



The
**Ehlers
Danlos**
Society

IMPACT REPORT

1st May, 2024 - 30th April, 2025



Letter From the President and Chair of the Board of Directors

Dear Friends and Supporters,

As we reflect on 2024, we do so with deep gratitude and pride. It has been a year defined by **progress**, **innovation**, and **global collaboration**—a year that brought us closer to our vision of a world where people with Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD) are **recognised**, **understood**, and **supported**.

Thanks to your continued support, The Ehlers-Danlos Society has strengthened its role as a global leader in driving forward Care, Access, Research, and Education. In the UK and across the world, your involvement has made every achievement possible.

In 2024, we funded over **\$8 million USD*** in research across two vital streams: our **Research Grant Programme**, which awarded competitive grants to international researchers, and our funded research studies, developed in collaboration with leading institutions. Notably, this included a major gastrointestinal study led by **Professor Qasim Aziz at the Wingate Institute in London**, exploring the interactions between the nervous, immune, and digestive systems in people with EDS—paving the way for more personalised care.


Our flagship **HEDGE study**, the first population-wide genetic study of hypermobile EDS, reached a major milestone, with over 1,000 whole-genome sequences analysed. Early results were shared at the American Society of Human Genetics, and multiple publications are now in preparation. The UK has played an essential role in this work, including participants from our London screening event.

We also opened researcher access to our **DICE Global Registry**, and in 2025, we will launch the **EDS & HSD Global Biobank**, a resource that will further accelerate discovery and improve future clinical trials. We were honoured this year to receive a donation in memory of **Claire Mesman**, who lived with arthrochalasia EDS (aEDS), to help enrol individuals with rare types into the Biobank, ensuring research includes every voice.

This year also marked the start of **The Road to 2026**, a collaborative global effort to update the 2017 International Classification of the Ehlers-Danlos syndromes. Led by a committee of international experts and supported by The Ehlers-Danlos Society, this work will lead to clearer diagnostic criteria, more accurate tools, and better care for all types of EDS and HSD. Your feedback has shaped this process—through surveys, translations, and participation in the DICE Registry—and will continue to do so as the next phase of community input launches in 2025.

We also expanded our commitment to accessibility. Our **official Ehlers-Danlos Society app** launched in 2024 and has already been downloaded by **over 7,000 people globally, including 789 users in the UK**. The app allows individuals to track symptoms, manage medications, and access tools to support care conversations—bringing trusted resources directly into the hands of our community.

In addition, we launched **Body Systems pages** for each type of EDS and HSD, offering clear, easy-to-navigate information about how these conditions affect different parts of the body. These pages have empowered individuals to better understand their health, advocate for themselves, and share insights with their care teams.



Letter From the President and Chair of the Board of Directors

Our **EDS ECHO programme** celebrated its fifth anniversary, delivering 14 multidisciplinary programmes and welcoming **491 new participants**—including many UK-based healthcare professionals. Through dedicated ECHO programmes for clinicians, physiotherapists, students, and nutritionists, we are building a global network of professionals who are better equipped to recognise and manage EDS and HSD.

In July, we hosted our **Global Learning Conference in Philadelphia**, with over 2,200 attendees from 39 countries. This included **42 participants and 13 healthcare professionals from the UK**, making this one of our most globally representative conferences to date. We also delivered accredited virtual summits on **Emergency Care** and **Diet & Nutrition**, reaching thousands more across the UK and around the world.

Through it all, you—our community—have remained at the heart of everything we do. Whether you've raised awareness, joined a support group, attended a conference, made a donation, or shared your story, you have helped us grow a movement of visibility, care, and change.

We are incredibly proud of what we've accomplished together in 2024. With your continued support, we look forward to a 2025 filled with further breakthroughs, deeper understanding, and stronger connection.

Together, we are
transforming lives and
creating a future filled with
knowledge,
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 Our Community Across the United Kingdom

Helpline

The Ehlers-Danlos Society's helpline remains a trusted and compassionate source of information, guidance, and support for people living with Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD), as well as their families, caregivers, educators, and healthcare professionals.

