The Ehlers Danlos Society

IMPACT REPORT

January 1 - December 31, 2024

Letter From the President and Chair of the Board of Directors

Dear Friends and Supporters,

As we look back on 2024, we do so with a deep sense of **gratitude**, **pride**, and **purpose**. This year has been a remarkable chapter in our journey to improve the lives of individuals with Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD)—a year defined by **innovation**, **connection**, and **transformation**.

Thanks to your support, The Ehlers-Danlos Society has continued to grow as a global leader in EDS and HSD. Every step forward in CARE—Care, Access, Research, and Education—has been made possible by your belief in our mission.

Through our mission of CARE, we reached new heights. In 2024, we funded over $8 million in research across two critical streams: our Research Grant Program, which awarded competitive grants to international researchers, and our funded research studies, developed in collaboration with leading institutions to address urgent clinical questions.

Through the Research Grant Program, we supported pioneering projects in areas such as skin biology, proteomics, and biomarker discovery. We funded several studies including a major new gastrointestinal study led by Professor Qasim Aziz in the UK exploring how the nervous, immune, and digestive systems interact in EDS, with the goal of improving personalized treatment.

Our flagship HEDGE study—the largest-ever effort to uncover the genetic basis of hypermobile EDS—also reached a major milestone this year. With over 1,000 whole-genome sequences analyzed, early findings were presented at the American Society of Human Genetics, and several publications are now underway. This work is laying the foundation for future diagnostic tools, treatment trials, and scientific understanding of hEDS.

We also opened researcher access to our DICE Global Registry, enabling collaboration through anonymized real-world data. And looking ahead, our Global Biobank, launching in Fall 2025, will provide critical biological samples to support the next wave of discovery.

This year also marked the launch of a landmark initiative: The Road to 2026. Led by an expert committee from the International Consortium on EDS and HSD, this global effort will update the 2017 International Classification of the Ehlers-Danlos syndromes. The goal is to improve how all types of EDS and HSD are classified, diagnosed, and managed worldwide. The Ehlers-Danlos Society's role in this process is to provide administrative and financial support, and to bring the patient voice to the table and ensure lived experience is part of the research process.

When published in late 2026, these updates will offer clearer diagnostic criteria, more accurate clinical tools, and practical guidance for healthcare providers—helping reduce delays, misdiagnoses, and uncertainty for people living with EDS and HSD.

This year also brought important advances in how we share trusted information and connect with our global community. We launched the official Ehlers-Danlos Society app, putting education and resources directly into the hands of individuals, families, and professionals around the world. Designed for ease of use and accessibility, the app brings our support closer than ever—no matter where someone lives or where they are in their journey.

Letter From the President and Chair of the Board of Directors

We also launched new Body Systems pages for each type of EDS and for HSD, offering clear, accessible guidance on how these conditions affect every part of the body. These pages represent a significant step forward in our commitment to patient education, empowering people to understand their symptoms, advocate for their needs, and better manage their care.

Our EDS ECHO program celebrated its fifth anniversary by expanding across disciplines and borders. In 2024, we delivered 14 programs, hosted 155 sessions, and welcomed 491 new participants, including hundreds of healthcare professionals across 52 countries. With new initiatives for physical therapists, students, nutritionists, and advocates, EDS ECHO is reshaping the future of care.

We were honored to host our Global Learning Conference in Philadelphia, welcoming over 2,200 attendees from 39 countries—including our largest-ever Junior Zebras group. Our Emergency Care and Diet & Nutrition Summits reached thousands worldwide, offering accredited learning and practical tools for clinicians, caregivers, and community members alike.

Throughout it all, you—our community—have been the constant. You've attended sessions, completed surveys, supported peers, donated to research, and shared your stories. Whether from your home, your clinic, or your corner of the world, you've helped us ensure that no one faces these challenges alone.

We are proud of what we've accomplished together in 2024—and even more inspired by what lies ahead. With your continued support, we will keep breaking new ground in research, expanding access to care, and building a world where everyone with EDS or HSD can thrive.

Together, we are creating
a future filled with
knowledge,
connection,
and **hope**.

With heartfelt thanks,

Professor Lara Bloom
President and CEO
The Ehlers-Danlos Society

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

CARE

Supporting the EDS and HSD Community Every Step of the Way

Helpline

The Ehlers-Danlos Society's helpline continues to be a vital point of connection for individuals living with EDS and HSD, their families, caregivers, educators, and healthcare providers. Offering timely, accurate, and compassionate support, the helpline is often a lifeline during moments of uncertainty and isolation.

In 2024, demand for our helpline grew significantly, with a 53% increase in phone calls and an 11% rise in emails year-over-year. Our dedicated team responded to 809 calls and 2,766 emails, providing potentially life-changing advice and reassurance.

Whether it's sharing up-to-date information, referring to specialist providers via our Healthcare Professionals Directory (our most accessed online resource), or guiding individuals to support groups and community charities, the helpline is a trusted resource for thousands.

It also plays a vital role in:

- Empowering individuals with self-advocacy tools
- Supporting families and caregivers navigating care
- Assisting professionals seeking to better understand EDS and HSD
- Offering emotional validation and hope during challenging times
- Sharing updates on the latest research and resources

"Thank you so much. This is all extremely helpful. **It gives me hope after finding myself this morning on the verge of giving up**. Deep breath! There are possibilities."

Virtual Support Groups: Let's Chat

For many, our virtual support groups are the first time they've ever met someone else living with EDS or HSD. These safe, welcoming spaces bring people together across borders and time zones to share, connect, and be heard.

In 2024, we hosted **84 support group meetings with more than 1,800 participants** from around the world. Let's Chat groups were held for a wide range of individuals, including:

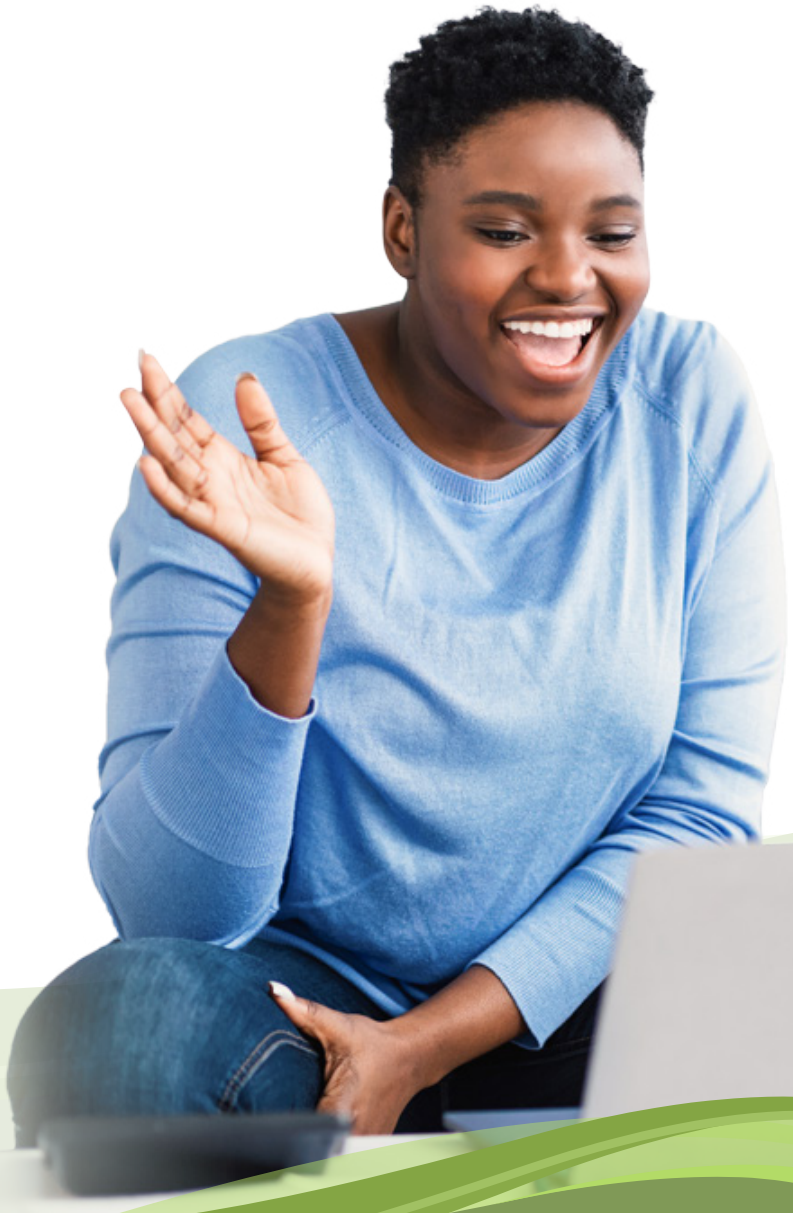
- People with all types of EDS and HSD
- Teens
- Parents and caregivers
- Partners and spouses
- Men
- LGBTQIA+ individuals
- Those affected by vascular EDS (vEDS)

