical Lead within KCHFT's Community Chronic Pain Service in the United Kingdom said:

"This is a fantastic achievement for the service and good news for people affected by EDS and HSD in Kent and Medway which affects an estimated 400 to 600 people in the region. We have a highly skilled team who understand the complex health problems associated with the conditions, which are often misunderstood. This means we are able to pick up on symptoms more quickly than they may otherwise be.

"By recognising the conditions faster, we can bring them to the attention of the correct clinicians, improving quality of life for our patients and shortening the pathway to the right support. We can also play a key role in upskilling other healthcare colleagues in their understanding of the conditions too. Being community-based means we are constantly sharing best practice with multi-disciplinary teams, including local GPs, orthopaedics, dieticians and physiotherapy."

COHORT 3 The Centers and Networks of Excellence looks forward to announcing its third cohort in June 2024.

Support Group and Charity Directory

The Ehlers-Danlos Society is committed to increasing care, access, research, and education for people with EDS, HSD, and related conditions globally. Support groups and organizations around the world are working hard to further this mission.

Our Support Group and Charity Directory helps individuals with EDS or HSD find local support groups and organizations so they can better access care and resources within their own communities. This frequently shared resource now lists 112 support groups and charities supporting people with EDS and HSD around the world.

Global Affiliation Program

The Global Affiliation Program facilitates collaboration between support groups and organizations worldwide. There is strength in numbers! Affiliates work together to spread awareness, provide resources, and educate about EDS and HSD where it is most needed. In 2023, the Global Affiliation Program welcomed 15 new members, expanding our network to 85 members in 20 countries, all committed to supporting those impacted by EDS, HSD, and associated conditions.

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.

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.

In 2023's $50,000 microgrant round, The Ehlers-Danlos Society awarded ten microgrants of up to $5,000 each to researchers worldwide.

The purpose of this funding was to assist researchers in undertaking small studies and activities such as surveys and collation and analysis of existing data in EDS and HSD. It will also be used to determine aspects of all types of Ehlers-Danlos syndromes and hypermobility spectrum disorders that can be further investigated to improve the management and outcomes. The following areas have been prioritized as areas that need attention in research:

Genotype and Phenotype
The identification of specific genotype and phenotype groups and subsequent prevalence studies.

Time to Diagnosis Reduction
Exploration of reducing the time it takes an individual to receive a diagnosis and earlier counseling.

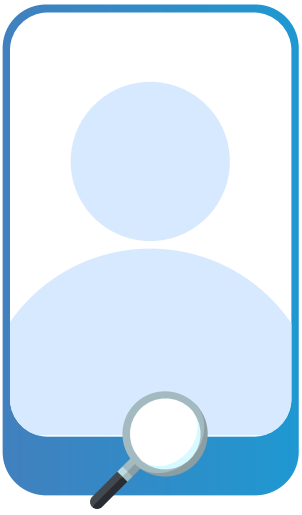
Centers of Excellence and Pathways
Encouraging research that improves the pathways to accurate diagnoses and the availability of proper centers that have the appropriate resources to assist patients.

Therapies and Management
Elucidation of mechanisms and therapies that can target these mechanisms of symptoms such as pain and fatigue, as well as the investigation of the mechanism behind comorbidities.

RESEARCH

Microgrant Awardees:

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.



Anna Junkiert-Czarnecka

miRNA in Ehlers-Danlos Syndrome Diagnostics (MIRED)

Collegium Medicum in Bydgoszcz, Nicolaus Copernicus University in Torun
Bydgoszcz, Poland

Next-generation sequencing (NGS) is the best tool for diagnosing different types of EDS because of the varied symptoms that can overlap between types. However, NGS is expensive and often not covered by insurance, leaving some patients undiagnosed or misdiagnosed.

The "miRNA in Ehlers-Danlos Syndrome Diagnostics (MIRED)" project aims to develop a more affordable and accessible diagnostic method. By measuring specific microRNAs (miR29a, miR29b, and miR29c) in a simple blood test, this approach could help identify mutations linked to certain types of EDS. This method would make diagnosis quicker, less expensive, and more widely available to patients.

Clair Francomano

Phenotypic Relationship Between Dercum Disease & Hypermobile Ehlers-Danlos Syndrome

Indiana University
Indiana, USA

So far, joint hypermobility has been noted in some patients and families with Dercum disease or angiolipoma, but this connection hasn't been thoroughly studied. The goal of this study is to determine whether people with Dercum disease or angiolipoma, who also have generalized joint hypermobility, may have hypermobile Ehlers-Danlos Syndrome (hEDS) or another related condition.

Dercum disease is a rare condition that causes painful growths of fatty tissue (lipomas or angiolipomas) on the body, often along with other health issues. The cause of Dercum disease is still unknown, and while removing the lipomas can help with pain, new ones often develop. This study will be a first step in exploring the genetic links between joint hypermobility, Dercum disease, and angiolipoma, laying the groundwork for a larger study to better understand these connections.

Cortney Gensemer

Investigating the Molecular Relationship Between Mast Cell Activation Disorders and the Ehlers-Danlos Syndromes

The Medical University of South Carolina
South Carolina, USA

A common and challenging condition seen in people with EDS is mast cell activation syndrome (MCAS). MCAS involves an abnormal reaction of mast cells, immune cells found in connective tissue, leading to symptoms ranging from allergic reactions to severe issues like anaphylaxis. This study aims to explore the link between MCAS and EDS, with the goal of finding new ways to manage and treat these complex symptoms.

Dmitry Rozenberg

Characterizing the Content and Quality of Internet Resources on Exercise Training in Ehlers-Danlos Syndrome (EDS) and Generalized Hypermobility Spectrum Disorder (G-HSD)

University Health Network, Toronto General Hospital
Toronto, ON, Canada

Exercise training can help manage symptoms like joint instability, dislocations, fatigue, and chronic pain. While many people turn to the internet for health information, the quality of online resources for exercise training in EDS and HSD is not well understood. Poor quality or outdated information can lead to harmful practices or incorrect self-diagnosis.

Given the importance of virtual care, especially with the rise of hybrid exercise programs, it's essential that people trust the online resources they use. This study aims to evaluate the readability, content, and quality of these online resources and compare them across EDS types. By identifying gaps and proposing evidence-based recommendations, the researchers hope to help patients and healthcare providers make informed decisions about exercise programs that enhance quality of life.

Fransiska Malfait

Developing the HCTD Screening Tool for the General Practitioner: When to Refer a Hypermobile Patient to a Center of Genetics for Diagnosis?

Ghent University Hospital
Ghent, Belgium

The healthcare costs associated with hypermobility are high. Effective symptom management requires specialist referrals and multidisciplinary care, but getting a diagnosis often takes a long time.

General practitioners face challenges in referring patients with joint hypermobility to the appropriate diagnostic pathways. Many patients are initially sent to centers for Medical Genetics to rule out heritable connective tissue disorders (HCTDs), which are linked to severe complications. However, only a small percentage of these patients have a genetic defect, leading to long waits and delays in diagnosis.

To address this, the research team is developing a screening tool to assess the risk of an underlying HCTD. This tool scores signs and symptoms like skin characteristics, skeletal features, and family history. It aims to shorten genetic center waiting lists, reduce healthcare costs by avoiding unnecessary tests, and ensure that patients with HSD and hEDS receive specialist care sooner.

The tool also provides a visual overview of a patient's symptoms, helping to identify genotype-phenotype relationships in HCTDs, differentiate between hEDS and HSD, and understand the diversity within patients with the same diagnosis.

Jane Simmonds

Development and Initial Validation of the Spider, a Multisystemic Symptom Impact Questionnaire for Patients with Hypermobility-Related Disorders

University College London
London, England

People with joint hypermobility often experience widespread chronic pain, fatigue, and joint instability, but their symptoms can vary greatly and affect more than just the musculoskeletal system. Non-musculoskeletal symptoms, such as orthostatic intolerance, digestive issues, and urinary incontinence, are also common and can significantly impact quality of life.