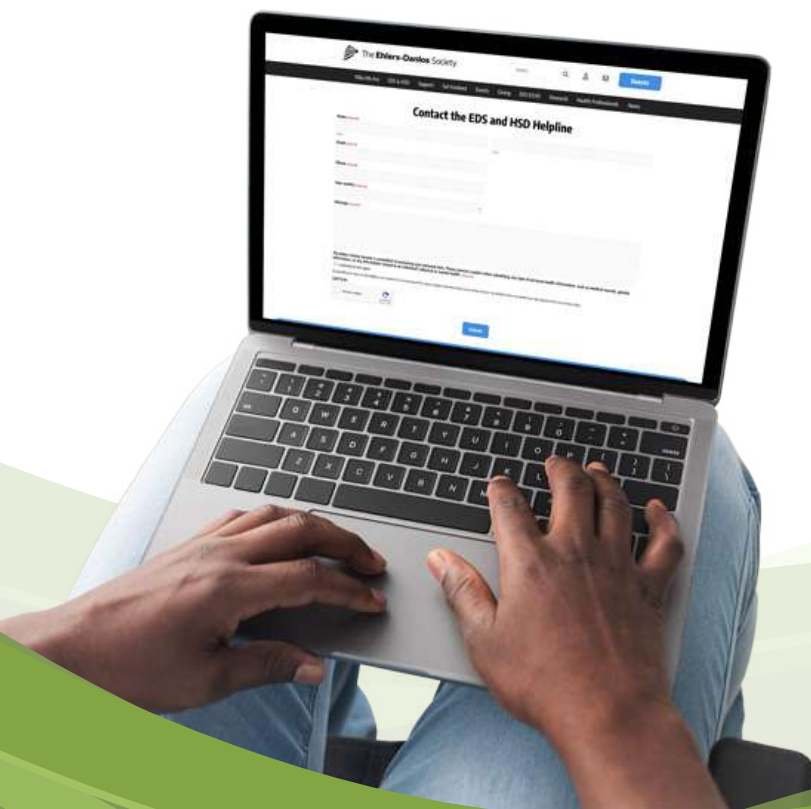
In 2024, demand for the helpline continued to grow. Our team responded to **44 phone calls** and **295 emails** from the UK, offering timely, potentially life-changing support and reassurance during moments of uncertainty and overwhelm.

Whether sharing trusted information, signposting to local charities, or referring to specialists via our **Healthcare Professionals Directory**, the helpline provides essential support. It also:

- Helps individuals prepare for appointments and advocate for themselves
- Supports newly diagnosed patients and their families
- Assists professionals in better understanding EDS and HSD
- Offers reassurance and connection during difficult times



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



CARE

Virtual Support Groups: Let's Chat

Our virtual Let's Chat groups offer safe, welcoming spaces for people across the UK to connect and be heard. For many, this is the first time they've met someone else living with EDS or HSD.

In 2024, these groups continued to bring people together to talk about life with these conditions, from symptoms and mental health to school, work, and relationships.

Dedicated Let's Chat sessions supported:

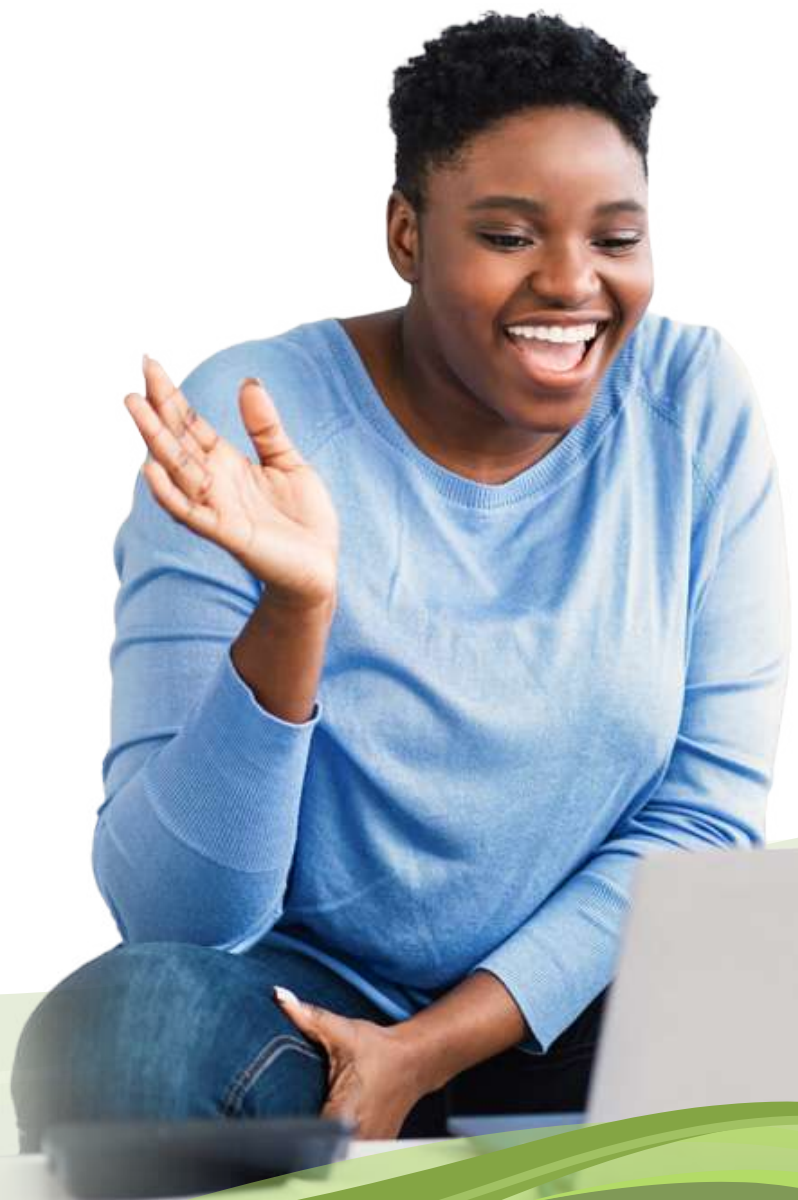
- People living with EDS and HSD
- Parents and carers
- Partners and spouses
- Teens
- Men
- LGBTQIA+ individuals
- Those living with vascular EDS (vEDS)