Topics regularly included:

- Managing symptoms and daily life
- Navigating doctor visits and diagnoses
- Coping with emotional and mental health challenges
- Building self-advocacy skills
- Connecting with others who "just get it"

"I've never spoken in the group because of my anxiety, but attending has helped me feel less alone. **These groups have saved me**."

"The information and **shared experience** is blowing my mind!"



Community Connections

Whether through online forums, social media, or storytelling, community connection continues to be at the heart of our mission.

On Inspire, our online message board, over **141,000 members** from **150+ countries** gather to share experiences, support one another, and discuss health providers, symptoms, and daily life.

Our social media communities grew to over **335,000 supporters** this year, with **over 32 million people reached** across Facebook, Instagram, LinkedIn, and YouTube—**a growth of 11 million over last year**. Our awareness campaigns, personal stories, and educational content help individuals feel seen and supported.

"For 31 years, I thought something was wrong with my body. I kept thinking I was defective. **I'm so glad I found medical professionals who understand how I feel**, and organizations like yours that explain everything so clearly."

CARE

Supporting Our Junior Zebras

Our Junior Zebras are the future of our community—and we're committed to supporting them at every age and stage. From diagnostic tools for pediatricians to virtual teen chats and in-person camp experiences, we're building resources for our youngest members and their families.

Let's Chat: Teens

Each month, teens aged 13–18 join a virtual space where they can share experiences, build friendships, and connect with others who understand life with EDS and HSD.

Junior Zebras at the Global Learning Conference

Our largest Junior Zebras program yet took place in 2024 at the Global Learning Conference in Philadelphia, **welcoming 75 kids and teens aged 6–17**. Led by our partners at Camp Joy, the program offered a packed schedule of crafts, games, music, and age-appropriate discussions with healthcare professionals.

We also partnered with the Pediatric Working Group of the International Consortium on Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders to advocate for earlier diagnosis and better care. In 2024, the American Academy of Pediatrics included our updated Pediatric Diagnostic Checklist in its CME program and in PREP Rheumatology—a vital step toward raising pediatrician awareness nationwide.

What did your child love 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."

"He enjoyed being in the company of others like him."

"Meeting another Junior Zebra from his state; not too far from where we live."

"Getting to meet other zebras and make new and international friends."

CARE

ACCESS

Breaking Down Barriers to Diagnosis, Care, and Information Worldwide

In 2024, The Ehlers-Danlos Society continued its commitment to removing the systemic, geographic, and informational barriers that too often delay care for people with EDS and HSD. From trusted digital tools and multilingual resources to expanding provider networks and collaborative alliances, we worked to help as many people as possible gain access to the knowledge, professionals, and support they need, wherever they live in the world.

The Road to 2026: Bringing Global Voices to the Table

The Road to 2026 is a global initiative to update the 2017 International Classification of the Ehlers-Danlos syndromes. This update is being led by experts from the International Consortium on EDS and HSD, with the goal of advancing understanding, improving diagnostic criteria, and reducing time to diagnosis for people with EDS and HSD worldwide.

But expert input alone is not enough. Lived experience must also shape the future of care. That's why, in 2024, we launched multilingual surveys and a global community feedback form to ensure real-world experiences guide this next chapter. This process will culminate in a series of scientific publications, including updates to classification and management guidelines, anticipated in late 2026.

Removing Language Barriers

To support *The Road to 2026* and other core initiatives, we expanded our translation efforts. Key resources and feedback forms were made available in **nine languages**: Arabic, Dutch, French, German, Italian, Japanese, Portuguese, Spanish, and Swedish.

This helps support people with EDS and HSD across the globe participate in conversations about their care.

ROAD TO 2026

Digital Access to Information

Our website remains the central hub for trusted, up-to-date content on EDS and HSD. In 2024, it **served over 1.8 million users globally.**

We launched new or expanded sections covering:

- All types of EDS and HSD
- Physical therapy
- Occupational therapy
- Braces, splints, and mobility aids
- Skin
- *The Road to 2026*

All medical content is reviewed in collaboration with working groups from the International Consortium, ensuring accuracy and alignment with the latest science.

"The resources on your site helped me find a specialist. After years of being dismissed, I finally got a diagnosis. Thank you so much for making this information accessible."

ACCESS

Improving Accessibility for All

This year, we launched **accessiBe**, an adaptive technology that improves website accessibility for people with disabilities, including those with sensory sensitivities, visual impairments, and neurodivergent traits. This tool supports our commitment to equity, inclusion, and making information usable for all.

Expanding Access Through Technology: The Ehlers-Danlos Society App

In 2024, we launched The Ehlers-Danlos Society App—a powerful tool designed to bring vital resources, education, and connection directly to our community's fingertips. With over 7,000 downloads to date, the app is already helping individuals, caregivers, and healthcare professionals navigate the complexities of EDS and HSD.

Built for accessibility and ease of use, the app supports our mission to remove barriers to care and education, no matter where someone lives in the world.

Key Features:

- **Helpful Resources:** Browse trusted education, management strategies, and links to support services
- **Symptom Summary:** Record symptoms and share summaries with your care team to support clearer, more informed conversations
- **Medication Summary:** Keep medications organised and ready for appointments
- **Healthcare Professional Hub:** Access tools and guidance tailored for clinicians caring for people with EDS and HSD
- **Diagnostic Tools:** Support early detection and better understanding of signs and symptoms
- **Community Connection (coming soon):** A new platform for sharing experiences and peer support

This is a major step forward in our commitment to improving global access, delivering tools that not only support day-to-day management but also improve communication with care teams and empower users to take charge of their health.

"The app makes it easier to track symptoms, prepare for appointments, and explain my story. **It's like having support in my pocket**."

ACCESS

Connecting People with Expert Care

Healthcare Professionals Directory

Our Healthcare Professionals Directory remains our most visited online tool. In 2024, we welcomed over **600 new providers**, now representing nearly **60 countries**.