To better understand and manage these symptoms, an international research group is developing "The Spider," a 31-item questionnaire that evaluates the impact of key symptoms associated with HSD/hEDS. The questionnaire covers eight domains and produces a visual "spider web" graph, giving healthcare professionals a clear overview of a patient's symptom profile. This tool will help prioritize treatment in a multidisciplinary setting.

The Spider has already shown promising results in adolescents, with studies validating its domains related to pain, fatigue, anxiety, depression, and other symptoms. The next step is to validate the tool with adults and assess its reliability and structure.

Jessica Eccles

Variant Connective Tissue: A Risk Factor for Long COVID

Brighton and Sussex Medical School
Hove, England

This study will explore whether hypermobility and connective tissue disorders, including EDS, increase the risk of developing Long COVID. The researchers of this study believe that Long COVID may present a specific sub-phenotype in individuals with HSD and EDS that has not yet been fully recognized.

Previous research has identified several risk factors for Long COVID, such as female gender, age, smoking history, BMI, and other pre-existing conditions. However, these studies often overlook the role of hypermobility and connective tissue disorders, which are frequently underdiagnosed and not routinely assessed in clinical settings.

To address this gap, their study will use the validated 5PQ questionnaire to assess hypermobility in participants and gather data on pre-existing conditions common in people with connective tissue disorders, such as neurological and autoimmune issues. By collecting information on symptoms before and after COVID exposure, they aim to better understand the relationship between connective tissue disorders and Long COVID.

Previous studies have found a high prevalence of hypermobility in individuals with conditions like ME/CFS and Fibromyalgia. If their findings support the hypothesis, it could lead to a deeper understanding of how connective tissue disorders contribute to Long COVID, potentially guiding future research on mechanisms and treatments for affected individuals.

Qasim Aziz

The Development of a Not-for-Profit Textbook Describing the Management of Gut Problems in hEDS/HSD

Barts and The London School of Medicine and Dentistry
London, England

The Aziz group has shown that people with hEDS/HSD are more likely to experience a range of gastrointestinal problems, especially disorders of gut-brain interaction, compared to those without these conditions. In a significant study, 33% of patients at the Royal London Hospital's gastroenterology clinics were found to have hEDS/HSD, a finding that has been replicated worldwide. Gastrointestinal issues are also common in related conditions like dysautonomia and MCAS.

People with hEDS/HSD often have to travel long distances to find healthcare professionals who understand their gastrointestinal issues, leading to high costs and long wait times. The lack of high-quality, evidence-based information on the internet further complicates their search for reliable guidance, which can negatively impact their health.

To address this, the researchers aim to collaborate with patient advocates and organizations like The Ehlers-Danlos Society to create a not-for-profit, patient-friendly textbook on gut issues related to hEDS/HSD, including nutritional guidance. The book will help improve patient education, healthcare outcomes, and quality of life. Profits will be reinvested into further research at the Wingate Institute of Neurogastroenterology, Queen Mary University of London, to continue studying these gastrointestinal challenges.

Tessa Hulburt

The Effect of a Combined Neuromuscular Training and Cognitive Behavioral Therapy Program on Physical Fitness, Strength, and Movement Biomechanics in Adolescents with Hypermobile Ehlers-Danlos Syndrome and Fibromyalgia Syndrome

Emory University School of Medicine

The wide range of symptoms and complex pain sources in hEDS make treatment challenging. Emerging therapies that combine cognitive behavioral therapy (CBT) with movement-based approaches show promise, but the lack of formal guidelines makes these treatments largely inaccessible.

To address this need, researchers aim to adapt an existing program, the Fibromyalgia Integrative Training program for Teens (FIT Teens), which has shown success in treating adolescent fibromyalgia. This program has demonstrated high participant retention, improved physical function, and safer movement without worsening pain. Given the similarities in pain presentation between hEDS and fibromyalgia, they believe that the FIT Teens program could benefit hEDS patients as well.

However, the unique challenges of hEDS, such as joint hypermobility and proprioception deficits, may affect how patients respond to this program. They propose a secondary analysis of FIT Teens data to compare changes in physical fitness, strength, and movement biomechanics between fibromyalgia patients and those who also meet the criteria for hEDS. This analysis will provide valuable insights to support the development of a tailored CBT and neuromuscular intervention specifically for the hEDS population.

Open Access Funding

In addition to funding research, The Ehlers-Danlos Society also offers open access funding for research papers. This is important for several reasons:

Increased Accessibility:
Open access ensures that research findings are freely available to everyone, including patients, healthcare professionals, researchers, and the general public. This democratizes knowledge and allows individuals affected by EDS and HSD to stay informed about the latest scientific advancements without the barrier of costly journal subscriptions.

Faster Dissemination of Knowledge:
Open access facilitates the rapid sharing of research findings across the global scientific community. This can accelerate the development of new treatments, improve diagnostic techniques, and enhance overall patient care by ensuring that important discoveries are quickly accessible to those who need them most.

Increased Impact and Citations:
Research papers that are freely available tend to be cited more often than those behind paywalls. This can increase the visibility and impact of our funded research, helping to advance the field of EDS and HSD by encouraging further studies and collaborations.

Supporting Patient Advocacy and Education:
Open access allows patients and advocacy groups to access the latest research, empowering them to advocate more effectively for themselves and others. It also supports our mission to educate the public and healthcare providers about EDS and HSD by providing evidence-based information that is readily available.

Global Reach:
Open access removes geographical barriers, enabling researchers and clinicians in low- and middle-income countries to access cutting-edge research. This is particularly important for rare conditions like EDS, where expertise may be limited and widely dispersed across the world.

Transparency and Trust:
By funding open access, the Society promotes transparency in research. Community members and caregivers can see exactly how research is conducted and how findings are applied to improve care.

The Ehlers-Danlos Society funded $12,254 for three research papers to be open access in 2023.

1. Extracutaneous features and complications of the Ehlers-Danlos syndromes: A systematic review
   Brent J. Doolan et al.

The Ehlers-Danlos syndromes are a group of inherited connective tissue disorders that can lead to skin fragility, joint problems, and severe complications like arterial rupture and bowel perforation. There are 14 identified types of EDS. Understanding the complications associated with each type is crucial for effective care and early diagnosis, which can prevent severe outcomes and improve patient quality of life. This research was partially funded by a microgrant from The Ehlers-Danlos Society.

2. Assessing Bleeding Symptoms in Pediatric Patients With Generalized Joint Hypermobility
   Nicole Kendel et al.

The Ehlers-Danlos syndromes are known to be associated with increased bleeding symptoms, including easy bruising, gum bleeding, and abnormal uterine bleeding. This bleeding is due to modifications in collagen that cause fragility of vessel walls, decreased support of those vessels, and affect the function of platelets (found in the blood, supporting healing, and important in helping to stop bleeding).

However, bleeding and bruising in people with generalized joint hypermobility (GJH), hypermobility spectrum disorders, and hypermobile Ehlers-Danlos syndrome has not been well-defined, particularly within the pediatric and adolescent populations.

As excessive bleeding symptoms could significantly impact overall health and quality of life, defining the general incidence and natural course of bleeding symptoms in this population are important. Early recognition in childhood or adolescence may help prevent bleeding and bruising concerns such as excessive bleeding during surgery or after trauma, and even incorrect diagnosis of physical abuse.

Led by Dr. Nicole Kendel, member of the International Consortium on Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders Hematology Working Group, a team from Akron and Columbus, Ohio, USA recently carried out research to assess bleeding symptoms in young people with generalized/benign joint hypermobility (GJH), compare bleeding scores to healthy historical pediatric controls, and determine whether a correlation exists between Beighton scores and bleeding scores.

The research team assessed eighty-one children aged between 10 and 16 years old with GJH. Seventy-eight percent of participants had abnormal bleeding scores, with a mean bleeding score significantly elevated compared to healthy controls. Commonly observed bleeding symptoms were oral bleeding (74%), easy bruising (59%), and bleeding with minor wounds (42%).