"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

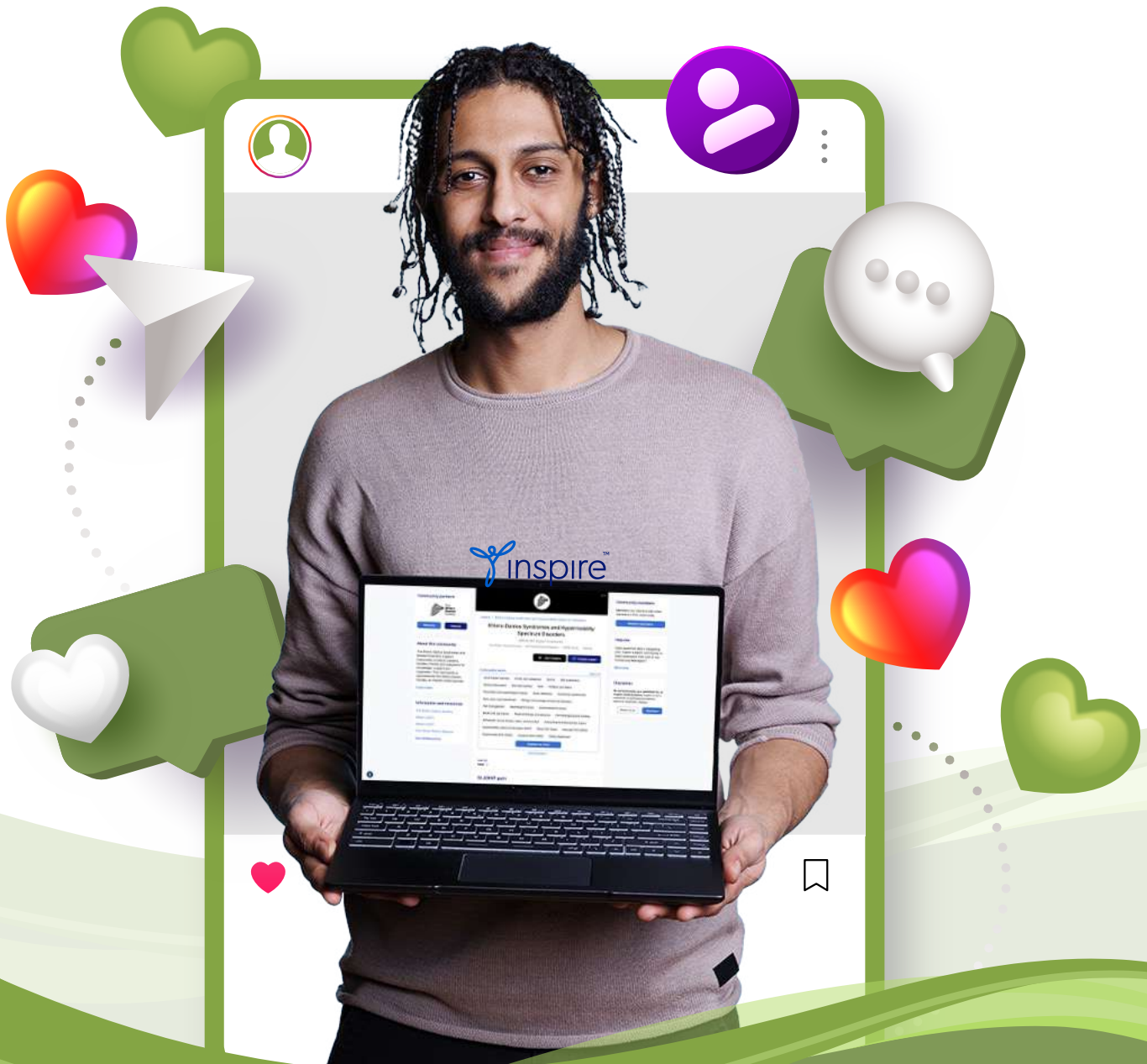
Building community and reducing isolation remain at the heart of our work. From social media to online discussion forums, we're creating more ways for people to connect, support one another, and access reliable information.