New countries this year include Kuwait, Qatar, Cyprus, South Africa, Sweden, Germany, China, Peru, Malaysia, Greece, and Costa Rica.

"I used the Directory to find a specialist in my area, and it made all the difference. I finally felt heard and got the help I needed."

CORE Network of Excellence

CORE NETWORK OF excellence
CARE - OUTREACH - RESEARCH - EDUCATION

The CORE (Collaboration, Outreach, Research, and Education) Network of Excellence is our global framework for improving care for people with EDS and HSD.

In 2024, we welcomed **15 new CORE members**, bringing the total to **38 multidisciplinary teams in 11 countries**: Australia, Canada, Chile, France, Germany, Italy, Kuwait, the Netherlands, Spain, the United Kingdom, and the United States.

CORE members are committed to:

- Delivering comprehensive, patient-centered care
- Offering multidisciplinary services under one roof or via coordinated pathways
- Supporting continued medical education and provider training
- Contributing to research and community engagement
- Promoting equity and inclusion in access to care

To be recognized as a CORE member, applicants must meet strict criteria in areas such as service availability, team composition, diagnostic experience, and quality assurance.

"The CORE Network is about more than a title, it's about action, commitment, and collaboration to ensure people with EDS and HSD receive the care they deserve."

ACCESS

Connecting People to Local Support

Our Support Group and Charity Directory helps people find trusted resources in their local communities. In 2024, we listed **112 verified groups and organizations** across dozens of countries, with new groups added from South America, Europe, and Asia.

The EDS & HSD Alliance

The Ehlers-Danlos Society
EDS & HSD
Global Alliance

Relaunched in August 2024, the EDS & HSD Global Alliance—formerly the Global Affiliation Program—is a growing global network of community groups, non-profits, and local leaders working to raise awareness and support individuals living with EDS and HSD.

We're proud to partner with 96 Alliance members from 21 countries, including Argentina, Australia, Belgium, Canada, Czech Republic, Denmark, France, Germany, Ireland, Israel, Italy, Japan, Luxembourg, New Zealand, Norway, Spain, Sweden, Switzerland, Uganda, the United Kingdom, and the United States.

Alliance members collaborate to:

- Share translated materials and resources
- Disseminate education and survey opportunities
- Represent their communities in global conversations
- Help shape equitable international policies

"Congratulations on the relaunch—the new Alliance name is clear and inclusive. It's so important that people in smaller countries feel seen."

ACCESS

RESEARCH

A Global Commitment to Discovery.

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. In 2024, we supported groundbreaking studies spanning genetics, epigenetics, proteomics, metabolomics, biomarkers, digestive health, and skin tissue—all with the potential to transform lives.

Research Grant Program

The Research Grant Program continues to support promising researchers and investigators in their pursuit of scientific advancements in EDS and HSD. Through funding and mentorship, we are fostering a vibrant research community dedicated to unraveling the complexities of these conditions.

This year, The Ehlers-Danlos Society awarded $1.2 million across four research studies.

Pathophysiological and Therapeutic Markers

This grant aims to advance our understanding of pathophysiology and the use of biological markers in EDS and HSD. By encouraging multidisciplinary teams to explore specific patient populations and underlying biological mechanisms, this initiative fosters collaboration for the benefit of the global community.

Grant Awardees:

Chantal Berna
Lausanne University Hospital, Lausanne, Switzerland
Grant Awarded: **$300,000**
Project: **Biomarker Identification in hEDS/HSD Sub-Phenotypes**

This study explores the wide variation in symptoms and comorbidities among people with hypermobile EDS (hEDS) and hypermobility spectrum disorders (HSD). By examining biological samples (blood, saliva, and stool) from a large group, the team will identify subgroups and potential biomarkers related to systems such as neurological, immune, cardiac, and digestive.

Marelise Eekhoff
Amsterdam University Medical Center, Amsterdam, Netherlands
Grant Awarded: **$297,000**
Project: **Evaluation of Stroma in Skin Biopsies in Comparison Between Genetically Determined cEDS and Clinical hEDS**

This project compares skin biopsies from people with genetically confirmed classical EDS (cEDS) and those with clinical hEDS to identify potential diagnostic and therapeutic biomarkers.

Vincent Mooser
The Royal Institution for the Advancement of Learning / McGill University, Montreal, Canada
Grant Awarded: **$300,000**
Project: **hEDS*omics—Leveraging Genomics and Proteomics to Identify Novel Biomarkers and Drug Targets for Hypermobile EDS**

This project uses genomic and proteomic tools to uncover new biomarkers and drug targets for hEDS.

Skin Biomarkers

This grant supports the search for biomarkers in hEDS and HSD by studying the biology of the dermal extracellular matrix, which may reveal clues for diagnosis and treatment.

Ulrich Valcourt
University Lyon, Paris, France
Grant Awarded: $265,000
Project: SKIN-hEDS/HSD—A Multimodal Approach to Identify Biomarkers and Understand Pathogenic Mechanisms Using Skin Biopsies

Research Inner Circle

The Research Inner Circle is a group of passionate supporters dedicated to advancing research into EDS and HSD. This program connects researchers with donors who share a deep commitment to funding diverse and meaningful research efforts.

In 2024, The Ehlers-Danlos Society funded **$2.3 million across two groundbreaking studies**.

Ganna Bilousova
University of Colorado Anschutz Medical Campus, Boulder, CO, USA
Grant Awarded: $1,299,333
Project: Scalable Manufacturing of Patient-Specific 3D Skin Tissue Models for Studying Ehlers-Danlos Syndromes and Developing Personalized Therapeutic Approaches

Fereshteh Jahanbani
Stanford Center for Genomics and Personalized Medicine, Stanford, CA, USA
Grant Awarded: $1,049,469
Project: Unraveling the Genetic-Mucosal Barrier-Infection-Autoimmunity Nexus in hEDS/HSD: A Multi-Omics Approach to High-Performance Biomarker Development

Open Access Funding

The Ehlers-Danlos Society also supports open access research publishing to ensure findings are accessible to all.

Why Open Access Matters:

- **Increased Accessibility:** Free for patients, clinicians, and the public.
- **Faster Sharing:** Speeds up global dissemination of findings.
- **Greater Impact:** Freely available research is cited more often.
- **Empowerment:** Informs advocacy, education, and decision-making.
- **Global Equity:** Enables access in low-resource regions.
- **Transparency:** Builds trust in research outcomes.

In 2024, The Ehlers-Danlos Society funded **$29,926** to make six research papers open access:

1. Anna Higo. **The Effectiveness of Conservative Interventions on Pain, Function, and Quality of Life in Adults with Hypermobile Ehlers-Danlos Syndrome/Hypermobility Spectrum Disorders and Shoulder Symptoms: A Systematic Review** DOI: 10.1016/j.arrct.2024.100360

Spotlight on Research: Conservative Shoulder Treatments in hEDS and HSD

Open Access Publication Funded by The Ehlers-Danlos Society

Shoulder pain and joint instability are extremely common among individuals living with hypermobile Ehlers-Danlos syndrome (hEDS) and hypermobility spectrum disorders (HSD)—impacting everything from work to daily self-care. But which non-surgical treatments are actually effective?

This systematic review, published in Archives of Rehabilitation Research and Clinical Translation, explored the current evidence on conservative (non-surgical) treatments—such as physiotherapy, exercise, taping, and compression garments—for shoulder symptoms in adults with hEDS and HSD.

To ensure wide access to this important research, The Ehlers-Danlos Society proudly funded the open access publication, allowing the global community of patients, clinicians, and researchers to benefit from the findings.