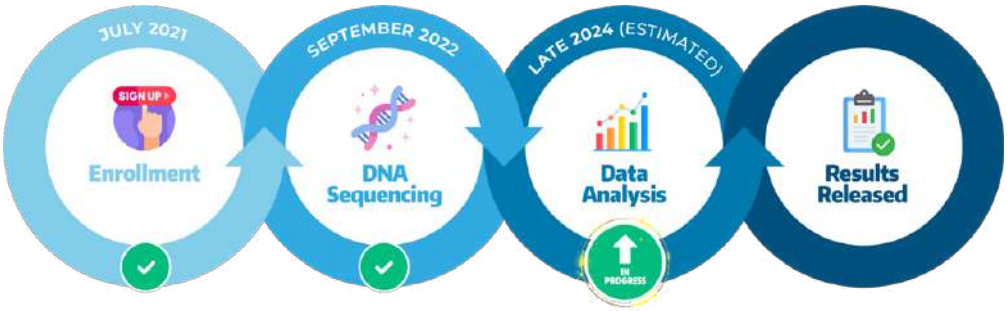
Bleeding scores did not depend on biological sex or nonsteroidal anti-inflammatory drug use, although there was a positive correlation with increasing age. Also, no correlation was found between a participant's bleeding tendency and their Beighton score.

Subsequently, the researchers propose that screening for bleeding symptoms should be integrated into routine care for people with GJH, with referral to hematology clinics for people with bleeding concerns.

3. Dermatologic manifestations and diagnostic assessments of the Ehlers-Danlos syndromes: A clinical review
   Brent J. Doolan et al.

The paper in the Journal of the American Academy of Dermatology examines the prevalence and clinical features of the EDS types in dermatology practice. It highlights the importance of recognizing skin and soft tissue manifestations in EDS for early diagnosis and management. The study emphasizes the role of dermatologists in identifying EDS-related complications and improving patient outcomes through timely referrals and appropriate care. The findings underscore the need for increased awareness of EDS among dermatologists to better serve this patient population.

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 (hEDS). 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.

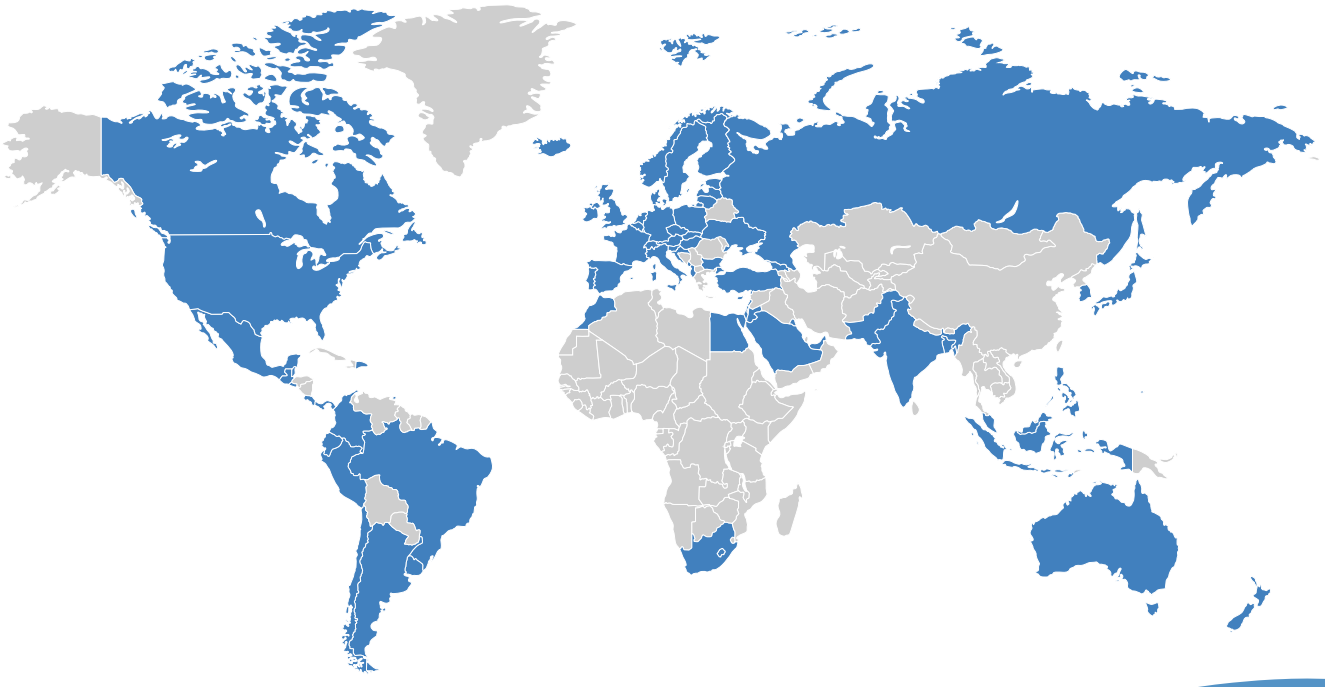
The HEDGE Study analysis team is currently analyzing **1,021** whole-genome sequences from individuals who have hypermobile Ehlers-Danlos syndrome (hEDS) by the 2017 clinical diagnostic criteria.

hEDS remains the only type of EDS that does not have known genetic markers and diagnosis cannot be confirmed through genetic testing. Many people with hEDS, therefore, experience delays in diagnosis, can be misdiagnosed and can experience delays in accessing suitable treatments.

The HEDGE study is a truly global collaborative effort with participants from **86 countries**. The HEDGE analysis team hopes to complete their analysis of the DNA samples in late 2024, with the publication of their findings expected in 2025.

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.

1,021 blood samples
Participants from 86 countries



The Ehlers-Danlos Society has funded a series of vital research studies alongside HEDGE to further the understanding of hEDS and HSD with the goal of finding the underlying causes for these conditions, as well as developing diagnostic tests.

Dr. Marco Ritelli, of the University of Brescia, Italy, was awarded $240,000 for his study, Targeted Serum Proteomics Through Proximity Extension Assay to Unravel Biomarkers for Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders.

Hypermobile Ehlers-Danlos syndrome (hEDS) is marked by joint hypermobility, musculoskeletal pain, and systemic issues, often leading to chronic disability without a known molecular cause. Diagnosis is challenging, relying on exclusion-based criteria, and many patients who don't meet these criteria are classified as having hypermobility spectrum disorders (HSD). Due to overlapping symptoms and the lack of a validated diagnostic biomarker, hEDS and HSD are often used interchangeably, complicating the diagnostic process. This research project aims to address these challenges by using targeted serum proteomics to identify potential biomarkers in hEDS and HSD patients. The findings could clarify whether these conditions are part of a spectrum or distinct disorders, leading to better diagnostic and therapeutic strategies. The project has significant potential to improve patient care, reduce unnecessary treatments, and lessen the social and economic burden associated with prolonged and uncertain diagnoses.

InVitro Cell Research, LLC (ICR) Pledges $2.375 Million for hEDS Research

On its global mission for change, The Ehlers-Danlos Society fosters collaboration and facilitates the progression and understanding of EDS and HSD. Toward that goal, we were delighted to receive a $2.375 million pledge from InVitro Cell Research, LLC (ICR) for research in hEDS. ICR is a privately funded regenerative medicine research company that is funding proteomics and metabolomics research in hEDS.

The study will focus on a subset of individuals with hEDS who donated their blood as part of The Ehlers-Danlos Society's HEDGE study and a control group.

ICR will use an integrative omics approach to find molecular "disease signatures" that could be used for diagnostics and identifying targets for future drug development.

We are grateful to ICR for its support, research, and commitment to research for the future of our community impacted by hEDS and HSD worldwide.

We would also like to especially thank each and every volunteer who has taken part in the HEDGE study and donated their time and DNA to help progress research.

Mike and Sofia Segal Family Foundation pledge $6.7 million to advance research

In December, we were delighted to announce a $6.7 million funding commitment from the Mike and Sofia Segal Foundation to advance groundbreaking research initiatives. This transformative pledge—which includes several gifts by the Foundation—is aimed at shaping a future where individuals affected by EDS and HSD can thrive.