In 2024, **16,205** members from the UK were active on our **Inspire** online forum, contributing to a global community of over 141,000 members across 150+ countries.

Our social media channels—Facebook, Instagram, LinkedIn, and YouTube—now reach over **335,000 people worldwide**, helping more individuals across the UK discover stories, find resources, and connect with others who understand.



"For years I thought something was wrong with me. Finding a **community that understands and an organisation that explains things clearly** has helped me feel less alone."



CARE

Supporting Our Junior Zebras

Our Junior Zebras hold a special place in our hearts, and we continue to create meaningful experiences and age-appropriate resources for children and young people living with EDS and HSD in the UK.

Let's Chat: Teens

Monthly online Let's Chat groups provide teens aged 13–18 with a space to talk, share experiences, and feel supported.

Junior Zebras at the Global Learning Conference

At the 2024 Global Learning Conference in Philadelphia, we welcomed our **largest Junior Zebras group to date**, including young people from the UK. **75 children and teens** took part in activities led by Camp Joy, including games, creative projects, and health education delivered in an accessible way.

We also worked closely with the **Pediatric Working Group** of the International Consortium to support earlier diagnosis in children. In 2024, our **Pediatric Diagnostic Checklist** was published in a continuing education module by the **American Academy of Pediatrics**, marking a step forward in raising global awareness.

What did your child love about the programme?



"Validation of what they were feeling, and that they're not alone."



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



"Meeting another Junior Zebra from his region."



"Getting to make new friends internationally."



CARE

ACCESS

Improving Access to Diagnosis, Care, and Information Across the UK

In 2024, The Ehlers-Danlos Society continued its mission to remove systemic, geographic, and informational barriers that delay care for people with Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD). Through digital tools, translated resources, and the expansion of provider networks across the UK and globally, we are helping more people gain the knowledge and support they need—wherever they are.

The Road to 2026: Bringing Global and Local Voices to the Table

The *Road to 2026* is a global initiative to update the 2017 International Classification of the Ehlers-Danlos syndromes. Led by the International Consortium on EDS and HSD, this process will improve diagnostic criteria, reduce delays, and enhance the understanding and management of EDS and HSD.

Lived experience is essential to shaping the future of care. As part of our logistical and advocacy support of this collaborative work, The Ehlers-Danlos Society launched multilingual surveys and a global community feedback form, ensuring that voices from the UK and around the world help inform these critical updates. Additionally, we utilised our DICE Global Registry to deliver a Community Experience Survey that explores topics like accessibility, barriers to care, and the impact EDS and HSD have on daily life. The findings of that survey will form part of a series of scientific publications, including new guidelines for diagnosis and management, expected in late 2026.

Removing Language Barriers

To support *The Road to 2026* and other key programmes, we expanded our translation efforts. Essential resources and surveys were translated into **nine languages**: Arabic, Dutch, French, German, Italian, Japanese, Portuguese, Spanish, and Swedish.

This ensures individuals across the UK who speak additional languages can participate fully and access resources in the language that works best for them.



ACCESS

Digital Access to Trusted Information

Our website remains a central hub for reliable, up-to-date information on EDS and HSD. In 2024, it served over **1.8 million users globally**, including **244,438 users across the United Kingdom**.