This open access study was led by a team of UK-based researchers and institutions:

- **Coventry University**
  (Research Centre for Healthcare & Communities and Research Centre for Physical Activity, Sport and Exercise Science)
- **Cardiff University** (School of Healthcare Sciences)

The lead authors—Anna Higo, Lucy Silvester, Gemma Pearce, and Jason Tallis—are all affiliated with UK institutions. Additionally, the ethical approval for the study was granted by the Coventry University Ethics Committee.

What Did the Study Look At?

Researchers screened over **17,000 studies**, narrowing it down to **4 clinical studies** that met their criteria. Treatments assessed included:

- **Shoulder strengthening exercises** (both high- and low-load)
- **Kinesiology taping (KT)**
- **Compression garments**
- **Tailored home-based physiotherapy**

What Did They Find?

- **Supervised exercise therapy** showed promising benefits in reducing pain, improving joint stability, and enhancing quality of life.
- **Compression sleeves** may help provide joint support, though more long-term data is needed.
- **Taping methods** offered short-term benefits for some, but results varied.
- **Consistency matters:** Home exercise programs were helpful when patients followed them regularly with professional support.

"This review gives us a clearer picture of what might help manage shoulder symptoms in people with hEDS and HSD. **More research is still needed—but the early signs are encouraging**."

Why It Matters

Despite the high rate of shoulder pain in people with hEDS and HSD, there's been limited research to guide treatment. This review brings together existing evidence to help clinicians and patients make better-informed decisions—and highlights the urgent need for more tailored studies.

1. Nicole Frost. Neuraxial biomechanics, fluid dynamics, and myodural regulation: rethinking management of hypermobility and CNS disorders DOI: 10.3389/fneur.2024.1479545
2. Noman Marcus. Effective Doses of Low-Dose Naltrexone for Chronic Pain – An Observational Study DOI: 10.2147/JPR.S451183
3. Jane Shubart. Outcomes of orthopaedic surgery in Ehlers-Danlos syndromes: a scoping review DOI: 10.1186/s12891-024-07937-6
4. Svetlana Blitshteyn. Sexual dysfunction in women with hypermobile Ehlers–Danlos syndrome and hypermobility spectrum disorders: an online community-based study DOI: 10.1093/rap/rkaf023
5. Jonneke van Gurp. Tenascin-X Deficiency Causing Classical-Like Ehlers-Danlos Syndrome Type 1 in Humans is a Significant Risk Factor of Gastrointestinal and Tracheal Ruptures DOI: 10.14309/ctg.0000000000000821

The Ehlers-Danlos Society Global Biobank

Thanks to a generous **$2.5 million donation**—part of a **$6.7 million** gift from the Mike and Sofia Segal Foundation—we are developing a state-of-the-art EDS and HSD biobank.

What is the Biobank?

It includes:

1. **Secure biological sample storage** (e.g., blood, skin, urine).
2. **Clinical and lifestyle data** (e.g., age, diagnosis, symptoms). It will include people with all types of EDS and HSD, people with similar conditions but without EDS or HSD, and healthy individuals ("controls").

What Will It Be Used For?

- Study disease mechanisms
- Improve diagnostics and treatments
- Support biomarker discovery
- Enable personalized medicine
- Advance clinical trials
- Foster global collaboration

Launch Timeline:

The biobank will launch in Fall 2025 and grow in phases through collaborative, approved studies. It will not be open for direct community enrollment like the HEDGE or DICE projects.

The Ehlers-Danlos Society biobank
ADVANCING EDS & HSD RESEARCH

Spotlight on Rare Types:
Advancing Research in Memory of Claire Mesman

Arthrochalasia Ehlers-Danlos syndrome (aEDS) is an ultra-rare type of EDS that affects fewer than 1 in 1 million people. aEDS is caused by genetic variants in the COL1A1 or COL1A2 genes and is inherited in an autosomal dominant pattern. Key features include congenital bilateral hip dislocation, significant joint hypermobility, and recurrent joint instability, often accompanied by skin fragility, muscle hypotonia, motor delay, and spinal curvature.

In 2024, The Ehlers-Danlos Society was honored to receive a generous donation of €5,000 to begin the process of enrolling individuals with aEDS into the Global Biobank. This gift was made by Willem Mesman in memory of his daughter, Claire, who lived with aEDS and tragically passed away in 2021.

"Claire was full of life, languages, and love. She earned multiple degrees, worked in government and foreign policy, and lived with an incredible passion for learning and people. But her condition made life increasingly difficult—and worse still, it was misunderstood.

"What failed Claire was not just a rare disease, but a lack of awareness, communication, and coordinated care. I'm supporting this biobank so that others with rare types like aEDS can have better answers, better treatment, and better lives."
—Willem Mesman, Claire's father

Claire's story is a powerful reminder of the urgent need for collaborative research, earlier diagnosis, and more effective care for every type of EDS—including those that are often underrepresented.

The Ehlers-Danlos Society's Global Biobank will support research into all types of EDS and HSD, providing scientists with the samples they need to study genetics, tissue, and proteins to uncover better treatment strategies.

While community members cannot apply directly to the biobank, individuals with aEDS are encouraged to join the DICE EDS and HSD Global Registry to be considered for future research studies.

By including rare types like aEDS in the Biobank's research roadmap, we are working to ensure that no one is left behind.

The Road to 2026: Redefining the Future of EDS and HSD

ROAD TO 2026

The publication of the 2017 International Classification of the Ehlers-Danlos Syndromes was a pivotal milestone that reshaped how the world understands EDS and HSD. It laid the foundation for scientific advances, clinical criteria, and much of the research that has followed.

Now, nearly a decade later, the next chapter begins.

The Road to 2026 is a global collaborative effort led by the International Consortium on Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders (IC). The goal: to update the classification, diagnosis, and management of all types of EDS and HSD, improving accuracy, shortening diagnostic delays, and ensuring equitable care worldwide.

The Ehlers-Danlos Society is serving as the administrative and financial partner for this initiative, facilitating the committee's work and ensuring the community voice is central throughout the process.

What will the Road to 2026 deliver?

The Road to 2026 committee is working across multiple focus areas:

- Updated Classification Criteria: Reflecting new knowledge across all EDS types and HSD
- Refined Diagnostic Pathways: Tools for clearer, more consistent diagnosis
- Assessment & Management Guidance: Addressing multisystem symptoms and comorbidities

How is the Community involved?

The Ehlers-Danlos Society launched a multilingual community feedback form in April 2024 to gather questions, hopes, and concerns. Translated into nine languages, it has reached thousands worldwide and will remain open until early 2025.

In April 2025, we will launch the 2025 EDS & HSD Community Experience Survey, collecting data on:

- Diagnostic journeys
- Symptom management
- Barriers to care
- Impact on daily life
- Mental health and emotional wellbeing
- Financial effects

This real-world insight will be submitted to the Road to 2026 committee and published in a peer-reviewed paper alongside the classification update.

The Road to 2026: Redefining the Future of EDS and HSD

Who Is Leading the Work?

The Road to 2026 committee includes leading experts in clinical care, molecular research, and lived experience. They are collaborating with International Consortium Working Groups, global researchers, and individuals impacted by EDS and HSD to ensure this update reflects the full scope of the conditions.