In 1978, Mike and Sofia Segal arrived in the U.S. from present-day Ukraine with $120, a young child, and just two suitcases. They created their family foundation to champion causes that have been overlooked and underfunded. The gift to The Ehlers-Danlos Society reflects their steadfast commitment to support cutting-edge treatments for, and educate the public about, a range of rare diseases.

This marks a turning point for both The Ehlers-Danlos Society and the EDS and HSD community. The support from the Mike and Sofia Segal Foundation is invaluable in propelling our research towards earlier diagnosis, better understanding of the complications, and better treatment options. The foundations we have laid since our inception in 2016 are now paving the way for substantial advancements and positive changes that lie ahead.

Global Registry

Help Progress Research, Treatment, and Understanding

In order to continue to research for our future, we made the decision to move our Registry from the previous setting to the new REDCap platform hosted by The Ehlers-Danlos Society. In addition to security enhancements, the DICE EDS and HSD Global Registry has been re-organized and updated with new questions to provide enhanced quality and specificity for researchers.

DICE – Data, Inclusion, Collaboration, and Excellence

The DICE EDS and HSD Global Registry is an important tool in collaborative research, allowing community members to complete surveys and share medical information, to assist with research into EDS and HSD. The Registry will help researchers throughout the world to advance understanding of the EDS, HSD, and related symptoms and conditions, through use of the Registry data and by sharing new surveys for Registry members to participate in.

Each person who joins will help:

- Map the experiences of those living with EDS and HSD, globally.
- Enable the gene search for hypermobile EDS (hEDS) and hypermobility spectrum disorders.
- Facilitate research into the frequency of related symptoms and conditions, which may be associated with the various types of EDS and HSD.
- Discover new types of EDS or HSD.
- Understand the relationships between EDS and HSD, and chronic pain, anxiety, and other problems such as neurological, mast cell, gastrointestinal, and autonomic disorders.

The DICE Registry is accessible globally, and participation is free to all. Sign up and access the registry today via smartphone, tablet, or desktop device here.

The community's involvement in the EDS and HSD Global Registry is critical to us being able to research for our future, working towards better information and diagnosis for all those with EDS and HSD.

EDS ECHO: An Evolution in Medical Education and Care Delivery

What is Project ECHO®

Project ECHO® addresses population health in a scalable way—moving knowledge instead of people via telementoring and collaborative care with the philosophy of we can "all teach, and all learn."

The heart of the ECHO model is its hub-and-spoke knowledge-sharing networks, led by expert specialist teams. The ECHO model is not "telemedicine" where specialists assume the care of the patient; it is a guided model aimed at practice improvement, in which providers retain responsibility for patients, and gain greater independence through increased knowledge, skills, empathy, confidence, and self-efficacy.

In April 2019, The Ehlers-Danlos Society started the EDS ECHO program with two hubs, one at Indiana University Health, Indianapolis, IN, USA, and the other at The Royal Society of Medicine, London, UK. Over time, our programs and courses have grown to be worldwide, supporting healthcare professionals across multiple disciplines and community advocates and leaders in EDS and HSD.

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 EDS, 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 other topics for community leaders and educators, exploring ways participants can better teach and support those living with EDS or HSD.

Participants in our programs 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. We also help local and regional groups start a program for the care of their patients, expanding the EDS ECHO network, bringing care closer to home.

In 2023, we saw participation grow in the number of participants and the breadth of healthcare specialists. We have had 1,880 individual healthcare professionals and community advocates participate in our programs and courses to date, with 350 new health professionals joining our programs this year!

Across 2023, we held fourteen programs, with four new additions to the EDS ECHO portfolio:

- Nutrition
- Genetics and Genomics
- Drop-in Sessions Australasia
- Integral Movement Method (IMM) Drop-in Sessions

137
Sessions

196
Teaching/Learning Hours

147
Continuing Educational Credits Available

In addition, EDS ECHO ran two incredibly successful summit events this year:

Hypermobility Spectrum Disorders (HSD), and Fatigue - Causes and Management.

The feedback from participants has been amazing, and we are truly delighted that EDS ECHO is appreciated so much by so many. Enthusiasm and engagement were clear from the vibrancy of sessions throughout the EDS ECHO portfolio and the networking.

"I see a lot of young people with hypermobility who have not heard of or been diagnosed with a hypermobility disorder I will use this knowledge to advance my own screening process to assist in facilitating further need to see a specialist for diagnosis as needed."

"I feel more confident in applying diagnostic criteria. I plan to attend all sessions and hope this will help me provide better management."

"It was so interesting to hear the clinical reasoning of experts in their field. I thought the reflection about the moral and ethical duty to patients to first of all look for treatables was really good."

"I will pay more attention to the possibility that patients present characteristics of EDS and HSD and therefore take the appropriate measures so that they have optimal treatment."

EDS ECHO awarded ECHO Excellence Award at MetaECHO® 2023

The Ehlers-Danlos Society's EDS ECHO team were delighted to receive an ECHO Excellence Award at the MetaECHO® conference in Albuquerque, New Mexico at the 2023 MetaECHO Conference. The conference celebrated 20 Years of Project ECHO® and the ECHO Excellence recipients who have helped the movement grow into what it is today. The ECHO Excellence Awards recognize outstanding ECHO teams for their contributions to the ECHO global community.

Accepting the award on behalf of The Ehlers-Danlos Society, Dr. Hakim said, "Thank you Project ECHO. This is a huge honor. On behalf of the EDS ECHO team, I'd like to first thank our Facilitators, Administrators, Speakers, and Participants.

> "Second, all the teams at The Ehlers-Danlos Society and our generous donors and sponsors; to everyone, thank you for the amazing support.
>
> "Finally, there are two members of the team we'd like to give a loud shout-out to for their incredible dedication and hard work — Stacey Simmonds, Events Director, and Paul Gardener, EDS ECHO Manager.
>
> "We're looking forward to another wonderful and busy year next year that will also be our 5th anniversary. This award is a fabulous gift towards that."

The Ehlers-Danlos Society EDS ECHO team was there to share insights and accomplishments from our educational programs and events and were delighted to also receive this award. Assoc. Prof. Dr. Alan Hakim, Chief Medical Officer, Director of Education, Director of Research, and Lead for EDS ECHO at The Ehlers-Danlos Society; Dr. Clair Francomano, Professor, Medical and Molecular Genetics, Indiana University School of Medicine; Dr. Rebecca Bascom, Professor, Penn State College of Medicine EDS ECHO; Prof. Lara Bloom, President and CEO, The Ehlers-Danlos Society; EDS ECHO; and Paul Gardener, EDS ECHO Manager, presented a poster and plenary discussions sharing their research, insights, and learnings from our programs, events, and courses over the past four years.

EDS ECHO has facilitated and progressed research since October 2020, initially bringing together experts for a conference on comorbidities in EDS and HSD. The presentations and selected new research were then collated by Dr. Hakim, Dr. Brad Tinkle, and Dr. Francomano (Guest Editors) into a Special Issue of the American Journal of Medical Genetics, Part C, published in 2021.