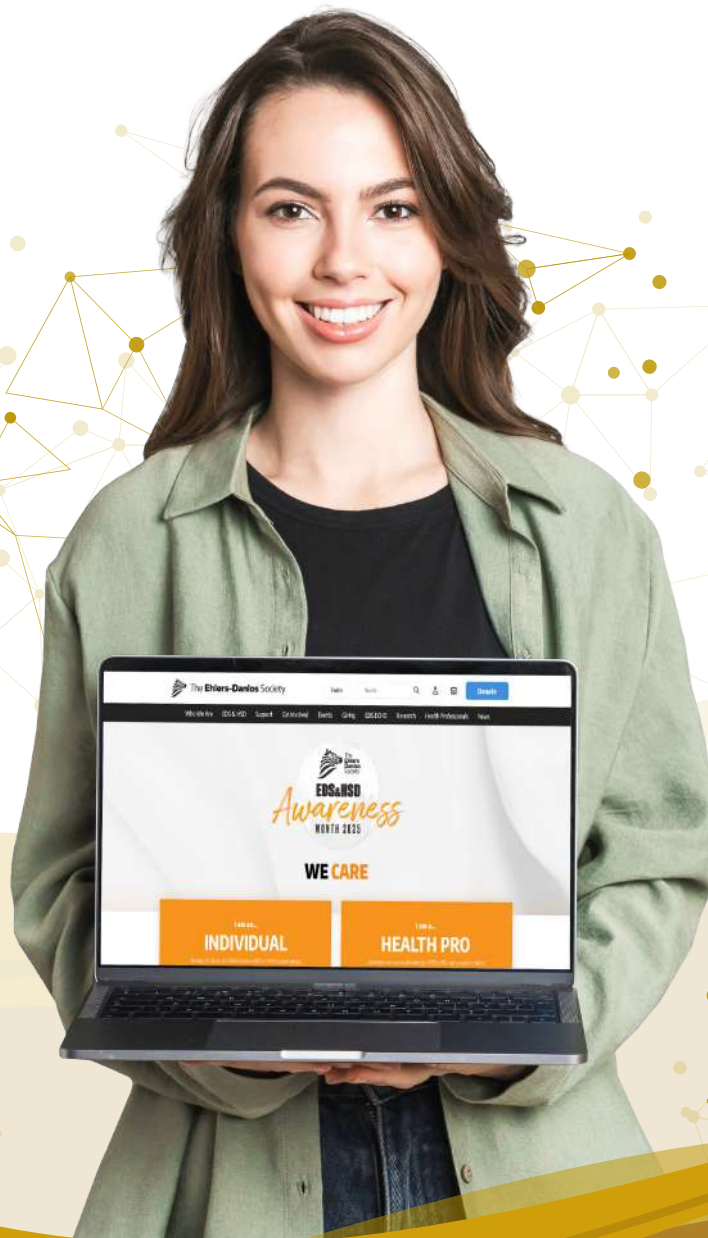
We expanded and launched new sections covering:

- All 13 types of EDS and HSD
- Physiotherapy
- Occupational therapy
- Braces, splints, and mobility aids
- Skin
- *The Road to 2026*

All content is developed in collaboration with the International Consortium's working groups to ensure it reflects the latest evidence and clinical guidance.



"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

We launched **accessiBe**, an adaptive technology improving our website's accessibility for users with sensory sensitivities, visual impairments, and neurodivergent traits. This supports our commitment to inclusion and ensures everyone can access the tools and content they need.

Expanding Access Through Technology: The Ehlers-Danlos Society App

In 2024, we launched **The Ehlers-Danlos Society App**, a free, easy-to-use platform designed to connect individuals and professionals with vital tools, education, and support. With over **7,000 downloads globally**, including **789 users in the UK**, the app empowers people to better manage their care and advocate for their needs.

Key Features:

- **Helpful Resources:** Browse curated education and support content
- **Symptom Summary:** Record and share symptoms with healthcare teams
- **Medication Summary:** Stay organised and prepared for appointments
- **Professional Hub:** Access tools developed for clinicians
- **Diagnostic Tools:** Aid early recognition and informed referrals
- **Community Connection (coming soon):** A space to connect with others living with EDS and HSD

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 helps me feel more in control of my care and makes sharing my symptoms with doctors so much easier. **It's a game changer.**"

ACCESS

Connecting People with Knowledgeable Providers

Healthcare Professionals Directory

Our **Healthcare Professionals Directory** remains one of the most-used sections of our website. In 2024, we added over **600 new providers**, now representing nearly 60 countries, including many in the UK.

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



"I found a physiotherapist who understands EDS through your directory. It's the first time I've felt truly supported."

CORE Network of Excellence



The **CORE (Collaboration, Outreach, Research, and Education) Network of Excellence** is our global cohort of multidisciplinary teams providing best-practice care for EDS and HSD.

We are proud to have **three UK-based CORE members**:

- Kent Community Chronic Pain Service
- Kent Hypermobility Network
- London Hypermobility Network

To be recognised as a CORE member, teams must meet robust criteria in care delivery, staff expertise, training, and patient engagement. There are now **37 CORE members globally** across **11 countries**.

Once approved as a CORE Network team, members of the CORE Network collaborate on research, education, and access-focused programme activities as part of their participation. These activities include sharing case studies and best practices, collaborating on research and funding proposals, delivering educational talks and workshops, as well as sharing their expertise at conferences and scientific meetings around the world.