Committee members include:

- Jessica Bowen
- Dr. Peter Byers
- Professor Marina Colombi
- Dr. Serwet Dermidas
- Dr. Clair Francomano
- Assoc. Professor Dr. Alan Hakim
- Dr. Glenda Sobey
- Dr. Hanadi Kazkaz
- Professor Fransiska Malfait
- Dr. Roberto Mendoza
- Professor Marianne Rohrbach
- Dr. Sherene Shalhub
- Professor Lara Bloom
- Scarlett Eagle
- Rebecca Gluck, PA-C

What Happens Next?

- **2024–2025:** Committee meetings, feedback collection, and expert review
- **April 2025:** Community Experience Survey launches
- **October 2025:** Scientific symposium and stakeholder meeting in Toronto, Canada
- **Late 2026–Early 2027:** Final publications released in two Special Issues of the American Journal of Medical Genetics

All Road to 2026 publications will be open access, funded by The Ehlers-Danlos Society, and accompanied by clear, translated resources including:

- Lay summaries
- Clinical diagnostic and management guides
- Videos and explanatory tools for professionals and community members

Together, this work will reshape the way EDS and HSD are understood, diagnosed, and managed across the world—and the community is at the heart of every step.

New hEDS Gastrointestinal Study

Thanks to a generous **$2 million donation** (part of the $6.7 million gift from the Mike and Sofia Segal Foundation), The Ehlers-Danlos Society is funding a new study to explore gastrointestinal symptoms in hypermobile EDS (hEDS) and their connection with the nervous, immune, and endocrine systems.

Study Lead:

Professor Qasim Aziz
Wingate Institute of Neurogastroenterology, London, UK

Professor Aziz completed his undergraduate medical training in his native Pakistan in 1983. After this, he came to the United Kingdom for higher medical training. He started his research career at the University of Manchester and obtained his PhD in 1996. He is now Professor of Neurogastroenterology at Barts and The London School of Medicine and Dentistry at Queen Mary, University of London.

Professor Aziz's research focuses on understanding the neurophysiological basis of human brain-gut communication. He has made an important contribution to the understanding of how gut pain is processed in the brain, and how both inflammation/injury to gut nerves and psychological factors can lead to the development of chronic gut pain.

Professor Aziz has received national and international awards for his research including the British Society of Gastroenterology Research Gold Medal and the American Gastroenterology Association, Janssen Award for Basic and Clinical Research. He has published numerous original articles in medical journals such as *Nature*, *Medicine*, *Nature Neuroscience*, *Lancet*, and *Gastroenterology*.

Key Study Aims:

- **Identify Subgroups:** Define specific patient groups with overlapping conditions like IBS, POTS, MCAS, allergic reactions, and pain sensitivity.

- **Understand Physiological Responses:** Explore how these groups respond to eating—measuring changes in gut function, heart rate, immune responses, gut permeability, and sensation.

Why This Study Matters:

Functional dyspepsia (FD), a common condition in people with hEDS, severely impacts quality of life. This study aims to uncover the mechanisms behind FD by analyzing how different biological systems interact. The goal is to pave the way for targeted therapies and more effective, personalized treatment strategies.

HEDGE Study: Hypermobile Ehlers-Danlos Genetic Evaluation

The HEDGE study is the largest-ever effort to identify the genetic basis of hEDS, the only type of EDS without a known genetic marker.

- **Participants:** 1,021 individuals from 86 countries.
- **Method:** Whole-genome sequencing based on the 2017 clinical criteria for hEDS.
- **Goal:** Discover genetic clues that could lead to earlier diagnosis, better treatments, and a deeper understanding of hEDS.

The analysis team is preparing multiple publications from the study, expected in 2025. Some early findings were presented at the American Society of Human Genetics (ASHG) 2024 conference in Denver, Colorado. Accepted abstracts include:

1. Assessment of Suspected Candidate Gene Variants in hEDS Patients from the HEDGE Study Cohort
2. Identifying Rare Variants Using a Case-Only Cohort and Biobank Controls
3. Multi-Ancestry GWAS for Hypermobile Ehlers-Danlos Syndrome

A Q&A webinar, lay summaries, and FAQs are available here to help the community understand what these findings mean.

Research Spotlight: Blood-Based Biomarkers for hEDS and HSD

A study funded by The Ehlers-Danlos Society and published in the *American Journal of Medical Genetics* revealed promising findings that could revolutionize the diagnosis of hypermobile Ehlers-Danlos syndrome (hEDS) and hypermobility spectrum disorders (HSD).

Researchers identified a 52 kDa fibronectin fragment found in all individuals with hEDS and HSD but absent in healthy controls and individuals with other types of EDS or various forms of arthritis. A collagen I fragment was also consistently found in hEDS and HSD participants, although it was present in other conditions as well.

These results suggest a shared underlying biology between hEDS and HSD and present a potential breakthrough in identifying a reliable biomarker.

Key Findings

- **Unique Marker:** The 52 kDa fibronectin fragment was only found in those with hEDS and HSD.
- **Differentiation from Other Conditions:** Distinct fragments were identified for conditions like rheumatoid arthritis, psoriatic arthritis, and osteoarthritis.
- **Shared Profile:** hEDS and HSD participants showed nearly identical biomarker patterns, questioning distinctions between the two diagnoses.

Why It Matters

- **Toward a Diagnostic Test:** This may lead to the first blood test for hEDS and HSD—a critical advancement, considering current diagnosis takes an average of 12 years.
- **Faster Diagnosis:** A reliable biomarker would reduce delays, allowing earlier intervention and more effective treatment planning.
- **Improved Understanding:** These insights contribute to the understanding of EDS and HSD pathophysiology and will support future trials.

Next Steps

Additional validation studies are required. The Ehlers-Danlos Society is funding this next phase of research to confirm findings and assess diagnostic utility.

"This is a critical step toward a diagnostic tool that our community has long needed. We're deeply grateful to the researchers, participants, and donors who made this possible."

Study Participants:

- 381 recruited from the University of Brescia, Italy
- 85 recruited in the USA by The Ehlers-Danlos Society
- 154 female and 20 male participants with hEDS or HSD

DICE: Data, Inclusion, Collaboration, and Excellence Global Registry

The **DICE Registry** is a global research database that invites individuals with EDS and HSD to share medical information and complete surveys to support ongoing research.

By joining, participants help to:

- Map lived experiences of people with EDS and HSD worldwide
- Advance discovery of genetic causes
- Explore symptom frequency and overlapping conditions
- Identify potential new types of EDS and HSD
- Study connections with chronic pain, anxiety, MCAS, GI, neurological, and autonomic conditions.

To date, an incredible **5,449 participants from 63 countries** have joined!

Participation is free and open globally. You can join from your smartphone, tablet, or computer.

Researcher Access Now Available

In April 2024, The Ehlers-Danlos Society launched its DICE 3rd Party Access (3PA) process, which facilitates applications for researcher access to DICE Global Registry data. This extensive resource includes demographic, morbidity, and co-morbidity data, enabling:

- Cohort and nested case-control studies
- Inter-population comparisons
- Access to targeted groups for participation in new studies

Researchers can now request access to data and use the registry for future investigations into EDS and HSD. As we approach the first anniversary of this program, we're proud to have processed six approved studies to-date, with additional studies anticipated throughout the remainder of the year. The 3rd Party Access process expands The Ehlers-Danlos Society's research impact by providing opportunities for external studies to study, collaborate, and recruit from a globally populated EDS and HSD database.