Five Years of EDS ECHO

Ehlers Danlos Society ECHO

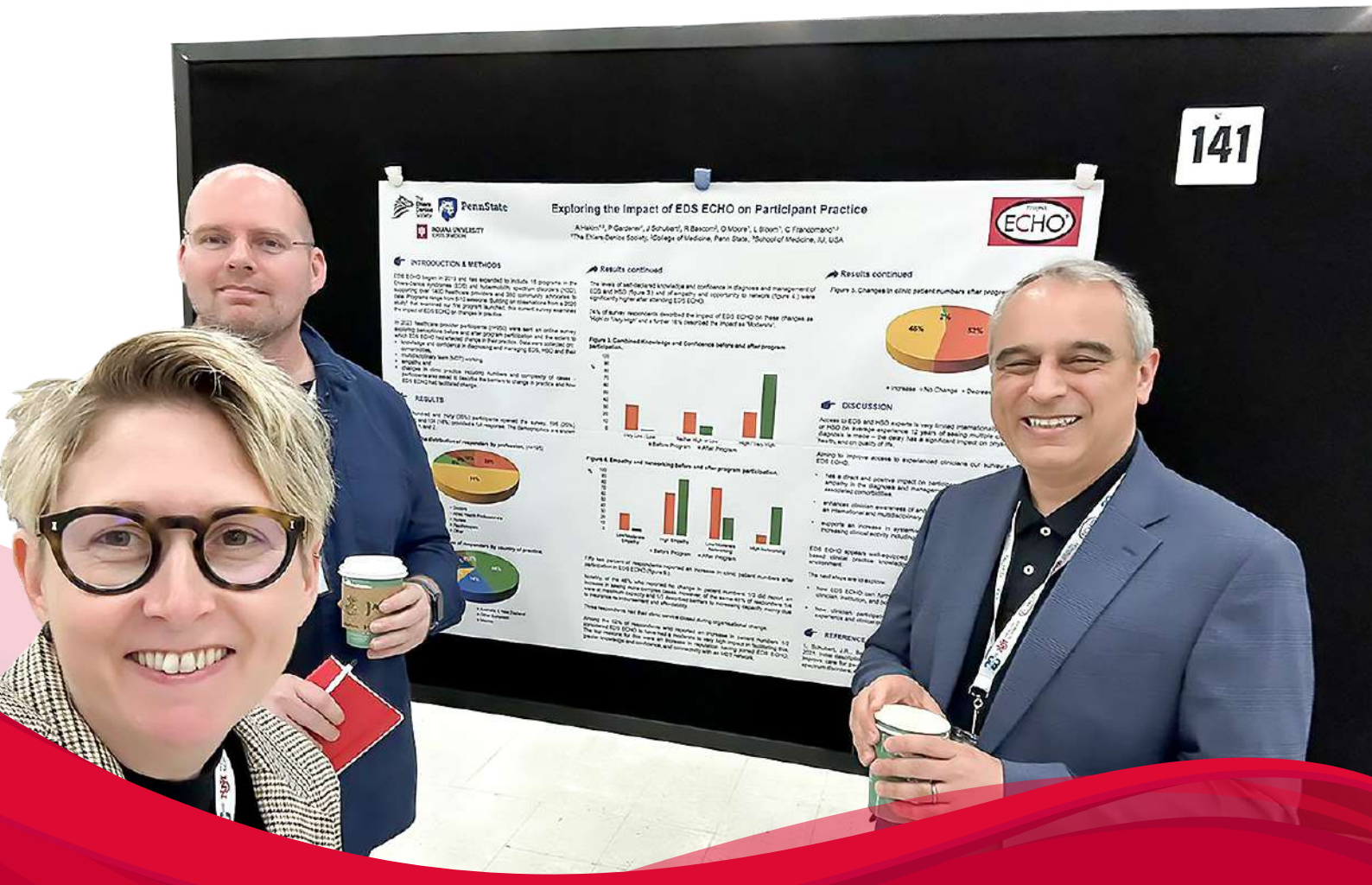
Project ECHO®

CELEBRATING 5 YEARS OF EDS ECHO
Educating, Empowering, and Expanding Horizons

As we head into 2024, and celebrate five years of this incredible program, we are delighted to soon be launching some exciting new programs and initiatives to EDS ECHO:

- The EDS ECHO Finding Functional Foundations (FFF)™ course for licensed physical therapists/physiotherapists wanting to learn how to use principles of neuroplasticity to retrain alignment and stability in hypermobile patients.
- The Ehlers-Danlos Society USA Medical School Fee Scholarship 2023-2024.
- The inaugural EDS ECHO Healthcare Student Program for 2024.

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

Advancing Knowledge and Building Connections: The Ehlers-Danlos Society Events

The Ehlers-Danlos Society's events program is a crucial platform for education, community building, and raising awareness about EDS and HSD. These conferences are vital for health professionals to access the latest research, treatment strategies, and expert insights, which directly contribute to improved patient care and outcomes.

In 2023, we continued to offer fully hybrid events, returning to in-person gatherings while ensuring broad participation through a robust virtual attendance option. To enhance accessibility, we provided all attendees with a dedicated event app, Whova, enabling them to engage fully by asking questions, participating in polls, voting in contests, and networking with peers.

Over the course of the year, we hosted five educational events that brought together leading experts for interactive discussions, presentations, and Q&A sessions. These events offered invaluable insights, shared experiences, and critical support for attendees. We were thrilled to welcome 974 health professionals, including 65% first-time attendees, highlighting the importance of reaching new professionals to expand the network of knowledgeable providers equipped to care for individuals with EDS and HSD.

Healthcare Professional Attendees

2022

56%

2023

65%

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. The Ehlers-Danlos Society's EDS ECHO program supports clinicians by increasing their knowledge; helps clinicians network with each other to discuss management strategies; improves access to care by increasing the number of experienced clinicians; and supports community advocates in raising awareness of EDS and HSD.

EDS ECHO Summit: Hypermobility Spectrum Disorders (HSD)

We were delighted to kickstart our exciting 2023 program of events with the virtual EDS ECHO Summit Series: Hypermobility Spectrum Disorders conference on April 1, 2023. This was our first event focused on HSD only!

This event was aimed at healthcare professionals, people who have been diagnosed with or are seeking a diagnosis of hypermobility spectrum disorder (HSD), their families, and caregivers. This event was also suitable for those previously diagnosed with hypermobility syndrome or joint hypermobility syndrome. Health professionals were able to claim up to 5.5 CME/CEU/CE credits for attending the event.

We welcomed **1,236 attendees**, including **564 healthcare professionals**, in 35 countries: **Albania**, **Armenia**, **Australia**, **Austria**, **Belgium**, **Brazil**, **Canada**, **Chile**, **Colombia**, **Finland**, **France**, **Germany**, **India**, **Ireland**, **Italy**, **Japan**, **Lithuania**, **Malaysia**, **Mexico**, **Netherlands**, **New Zealand**, **Norway**, **Panama**, **Peru**, **Philippines**, **Poland**, **Portugal**, **Romania**, **Singapore**, **South Africa**, **Spain**, **Sweden**, **Switzerland**, the **United Kingdom**, and the **United States**. Over 60% were first-time attendees to an Ehlers-Danlos Society conference, and we are delighted to continue to reach new community and professional audiences. Scholarships were awarded to more than 140 people to enable attendance and break down financial barriers.

The event covered topics including:

- Movement Therapy and Training
- Pediatric and Adolescent Types of HSD
- Lifestyle Strategies and Self-Pacing
- Coping with Autonomic Symptoms
- Dental and Facial Pain in HSD
- New Insights in Physical Therapy

Assoc. Prof. Alan Hakim, CMO, Research Director and Education Director at The Ehlers-Danlos Society, opened the event with a review of the latest literature and insights into HSD, looking broadly at what we have learned in the last five years about HSD, its associations with comorbid conditions and treatment, and setting the scene for the event. HSD are connective tissue disorders that cause joint hypermobility, instability, injury, and pain. Other problems such as fatigue, headaches, GI problems, and autonomic dysfunction are often seen as part of HSD.

> "We have an ever-growing evidence base that supports our clinical experience and recognizes the presence and the nature of ill health in HSD and EDS, also the possible mechanisms of disease, and the many treatment options that are available to us."

> "I believe it then becomes harder for those who prefer to dismiss us by insisting this is all either made up or by stating that there is nothing that can be done for people with HSD or EDS. Still too many in the HSD or EDS community experience unnecessarily arduous journeys en route to getting a diagnosis and treatment, and I just don't think that this can be justified by such opinions anymore."

> "Not only is this hugely important in supporting experienced clinicians and patients in understanding how best to manage HSD and EDS, but it should become easier for those not familiar with HSD or EDS to find more information."

Global Learning Conference 2023, Dublin, Ireland

The Ehlers-Danlos Society was thrilled to host its highly anticipated 2023 Global Learning Conference, in the vibrant city of Dublin, Ireland. This landmark event took place August 2-5, bringing together experts, medical professionals, researchers, and individuals from around the world.

The Global Learning Conferences provide a dynamic platform for exchanging knowledge, research advancements, and lived experiences. Attendees have the opportunity to engage in interactive discussions, attend workshops, and gain valuable insights into the latest developments in EDS and HSD management and care.