"The CORE Network represents our shared commitment to evidence-based, compassionate care for people with EDS and HSD."

In 2024, the CORE Network of Excellence introduced its **Integrated Community Voice** framework, which outlines an infrastructure for acquiring various streams of feedback, advocacy, and experiences from those living with EDS and HSD to be incorporated directly into programme operations. By including the EDS and HSD community as a central part of the programme's work, we transform otherwise separate streams of input into **rich, global data** that can be actioned locally by CORE Network members or collectively by the programme as a whole.

Connecting People to Local Support

Our **Support Group and Charity Directory** helps individuals find trusted community support across the UK. In 2024, we listed **112 verified groups and organisations**, with several based in England, Scotland, Wales, and Northern Ireland.

The EDS & HSD Alliance



Relaunched in 2024, the **EDS & HSD Global Alliance** (formerly the Global Affiliation Programme) is a growing international network of charities, community groups, and support organisations dedicated to improving outcomes for people with EDS and HSD.

The UK is proudly represented by **five Alliance members** who:

- Share translated resources
- Disseminate education and survey opportunities
- Raise local awareness
- Represent the UK in international conversations



"Being part of the Alliance has helped us connect, collaborate, and bring forward the voices of people with EDS and HSD here in the UK."



ACCESS

RESEARCH

A Global Commitment to Discovery.

Funded Research

The Ehlers-Danlos Society remains committed 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, biomarkers, digestive health, and skin tissue — all with the potential to transform lives.

Research Grant Programme

The Research Grant Programme 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 unravelling 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.



RESEARCH

Grant Awardees:



Dr 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 hEDS and HSD. By examining biological samples (blood, saliva, and stool) from a large group, the team will identify subgroups and potential biomarkers related to neurological, immune, cardiac, and digestive systems.



Dr Marelise Eekhoff

Amsterdam University Medical Centre, 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 and those with clinical hEDS to identify potential diagnostic and therapeutic biomarkers.



Professor Vincent Mooser

McGill University, Montreal, Canada

Grant Awarded: \$300,000*

Project: hEDSomics – 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 potential 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.



Dr 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 programme connects researchers with donors who share a deep commitment to funding diverse and meaningful research.

In 2024, The Ehlers-Danlos Society awarded **\$2.3 million*** across two studies:



Dr Ganna Bilousova

University of Colorado Anschutz Medical Campus, USA

Grant Awarded: \$1,299,333*

Project: Scalable Manufacturing of Patient-Specific 3D Skin Tissue Models for Studying Ehlers-Danlos Syndromes and Developing Personalised Therapeutic Approaches



Dr Fereshteh Jahanbani

Stanford Center for Genomics and Personalised Medicine, 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

RESEARCH

Open Access Funding

The Ehlers-Danlos Society supports open access publishing to ensure that important research findings are accessible to all — patients, clinicians, and researchers alike.

Why Open Access Matters:

- **Increased Accessibility:** Freely available for everyone
- **Faster Sharing:** Speeds up global dissemination
- **Greater Impact:** More likely to be cited and used
- **Empowerment:** Informs care, advocacy, and awareness
- **Equity:** Access for people in low-resource settings
- **Transparency:** Builds trust in science

In 2024, The Ehlers-Danlos Society funded **\$29,926*** for the open access publication of six peer-reviewed research papers.

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**

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, led by UK-based researchers, investigated which non-surgical treatments are most effective for managing shoulder symptoms in people 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.

Lead institutions:

- **Coventry University** (Research Centre for Healthcare & Communities)
- **Cardiff University** (School of Healthcare Sciences)

Authors: Anna Higo, Lucy Silvester, Gemma Pearce, and Jason Tallis

Ethics Approval: Coventry University Ethics Committee



RESEARCH

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**

Key Findings:

- **Supervised shoulder exercises** reduced pain and improved stability.
- **Compression sleeves** may support joint function.
- **Kinesiology taping** offered short-term relief.
- **Home-based programmes** worked best with consistency and guidance.



"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 - Biomechanical considerations in central nervous system disorders associated with the Ehlers-Danlos Syndromes.
2. Noman Marcus - Effective Doses of Low-Dose Naltrexone for Chronic Pain – An Observational Study.
3. Jane Shubart - Outcomes of Orthopaedic Surgery in the Ehlers-Danlos Syndromes: A Scoping Review.
4. Svetlana Blitshteyn - Sexual dysfunction in women with hypermobile Ehlers-Danlos syndrome and Hypermobility Spectrum Disorders: An online community-based study.
5. Jonneke van Gurp - Tenascin-X deficiency causing classical-like Ehlers Danlos syndrome type 1 in humans is a significant risk factor for GI and tracheal ruptures.