Topics from 3PA's inaugural year include:

- Comorbid and co-occurring condition rates
- Diagnostic odyssey
- Gender dysphoria
- Headache disorders and craniocervical imaging
- Patient-provider relationships
- Prognostic indicators
- Symptom profiles

DATA • INCLUSION • COLLABORATION • EXCELLENCE

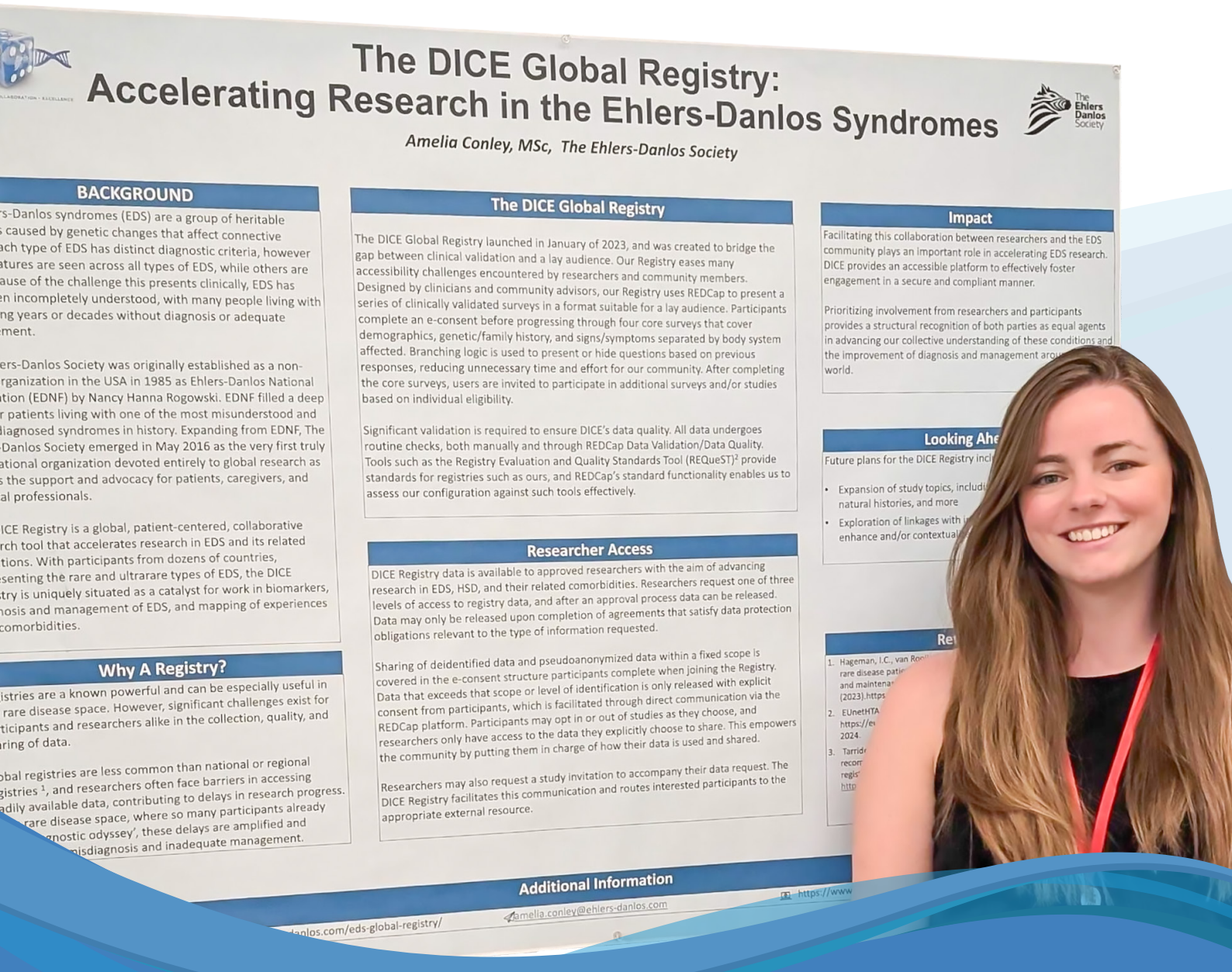
RESEARCH

REDCapCon 2024

Our Registry & Research Program Manager, Amelia Rinker, represented The Society at REDCapCon 2024—the annual conference for users of the REDCap platform, which is used to build our customized and secure environment for projects like HEDGE, BioBank, and the DICE Registry and Repository.

Amelia presented a poster on the DICE Registry, highlighting how it accelerates EDS and HSD research through collaborative data collection and participant engagement. REDCap is used by over 7,000 institutions in 159 countries, and this year's conference spotlighted rare diseases—including pediatric rare disease research at Johns Hopkins.

The Ehlers-Danlos Society is proud to be part of this global community using cutting-edge tools to advance understanding and care.



RESEARCH

EDUCATION

EDS ECHO: Empowering Healthcare Through Global Collaboration

Ehlers Danlos Society ECHO

Project ECHO®

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

In 2024, The Ehlers-Danlos Society celebrated five years of EDS ECHO—a pioneering initiative designed to revolutionize how healthcare professionals understand and care for people living with Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD).

Using the proven Project ECHO® model's "all teach, all learn" philosophy, EDS ECHO moves knowledge not people, connecting clinicians worldwide in a collaborative, virtual learning environment. Through live case discussions, expert-led presentations, and peer support, healthcare professionals across disciplines enhance their skills, improve patient care, and become part of a global network dedicated to rare disease excellence.

2024 By the Numbers

14 PROGRAMS & COURSES DELIVERED

155 SESSIONS CONDUCTED

220 HOURS OF LIVE LEARNING

170 CONTINUING EDUCATION (CE) CREDITS AVAILABLE

OVER **2,350** TOTAL PARTICIPANTS TO DATE, INCLUDING:
- 1,958 HEALTHCARE PROFESSIONALS
- 410 COMMUNITY MEMBERS AND ADVOCATES

491 NEW PARTICIPANTS IN 2024 ALONE

PARTICIPANTS FROM **52** COUNTRIES, WITH 8 NEW COUNTRIES JOINING THIS YEAR, INCLUDING: INDIA, CHINA, SAUDI ARABIA, & SINGAPORE

New Programs Launched in 2024

To address growing demand and emerging gaps, EDS ECHO introduced seven new programs, including:

- Multidisciplinary Team Practice (Europe and Australasia)
- Finding Functional Foundations (FFF) – A neuroplasticity-based training course for licensed physical therapists & physiotherapists
- FFF Drop-in Sessions – Ongoing mentorship and practical skill-building
- CORE Network of Excellence (CNE) ECHO
- Healthcare Student Program
- Health Advocacy Program – Relaunched in 2024

In addition, EDS ECHO ran two incredibly successful summit events this year: Emergency Care and Diet and Nutrition.

Refinements and Innovations in 2024

- Integrated Patient Perspectives: Patient voices were embedded into professional sessions, helping providers connect theory to lived experience.
- Streamlined Case Study Submissions: A new online tool boosted peer learning.
- Relaunched Advocacy Program: An updated curriculum equips advocates with the knowledge and tools to support others.

Global Reach, Local Relevance

"This program has improved my clinical reasoning. I now see a bigger picture of EDS, and it's changed the way I support my patients."
- Clinician, North America

"I'm currently using this approach with all my hypermobile patients, and I'm seeing real results. This course was by far the most valuable I've taken."
- FFF Participant

"I feel so honored to participate in EDS ECHO. You are doing fantastic work."
- Multidisciplinary Team Practice Europe Participant

EDUCATION

Recognition and Results

Program evaluations consistently show:

Increased confidence and knowledge among healthcare professionals

Improved diagnostic and care outcomes

Strengthened interdisciplinary collaboration

Growing engagement from first-time attendees and early-career professionals

Looking Ahead to 2025

In 2025, we plan to deliver:

- **14** Programs
- **164** Sessions
- **234** Teaching Hours
- **173** CE Credits

New programs in development:

- EDS ECHO for Caregivers
- EDS ECHO Nutrition – Australasia
- EDS ECHO Dentistry

Together, we're building a world where every person with EDS or HSD is met by a **clinician who understands**.