The conference featured a comprehensive program, including keynote presentations by esteemed specialists, and panel discussions on patient advocacy, research advancements, and quality-of-life improvements. Health professionals were encouraged to attend, with the opportunity to claim 21.5 Continuing Education credits for sessions attended live.

The theme of the conference was "Difficult Conversations in EDS and HSD" and covered topics that are often challenging for both patients and providers including effective communication for medical appointments, sexual health, neurodiversity, managing symptom flares, and gastrointestinal issues.

Throughout the conference, we were joined by **957 people** in **43 countries**, reaching eight new countries this year, including: **Australia**, **Austria**, **Belgium**, **Brazil**, **Canada**, **Chile**, **China**, **Costa Rica**, **Denmark**, **England**, **France**, **Georgia**, **Germany**, **Greece**, **India**, **Republic of Ireland**, **Israel**, **Italy**, **Japan**, **Luxembourg**, **Macedonia**, **Mexico**, **Netherlands**, **New Zealand**, **Norway**, **Northern Ireland**, **Panama**, **Peru**, **Philippines**, **Poland**, **Portugal**, **Qatar**, **Russia**, **Scotland**, **Singapore**, **South Africa**, **Spain**, **Sweden**, **Switzerland**, **United States**, **Uruguay**, **Venezuela**, and **Wales**. Of those, 40% were first-time attendees to a Society conference.

Global Learning Conference 2023, Dublin, Ireland

> "I loved how you facilitated virtual attendees to make sure we got the 'full' conference experience. I think meeting people is a big part of a conference and the Whova app was a great way to do so."

> "I think the multidisciplinary nature of the presentations were particularly helpful; while I understand potential approaches from a PT standpoint, it's so helpful to hear from other types of providers to hear them describe their approaches and concerns."

> "I work in a chronic pain program and have many patients with EDS or HSD. These conferences are invaluable for me to learn about how to help them."

> "I was extremely grateful for my scholarship. I liked the Whova app and being able to connect with others. It was very empowering and I really liked the emphasis on and acknowledgment of medical gaslighting and realistic ways to address it that is beneficial to patient and provider. I really enjoyed the emotional aspects of the event as well. I liked all of it really. I was grateful for the different cultural perspectives as well. The lectures were very validating and the whole presentation made me feel very at home."

> "The information guiding patients how to have difficult discussions with their providers was very helpful. I'm a Physical Therapist and specialize in treating hEDS/HSD and most of my patients have physicians that know nothing about these conditions and I regularly need to coach my patients through strategies to help these interactions be more productive and less stressful."

We were very proud to be joined by our incredible Partner Sponsors for this event, DM Orthotics and Body Braid, Collaborator Sponsor Lipedema Foundation, Non-Profit Sponsor Irish EDS and HSD Foundation, and our Supporter Sponsors Silver Ring Splint Company, Bionical Emas, and Zebra Splints.

Addressing the Unmet Needs of People with EDS and HSD in Ireland

The Ehlers-Danlos Society recognizes the lack of access to proper care and barriers to diagnosis experienced by those living with EDS and HSD in Ireland. The Global Learning Conference also facilitated a discussion for Irish community members, support groups, and healthcare professionals to better understand the unmet needs of those living in Ireland and how organizations can work collaboratively to improve this.

"We hope The Ehlers-Danlos Society hosting their annual Global Learning conference in Ireland demonstrates the prevalence of EDS and HSD in our country and helps grow much-needed awareness of these life-altering, complex conditions. EDS and HSD need to be recognized here by both our government and the medical profession, and there is an urgent need for a multidisciplinary medical team for EDS and HSD patients," said Anne Micks, Chair of Irish EDS and HSD, an Irish support organization.

The discussion was opened with an overview by Ms Micks, supported by Assoc. Prof. Alan Hakim, CMO, Research Director and Education Director at The Ehlers-Danlos Society; Lara Bloom, President and CEO at The Ehlers-Danlos Society; and medical genetic specialist Dr. Anand Saggar. It was attended by community members in person and virtually.
Ms Micks began by highlighting the importance of raising awareness about EDS and HSD among Irish patients, as the population affected by these conditions is steadily growing. While some improvements have been made in recent years, the progress has not been sufficient to meet the needs of the community.

One positive development mentioned was the monthly clinic organized by Dr. Saggar, which has significantly improved the lives of individuals with EDS and HSD Currently, it is estimated that there are over 2,000 diagnosed EDS patients and 650 diagnosed HSD patients in Ireland. Previously, patients had to travel to England for a proper diagnosis and treatment before Dr. Saggar's clinic was established. However, recent prevalence studies suggest at least 6,250 people have a type of EDS or HSD in Ireland and there is increased need for pathways to diagnosis and care.

It was emphasized that each person's journey with EDS and HSD is unique, and individuals must take responsibility in seeking answers and support. One of the challenges mentioned was the lack of validation and alternative treatment options from medical professionals, which can be demoralizing and traumatic for patients and their families.

The discussion focused on potential solutions to address these issues. One suggestion was to identify individuals who are passionate about making a difference and involve them in the process of change. Establishing a multidisciplinary team that can coordinate care was seen as crucial for providing comprehensive support. The Kent model, where patients and healthcare professionals engage in cross-dialogue, was highlighted as a potential approach to bringing about change and improving understanding.

It was acknowledged that addressing the unmet needs of individuals with EDS and HSD is not unique to Ireland but is a global issue. Efforts are being made by The Ehlers-Danlos Society to educate and re-educate healthcare professionals through EDS ECHO and educational events, with the 2017 criteria currently being revised. The launch of the Centers and Networks of Excellence program aims to reach out to local healthcare professionals and experts in Ireland and beyond to enhance their knowledge and expertise.

Addressing the Unmet Needs of People with EDS and HSD in Ireland

The importance of networking, camaraderie, and building a directory of local specialists was emphasized. It was noted that allied health professionals, such as physiotherapists, play a significant role in providing support to patients and should be included in the care team.

Another need highlighted during the discussion was the requirement for a centralized hub of knowledge on EDS and HSD. Currently, information sharing between hospitals is limited, causing patients to start their journey anew with each new healthcare provider. Official backing from The Ehlers-Danlos Society, healthcare professionals, and various stakeholders was deemed essential to address this issue and ensure that doctors are properly educated about these conditions.

The discussion also touched upon the financial implications of inadequate services for patients and the potential long-term benefits for the government by acknowledging and addressing these needs. Collaborative efforts between individuals, The Ehlers-Danlos Society, and relevant stakeholders were seen as crucial to drive positive change.

In conclusion, The Ehlers-Danlos Society will continue working with Anne Micks and other key stakeholders to improve support for individuals with EDS and HSD in Ireland. Efforts are being made to raise awareness, educate healthcare professionals, establish coordinated care systems, and advocate for the acknowledgement of these conditions at the governmental level. By addressing these unmet needs, steps are being taken to better support the EDS and HSD community in Ireland.

The 2024 Global Learning Conference will be held in Philadelphia, Pennsylvania, USA, July 17-21, 2024. The conference theme is "EDS and HSD: From Head to Toe" and will feature presentations, case studies, and panel discussions led by experts on the management of symptoms and comorbidities from head to toe in EDS and HSD.

Genetically-Defined EDS: Strategies and Solutions for Unmet Needs

Scientific Chair:

Fransiska Malfait, MD, PhD, Ghent University Belgium

Scientific Committee:

- Karelle Benistan, MD, Head of Clinic, Center for Medical Genetics, Hôpital Raymond Poincaré, France
- Lara Bloom, President and CEO, The Ehlers-Danlos Society, Academic Affiliate Professor of Practice in Patient Engagement and Global Collaboration, Penn State College of Medicine
- Marco Castori, MD, Chief, Division of Medical Genetics, Foundation IRCCS-Casa Sollievo della Sofferenza, Italy
- Serwet Demirdas, MD, PhD, Coordinator/Head of Expertise Center for Ehlers-Danlos Syndrome, Erasmus MC, Netherlands
- Alessandro Ferraris, MD, PhD, Center for Medical Genetics, San Camillo Forlanini Hospital Italy
- Michael Frank, MD, PhD, Hôpital Européen Georges Pompidou, France
- Zoltan Szekanecz, Professor of Rheumatology, Immunology, and Medicine, University of Debrecen, Faculty of Medicine, Hungary

From August 30-31, 2023, The Ehlers-Danlos Society, The Ehlers-Danlos Society's Chief Scientific Officer and Scientific Chair Professor Fransiska Malfait, and the Scientific Committee began two days of discussions and collaborations at the Genetically-Defined EDS: Strategies and Solutions for Unmet Needs Hybrid Meeting in Ghent, Belgium, and live-streamed around the world. The term "genetically defined" applies to those types of EDS with known genetic causes.