RESEARCH

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).

The biobank will include people with EDS or HSD, individuals 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 personalised medicine
- Advance clinical trials
- Foster global collaboration

Launch Timeline:

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



RESEARCH

Spotlight on Rare Types:

Advancing Research in Memory of Claire

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’re working to ensure that no one is left behind.



RESEARCH

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.

RESEARCH

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.



RESEARCH

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 analysing how different biological systems interact. The goal is to pave the way for targeted therapies and more effective, personalised 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, including the UK via our London screening event.
- **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.

Accepted abstracts included:

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 (genome-wide association study) 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 revolutionise 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



RESEARCH

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, **642 participants from the UK** have joined the Registry. Participation is free and open globally. You can join using a smartphone, tablet, or computer [here](#).

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 programme, 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 Programme Manager, Amelia Rinker, represented The Society at REDCapCon 2024—the annual conference for users of the REDCap platform, which is used to build our customised 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.



The DICE Global Registry: Accelerating Research in the Ehlers-Danlos Syndromes
Amelia Conley, MSc, The Ehlers-Danlos Society

BACKGROUND

Ehlers-Danlos syndromes (EDS) are a group of heritable conditions caused by genetic changes that affect connective tissue. Each type of EDS has distinct diagnostic criteria, however similarities are seen across all types of EDS, while others are unique. The challenge this presents clinically, EDS has not been completely understood, with many people living with the condition for years or decades without diagnosis or adequate management.

The Ehlers-Danlos Society was originally established as a non-profit organization in the USA in 1985 as Ehlers-Danlos National Foundation (EDNF) by Nancy Hanna Rogowski. EDNF filled a deep need for patients living with one of the most misunderstood and diagnosed syndromes in history. Expanding from EDNF, The Ehlers-Danlos Society emerged in May 2016 as the very first truly international organization devoted entirely to global research as well as the support and advocacy for patients, caregivers, and healthcare professionals.

The DICE Registry is a global, patient-centered, collaborative research tool that accelerates research in EDS and its related conditions. With participants from dozens of countries, representing the rare and ultrarare types of EDS, the DICE Registry is uniquely situated as a catalyst for work in biomarkers, diagnosis and management of EDS, and mapping of experiences and comorbidities.

Why A Registry?

Rare diseases are a known powerful and can be especially useful in the rare disease space. However, significant challenges exist for participants and researchers alike in the collection, quality, and sharing of data.

Global registries are less common than national or regional registries¹, and researchers often face barriers in accessing readily available data, contributing to delays in research progress. In the rare disease space, where so many participants already experience a 'diagnostic odyssey', these delays are amplified and can lead to misdiagnosis and inadequate management.

The DICE Global Registry

The DICE Global Registry launched in January of 2023, and was created to bridge the gap between clinical validation and a lay audience. Our Registry eases many accessibility challenges encountered by researchers and community members. Designed by clinicians and community advisors, our Registry uses REDCap to present a series of clinically validated surveys in a format suitable for a lay audience. Participants complete an e-consent before progressing through four core surveys that cover demographics, genetic/family history, and signs/symptoms separated by body system affected. Branching logic is used to present or hide questions based on previous responses, reducing unnecessary time and effort for our community. After completing the core surveys, users are invited to participate in additional surveys and/or studies based on individual eligibility.

Significant validation is required to ensure DICE's data quality. All data undergoes routine checks, both manually and through REDCap Data Validation/Data Quality. Tools such as the Registry Evaluation and Quality Standards Tool (REQueST)² provide standards for registries such as ours, and REDCap's standard functionality enables us to assess our configuration against such tools effectively.

Researcher Access

DICE Registry data is available to approved researchers with the aim of advancing research in EDS, HSD, and their related comorbidities. Researchers request one of three levels of access to registry data, and after an approval process data can be released. Data may only be released upon completion of agreements that satisfy data protection obligations relevant to the type of information requested.

Sharing of deidentified data and pseudoanonymized data within a fixed scope is covered in the e-consent structure participants complete when joining the Registry. Data that exceeds that scope or level of identification is only released with explicit consent from participants, which is facilitated through direct communication via the REDCap platform. Participants may opt in or out of studies as they choose, and researchers only have access to the data they explicitly choose to share. This empowers the community by putting them in charge of how their data is used and shared.

Researchers may also request a study invitation to accompany their data request. The DICE Registry facilitates this communication and routes interested participants to the appropriate external resource.