Events: Expanding Education, Connection, and Care

The Ehlers-Danlos Society's events program plays a vital role in our mission—serving as a powerful platform for education, awareness, and community-building. These conferences are essential in equipping healthcare professionals with the latest research, treatment strategies, and expert insights—knowledge that directly improves patient outcomes.

In 2024, we continued our commitment to accessibility and global engagement by offering fully hybrid events. Our return to in-person gatherings was complemented by robust virtual participation, made possible through the Whova event app. This platform allowed attendees to ask questions, respond to polls, join discussions, vote in contests, and network seamlessly—whether on-site or online.

We hosted four major educational events, each bringing together global experts for engaging presentations, Q&As, and interactive discussion. These gatherings offered not only critical knowledge but also space to share lived experiences and strengthen support networks.

Emergency Care Summit: A Global Learning Moment

Date: March 16, 2024
Attendees: 714
Countries Represented: 49
Speakers: 13 experts from rheumatology, vascular surgery, pain management, and neurogastroenterology

Summit Highlights:

- Acute injuries, pain, and dislocation care plans
- Vascular and GI emergencies (vEDS, MCAS)
- Circulatory dysfunction and syncope
- Mental health and caregiver planning
- Emergency documentation and medical ID tools
- UK primary care navigation with Dr. Daniela Vaca
- US emergency rights and insurance access

"I loved the wide variety of speakers and the way you could interact with other attendees through the app. I learned so much."
- Participant

"The Q&A sessions were thoughtful and addressed relevant issues. I appreciated the openness and expertise."
- Attendee

EDUCATION

Engagement That Drives Change

Participants accessed a dynamic mix of expert talks, Q&As, live chat, and shared experiences through the **Whova platform**, including:

- Virtual networking rooms
- Roundtable discussions
- Community-submitted case studies
- Tips, tools, and practical resources
- Interactive polls and contests
- Follow-up feedback and ongoing conversations

The Summit also supported global collaboration and the sharing of lived experience through our "**Conversations With...**" webinar series—continuing our commitment to education through open dialogue.

This Summit was not only a powerful moment of knowledge-sharing—it was a community-driven effort to ensure safer, more informed emergency care for everyone living with EDS and HSD.

EDS ECHO Summit: Diet and Nutrition

Date: November 2, 2024
Attendees: 1,005
Healthcare Professionals: 473
Countries Represented: 33
CME/CEU Credits: Up to 7.0 for live participation
First-Time Conference Attendees: 51%

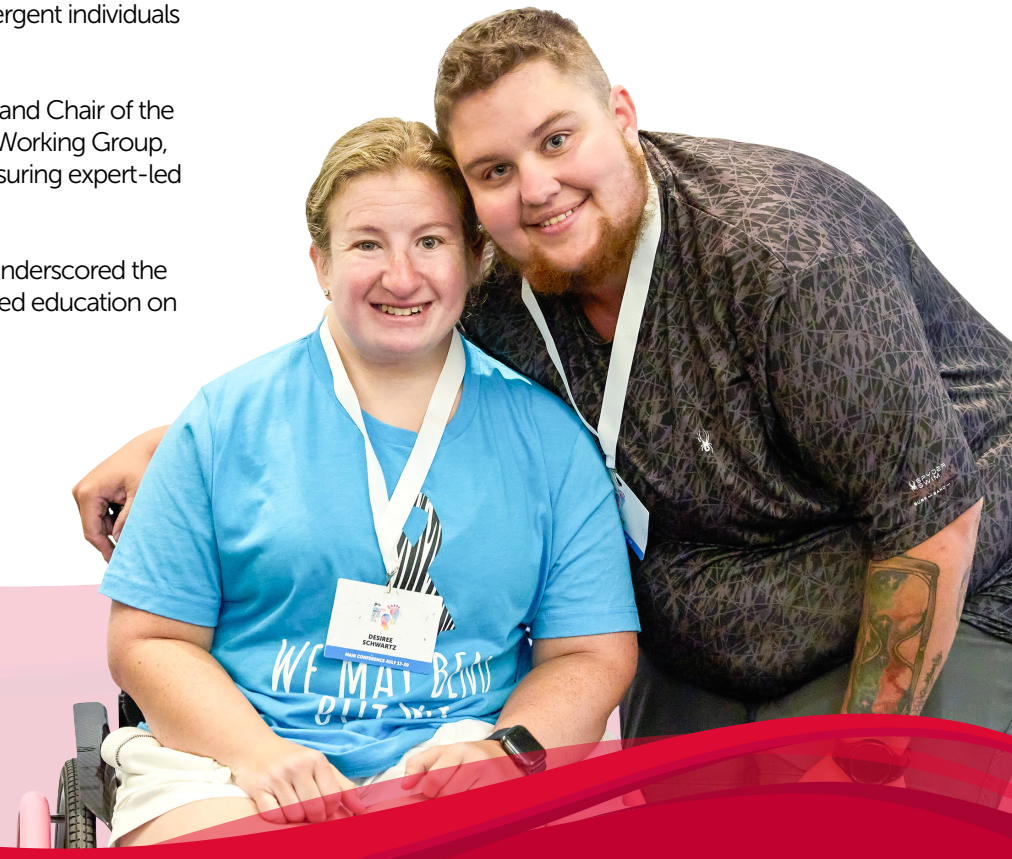
The Ehlers-Danlos Society hosted this virtual Summit to explore how nutrition can support and manage symptoms in individuals living with EDS and HSD. The day featured presentations, case studies, and panel discussions tailored for both healthcare professionals and the broader community.

Topics Included:

- Food allergies and safe dietary care
- Non-oral nutrition
- Nourishing the EDS and HSD body
- Optimizing diet and nutrition for neurodivergent individuals
- Understanding supplementation

Lorna Ryan, Registered Clinical Nutritionist and Chair of the International Consortium's Diet & Nutrition Working Group, served as lead facilitator and co-planner, ensuring expert-led and evidence-informed programming.

The high number of first-time participants underscored the growing global appetite for trusted, expert-led education on nutrition in EDS and HSD care.



2024 Global Learning Conference: From Head to Toe

Date: July 17–21, 2024
Location: Philadelphia, PA, USA (Hybrid)
Attendees: 2,206
Countries Represented: 39
First-Time Attendees: 60%
Sessions: 18
CME/CEU Hours: 29.25

This five-day hybrid event brought together individuals and families, healthcare professionals, researchers, and advocates for a comprehensive learning experience. The theme, EDS and HSD: From Head to Toe, explored symptoms, comorbidities, and care strategies across every aspect of the body.