The event brought together 200 scientists, healthcare providers, patient advocate groups, and patients from around the world to discuss current knowledge on the genetic and pathophysiological basis of genetically defined types of EDS, classification, and strategies needed to optimize diagnosis, care, and treatment. A truly global meeting, attendees joined in person and virtually from countries including Belgium, France, USA, Canada, Japan, Netherlands, Hungary, Sweden, Switzerland, and the UK.

Since the clinical picture of EDS is complex, it requires a range of experts in basic research in the fields of genetics and extracellular matrix biology, clinicians who deal with these diseases and their complications, genetic counselors, and allied health workers who are involved in the multidisciplinary management of these patients.

The focused interactions between these professionals and community members are crucial to enable constructive multidisciplinary debates focusing on the multiple clinical and research needs of the EDS types.

Genetically-Defined EDS: Strategies and Solutions for Unmet Needs

This networking event had four main objectives:

(1) to share knowledge on the genetically defined EDS types among healthcare professionals, researchers, and patients, taking advantage of bringing together and expanding different European and international networks involved in EDS (including participants from underrepresented countries);

(2) to develop new research hypotheses, priorities, and strategies;

(3) to encourage new interdisciplinary international collaborations; and

(4) to provide international resources for clinical and molecular diagnosis and care.

Leading expert speakers shared knowledge on the genetically defined types of EDS taking advantage of bringing together and expanding different European and international networks involved in EDS (including participants from underrepresented countries). The networking event encouraged new interdisciplinary international collaborations, provided international resources for clinical and molecular diagnosis and care, and the opportunity to develop new research hypotheses, priorities, and strategies. Health professionals also had the opportunity to claim up to 13.5 Continuing Education credits.

Community member Edward Fraser opened the event by sharing his experience with attending health professionals and scientists, of PLOD1-related kyphoscoliotic Ehlers-Danlos syndrome. Mr Fraser shared what finally having a confirmed genetic diagnosis meant to him, and how it benefits his subsequent medical care under the EDS Diagnostic Service in the UK.

Edward struggles with achalasia, which makes it difficult for food and liquid to pass into the stomach. Edward lost a lot of weight and had severe difficulties swallowing. Edward shared how often his challenges with health lead to surgery, and the intense planning and monitoring needed from his surgical team to care for him safely and ensure a successful surgery.

Edward's journey highlighted why this international event was so vital to encourage new interdisciplinary international collaborations and to provide global resources for clinical and molecular diagnosis and care.

Community voices were also shared from individuals from around the world living with classical-like EDS, dermatosparaxis EDS, vascular EDS, and periodontal EDS.

> "I have only had my son's diagnosis for about a month and have minimal information. This helped me understand that some of my thoughts were accurate as to what should be happening. I definitely feel that I know some things to prepare for now that I wasn't aware of. I still have so much to learn."

> "Thrilled to keep myself up to date with the new knowledge that was shared. I enjoyed the discussions and debates. Top quality speakers and attendants, very good opportunity for networking."

EDS ECHO Summit: Fatigue - Causes and Management

Around three-quarters of people with a type of EDS or HSD report some degree of persistent fatigue. Persistent or chronic fatigue is the medical term used to describe extreme tiredness or a lack of energy that prevents a person from functioning normally. Chronic is the term used when fatigue is persistent for more than six months - it may be constant, have bad days and better days, or keep recurring - all with a marked impact on a person's quality of life.

The main symptom is tiredness, but it is much more than the normal tiredness that every person experiences. People with persistent fatigue often describe it as a total exhaustion of every muscle in their body and/or "brain fog" (i.e., problems with concentration, thinking, and memory).

The EDS ECHO Summit Series: Fatigue - Causes and Management was held on October 21, 2023, welcoming 1,130 health professionals and community members from 33 countries: Algeria, Australia, Austria, Belgium, Brazil, Canada, Chile, Colombia, Costa Rica, Ecuador, Finland, France, Germany, Iceland, Republic of Ireland, Israel, Italy, Japan, Jordan, Luxembourg, Mexico, Netherlands, New Zealand, Norway, Poland, Portugal, Singapore, South Africa, Spain, Sweden, Switzerland, the United Kingdom, and the United States.

A comprehensive event program included presentations on topics including:

- Causes, Assessment, and Management of Fatigue
- Pacing, Exercise, and Managing Daily Activities
- Headaches
- Dysautonomia
- Sleep Quality and Sleep Disturbance
- Nutrition and Fatigue
- Mast Cell Disorders
- Psychological Health and Fatigue

This event was approved for up to 7.0 CME/CEU/CE credits for healthcare professionals to claim for sessions attended live.

> "I loved hearing about the current research and practical management tips. The blend of both was great. I'm now going to ask my doctor about potential Vit D, B12, or magnesium deficiencies and how OT might be able to help me."

> "The fact that this event was being recorded will help myself and many others like me who live with chronic fatigue but still want to learn and be immersed in the Society events."

> "Thank you so much for everything you all did to make this event so successful. I feel seen and validated. It was valuable to learn how fatigue and migraine are linked."

In 2024, we look forward to EDS ECHO Summits on emergency care and diet and nutrition.

Externally Led Patient-Focused Drug Development Meeting

On October 31, 2023, the Externally Led Patient-Focused Drug Development (PFDD) Meeting provided a crucial platform for patients with hEDS and HSD to share their experiences. This event aimed to offer valuable insights into the daily challenges faced by those living with these conditions, directly informing the FDA and other stakeholders involved in drug development.

The PFDD program is designed to gather input from patients about their diseases and current treatment options, helping the FDA make more informed decisions when approving new drugs. During PFDD meetings, the FDA, pharmaceutical companies, healthcare providers, and patient advocates listen to patients and their families discuss the most significant symptoms, the impact on their daily lives, and their experiences with existing treatments. This feedback is essential for guiding drug development and approval processes.

The objectives of this meeting were:

- To explore the need for therapies to manage the complex symptoms of hEDS and HSD.
- To highlight how untreated symptoms affect the daily lives and quality of life for individuals with these conditions.
- To identify the challenges patients face in accessing appropriate therapies or medications.

This event provided a deeper understanding of the impact of hEDS and HSD on patients' lives, as well as the effectiveness of current treatments, care, and ongoing research.

> "What a profound experience presenting to FDA representatives at the Externally Led Patient-Focused Drug Development Meeting in DC yesterday. Seeing old friends and colleagues, meeting new zebra friends and working to change the future of care for people living with EDS and HSD."
>
> **Mars Lombardi**, Treatment: Adaptive Aids and Devices to Help with Symptoms

> "So many great moments from a zebra-themed day! It was such an honor to be invited to speak at today's meeting, where we had the opportunity to share more about hEDS and HSD with the FDA. A huge theme across our many conversations today was community, and I feel so lucky to have so many new incredible people to consider a part of my dazzle."
>
> **Emily Rubenstein**, The Diagnostic Odyssey

> "Today was wonderful, I met and talked to so many great people! My spirit needed all of today. It felt great to be able to speak to national and International doctors who are EDS-knowledgeable and wanted to hear from us directly about our lived experiences. And speaking to FDA Representatives directly - WOW!"
>
> **Sabra Thomas**

EXTERNALLY LED PATIENT-FOCUSED DRUG DEVELOPMENT MEETING
OCTOBER 31 2023

Externally Led Patient-Focused Drug Development Meeting

The meeting concluded with the creation of a "Voice of the Patient" report, capturing the insights shared by patients and their representatives.

> "I really enjoyed hearing from individuals with lived experience. I learned a lot more about what The Ehlers-Danlos Society does, particularly funding research and advocating for better care and treatment options for EDS and HSD."

> "The event gave me more confidence in approaching health care providers about conditions associated with EDS."

> "Just hearing other people going through the same journey makes me feel stronger! Just today I got the wheels turning to get help at home and I felt strong because of this event. So thank you so much and keep up the amazing work."

Amplifying Voices During May Awareness Month

In May, we launched a powerful campaign to raise public awareness about EDS and HSD, uniting our global community like never before.

Through the Acts of Awareness social media initiative, educational resources, and community events, we engaged people worldwide, highlighting the challenges faced by those living with these conditions. This campaign fostered empathy, debunked myths, and inspired action, moving us closer to a society that truly understands and supports individuals with EDS and HSD.

Thanks to our dedicated supporters, an incredible **$85,019.21** was raised to further our global mission!

Take a hike EDS - Larissa is helping make our mission possible!

We're thankful for Larissa in Minnesota, USA, who completed an incredible 60 hikes fundraising for The Ehlers-Danlos Society, raising over $1,200 to support our global mission!

Across seasons, day and night, Larissa has hiked for awareness, sharing her walks and educating on EDS and HSD through social media - we've loved watching her journey unfold and thank everyone who has cheered her along from the community.

"After many years of seemingly random illness and ailments, I was finally diagnosed with EDS in 2021. From the day I learned of EDS, it was obvious that there was not a lot of information out there. And there aren't enough doctors knowledgeable on the matter, much less able to diagnose.

"My goal was to fundraise for The Ehlers-Danlos Society: the leading organization pushing for EDS care, access, research, and education."

For Ethan - Raising awareness so others don't have to suffer

Matthew Mann from the United Kingdom fundraised for The Ehlers-Danlos Society in support of his son Ethan. Matt has raised over £2,800 since starting his fundraising in May.

"Our eldest son Ethan was diagnosed with Ehlers-Danlos syndrome (EDS) at the end of 2022. The diagnosis came after over 70 dislocations that required scores of hours in hospital on a weekly basis.

"Ethan's condition continues to challenge our family to this day, presenting difficulties walking, attending school to learn, attending his much-loved Jiu-Jitsu lessons to train at Macmillan Martial Arts Academy. Our family has had to adapt to the challenges on a daily basis, trying our best to give him a new normal.

"I'll be continually fundraising and raising awareness of this terrible condition."

Matt completed 5,000 minutes of martial arts during May Awareness Month and has since set up a line of charity clothing and training apparel which is gradually being expanded. Proceeds of sales go to support our shared mission.

The Power of Community: Our End of Year Campaign

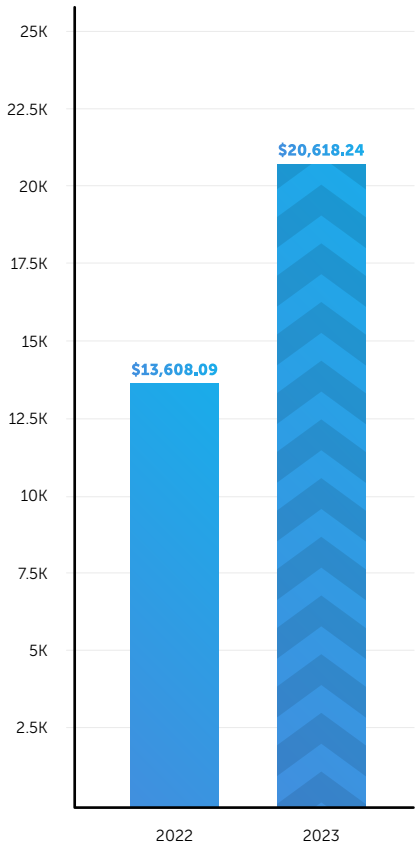
The End of Year campaign is more than just a fundraising effort—it is a powerful moment when our community comes together to drive our mission forward during the holiday season. This annual campaign is crucial in providing the resources needed to sustain and grow our programs, which are vital to improving the lives of those affected by EDS and HSD.

In 2023, we witnessed incredible generosity from our supporters, who helped us raise an outstanding **$337,040.25**. These funds are not just numbers; they represent hope, progress, and a shared commitment to transforming lives. Each donation, big or small, directly impacts our ability to advance research, enhance care, and expand access to essential resources.

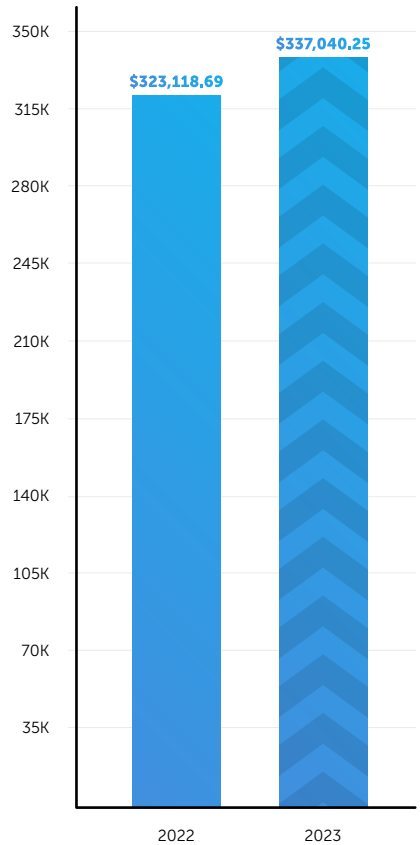
We were thrilled that an anonymous donor (whose family understands the journey of EDS and HSD) enabled us to run a matched giving campaign, matching our supporter's generous donations of up to $300,000. Their support now means double the progress!

May Awareness

Giving Tuesday



End Of Year



Join Us in Funding Our Shared Mission

While we celebrate the progress we've made over the past year, we know there's still so much more to accomplish. We invite you to be part of our mission to enhance care, expand access, fuel research, and advance education for those living with EDS and HSD.

Your support—whether through donations, volunteering, or spreading the word—directly contributes to our collective goal of transforming lives and building a brighter future for everyone affected by these conditions.

Let's continue to make an impact together.

Together, we dazzle.

Donate today at: ehlers-danlos.com/donate

Income & Expenses

Income	Amount
Corporate	$2,532,970
Grants	$85,844
Individual Donations	$7,156,250
Events	$396,622
TOTAL	**$10,171,686**

Expenses	Amount
Admin	$644,477
Fundraising	$352,976
ECHO	$149,703
General Research	$523,168
HEDGE	$312,733
Research Studies	$2,399,532
Events	$283,369
CNE	$95,057
Education	$617,743
TOTAL	**$5,378,758**

Staff

Lara Bloom
President & CEO

Mark Martino
Editor

Rebecca Gluck
Community Education & Support Director

Fransiska Malfait
Chief Scientific & Medical Officer

Faye Moran
Events Coordinator

Charlotte Peck
Website, IT & App Manager

Eric Alley
Finance Director

Scarlett Eagle
Community Content Coordinator

Amelia Rinker
Registry & Research Program Manager

Jack Annable
Senior Graphic Designer

Janae Davis
Grants & Corporate Partnerships Coordinator

Nina Fernandez
Community Support Coordinator

Rachel Boon
Design & Communications Manager

Alan Hakim
CMO, Research Director & Education Director

Stacey Simmonds
Education & Events Director

Erin Simons
Marketing Director

Sinead Waugh
Operations Director

Danielle Hohlier
Development Director

Paul Gardener
EDS ECHO Manager

Oumaima Nehaili
Research Program Manager

Bethann Pillow-Edwards
Biobank Manager

Rosie Harper
People Operations Coordinator

Emily Broughton-Shotbolt
Community Fundraising Coordinator

Samantha Lynch
Executive Assistant to President & CEO

Kellen Roach
US EDS ECHO Programs Coordinator

Barnum Pedryc
Creative Artworker