Key Topics Included:

- Pain and fatigue management
- Neurodivergence and mental wellbeing
- Orofacial, head, and neck complications
- Pelvic, gastrointestinal, and urogynecological concerns
- Fascia science and physical therapies
- Posture and movement strategies
- Research and emerging treatments
- Pediatric and rare EDS care

"Thank you for an amazing conference! I learned so much and feel validated, supported, and empowered."
- Heather Fougnier, attendee

"These movement snacks with Jeanne Di Bon are so incredibly helpful even with virtual attendance. Thanks for including them in the virtual attendance."
- Anonymous, virtual attendee

"I received one of your scholarships for the Global Learning Conference. I am a nurse practitioner with EDS and was hit hard by COVID in January 2020 and am still dealing with Long COVID, I remain homebound and am often bedbound, and as you can imagine, my work life and income have suffered. I would not have been able to attend this conference without your generous support, and I wanted to say thank you."
- Anonymous, 2024 GLC Scholarship Recipient

"My name is Alyssa, and I am one of the recipients of the 2024 Global Learning Conference scholarships. I wanted to take a moment to say 'THANK YOU' so much for the generous gift you have given me in allowing me to attend this conference. I am so grateful for the work you all are doing—the knowledge that I have gained through your webinars has been incredibly insightful and helpful to me. Thank you, thank you!"
- Alyssa, 2024 GLC Scholarship Recipient

Junior Zebras Take the Spotlight

We hosted our largest-ever Junior Zebras program, **welcoming 75 children and teens**. Led by Camp Joy, the youth program delivered age-appropriate education, creativity, fun, and peer support. Parents participated in sessions focused on practical strategies for navigating parenting with EDS or HSD.

"I already feel like I am home with a community that not only understands what it means to be a zebra but is eager to grow together." - Heather Van Rutgers, virtual attendee

A Day for the Rarer Types

Rarer Types Day focused on the lived experience of those with rarer types of EDS. Sessions addressed resilience, aging, caregiving, and the latest research—giving voice to community members who are often underrepresented.

"I can't thank you enough for making this event so accessible to those who are unable to travel. It's phenomenal." - Susan Robertson, virtual attendee

Global Impact

Attendees joined from **39 countries**, including the UK, USA, Canada, Australia, Ireland, New Zealand, Germany, Netherlands, Brazil, and Japan.

Sponsors

Partner Sponsors:
DM Orthotics, Silver Ring Splints, Body Braid, Aytu Biopharma.

Supporting Sponsors:
Lumia, Lipedema Foundation, Strive Physical Therapy, Actively Autoimmune, Mast Cell Society, The Zebra Club, Lighthouse Complex Care of Delaware, Zebra Splints, Gwen Miller Studio, Emeterm, Guava Health, XRPH, Aria Health.

Looking Ahead

We are thrilled to announce our first-ever Global Learning Conference in Brisbane, Australia, from February 7–9, 2025, and look forward to launching another inspiring year of education, collaboration, and connection.

EDUCATION

Fundraising

A Global Community Moving Mission Forward

In 2024, The Ehlers-Danlos Society community showed up with extraordinary passion, creativity, and generosity. From endurance challenges to online campaigns, every fundraiser helped expand our reach and support people living with EDS and HSD around the world.

Together, you've helped raise vital funds to power our mission—fueling research, advancing education, improving care, and amplifying the voices of our community.

May Awareness Month: Acts of Awareness in Action

May is a time to raise our voices—and this year, our global Acts of Awareness campaign united people across the world like never before. Through social media, educational events, and personal challenges, our community raised awareness and vital funds for EDS and HSD.

Thanks to your dedication, over **$82,347** was raised in support of our global mission.

Redemption Racers: Running 100 Miles for Marissa

During EDS Awareness Month, the Redemption Racers completed the Keys 100 Ultra Marathon, running day and night in honor of Marissa, who was recently diagnosed with EDS. Despite years of complex symptoms and treatments, Marissa completed her PTA degree and is now working to support others like her.

"Running for Marissa and The Ehlers-Danlos Society is an honor. This journey has been tough, but we've seen the strength of the EDS community firsthand."- Alyssa, Redemption Runner and Marissa's mum

We're incredibly grateful to Tara, Rachel, Alyssa Grit Fit, Lucka, and Erik for their inspiring dedication.

Walking and Rolling with Purpose

From New Zealand to Manchester, supporters walked, ran, and rolled their way through May:

- Hannah raised AUS$175, sharing her journey with hEDS after years of symptoms and new understanding through diagnosis.
- Louize ran the Manchester Half Marathon, raising £155 and sharing her lived experience as someone diagnosed in childhood.
- Matthew Chapple raised £286 in support of his partner, shining a light on the strength of caregivers and partners.
- Toyin, living with hEDS, raised £128.16 through her Instagram fundraiser, emphasizing the importance of community and research.

"This community has given me so much. I'm grateful to be giving something back." - Hannah, New Zealand

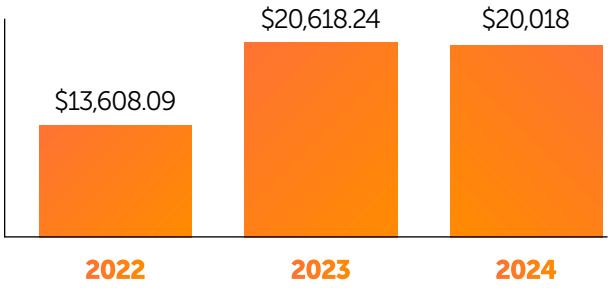
"I really hope the future is bright for our community." - Toyin, UK

FUNDRAISING

Giving Tuesday: Doubling Impact

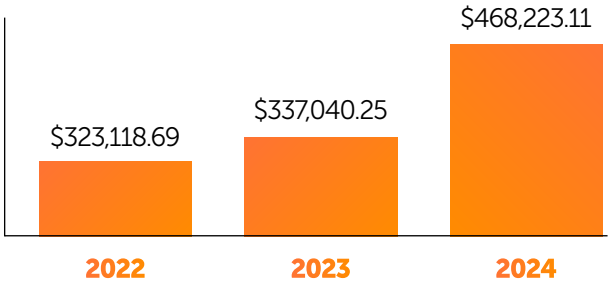
On Giving Tuesday, our supporters stepped up—and thanks to an anonymous match donation of up to $400,000, your generosity meant double the impact.

Your gifts helped drive forward education, fuel research, and expand care. Together, we made every donation count twice.



End of Year Campaign: Powering Hope

Each year, our End of Year campaign brings our community together to reflect, celebrate, and give hope. In 2024, your generosity once again exceeded expectations, helping us fund critical programs and new research initiatives.



Thank You to Our Global Fundraisers

This year, you ran, walked, baked, posted, streamed, and gave in so many ways. Each fundraiser—large or small—represents a story of strength, resilience, and hope.

We're so thankful to every single person who created a campaign, shared a story, or supported a friend. Together, you're not just raising funds; you're raising awareness, breaking down stigma, and building a global movement for change.

Join Us in Fueling the Future

While we celebrate all that we've achieved, we know there's still so much to do. Your continued support will help us accelerate life-changing research, improve care access, educate professionals, and uplift voices around the world.

Whether you're making a donation, hosting a fundraiser, or sharing your story, you're part of something bigger.

FUNDRAISING

Let's keep making an

impact – together.

Donate today:
ehlers-danlos.com/donate

Income & Expenses

Income	Amount
Corporate	$847,153
Grants	$75,000
Individual Donations	$3,590,436
Events	$538,854
Other	$53,401
TOTAL	**$5,104,844**

Expenses	Amount
Admin	$671,484
Fundraising	$424,963
ECHO	$290,826
General Research	$621,612
HEDGE	$229,071
Road to 2026	$122,804
Research Studies	$1,319,699
Events	$539,052
CNE	$71,370
Education	$584,603
TOTAL	**$4,875,484**

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