Impact

Facilitating this collaboration between researchers and the EDS community plays an important role in accelerating EDS research. DICE provides an accessible platform to effectively foster engagement in a secure and compliant manner.

Prioritizing involvement from researchers and participants provides a structural recognition of both parties as equal agents in advancing our collective understanding of these conditions and the improvement of diagnosis and management around the world.

Looking Ahead

Future plans for the DICE Registry include:

- Expansion of study topics, including natural histories, and more
- Exploration of linkages with other registries to enhance and/or contextualize data

References

1. Hageman, J.C., van Roon, J.H. (2023) Rare disease patient and maintenance (2023) https://doi.org/10.1007/978-94-007-9888-8_1
2. EUnetHTA (2023) <https://eunethta.eu/>
3. Tarrion-Pargament, J. (2024) https://doi.org/10.1007/978-94-007-9888-8_1

Additional Information

ehlers-danlos.com/eds-global-registry/
amelia.conley@ehlers-danlos.com
<https://www.ehlers-danlos.com/>

RESEARCH

EDUCATION

EDS ECHO: Supporting Healthcare Professionals Across the UK and Beyond



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 global education programme improving care for people with Ehlers-Danlos syndromes (EDS) and hypermobility spectrum disorders (HSD). Rooted in the Project ECHO® model, this initiative connects healthcare professionals in the UK and around the world through virtual, case-based learning.

EDS ECHO moves knowledge, not people — fostering collaboration, advancing clinical skills, and building an international network dedicated to rare disease education and support.

2024 Global Highlights

14



PROGRAMMES &
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, INCLUDING GROWING
NUMBERS FROM THE UK, EUROPE,
AUSTRALASIA, AND NORTH AMERICA

EDUCATION

UK Impact in 2024

- 420 UK healthcare professionals have participated since launch.
- 90 new UK participants joined in 2024.
- UK professionals took part in programmes focused on movement, multidisciplinary care, paediatrics, and advocacy.
- Drop-in sessions and UK-friendly timings improved accessibility across time zones.



"I feel so honoured to participate in EDS ECHO. You are doing fantastic work."

- Multidisciplinary Team Practice Europe participant, UK



"This has been one of the most enjoyable and informative courses I've ever done... I was able to use the knowledge straight away."

- Participant, Fundamentals of the Integral Movement Method

New Programmes in 2024

Seven new programmes launched in 2024, including:

- ⚙️ Multidisciplinary Team Practice Europe – UK participants joined experts across Europe to explore integrated, collaborative care.
- 👤 Finding Functional Foundations (FFF) – A specialist course for physiotherapists, with strong UK uptake.
- ⬇️ Drop-in Sessions – Continued professional development in small group, discussion-based formats.
- 👩🎓 Healthcare Student Programme – Supporting early-career professionals and students in understanding EDS and HSD.
- ⊕ Health Advocacy Programme – Relaunched to empower advocates in the UK and globally.

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 Programme: An updated curriculum equips advocates with the knowledge and tools to support others.

Participant Voices from the UK



"There were techniques, information, and peer-learning I hadn't encountered before — it was refreshing and immediately useful."

- IMM course participant



"These sessions are incredibly important, especially when it's hard to access education on these conditions elsewhere. The Drop-ins are particularly valuable."

- UK healthcare professional



"So much information to take back to my clients. This will help them immensely."

- Multidisciplinary Team Practice participant



"I'm doing my best to spread this information to every patient — and every physician I work with."

- UK doctor and ASD specialist



EDUCATION

Recognition and Results

Programme 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

In 2025, EDS ECHO will continue to grow, with **14 scheduled programmes**, **164 sessions**, and **173 CE credits** available. Upcoming initiatives relevant to the UK include:

14

Programmes

173

CE Credits

164

Sessions

New programmes in development:

➤ EDS ECHO for Caregivers

➤ Nutrition ECHO for Australasia (with global access)

➤ EDS ECHO Dentistry

With your support, we're ensuring that more UK healthcare professionals have the knowledge and tools to **recognise**, **diagnose**, and **care** for those with EDS and HSD — faster, more compassionately, and more effectively than ever before.

EDUCATION

Events: Expanding Education, Connection, and Care

The Ehlers-Danlos Society's events programme plays a vital role in our mission, serving as a powerful platform for education, awareness, and community-building around EDS and HSD. These conferences are essential for 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.

Throughout the year, we hosted four major educational events, each bringing together global experts for engaging presentations, live Q&A, and collaborative discussion. These gatherings provided not only vital knowledge but also a space to share lived experiences, build professional connections, and strengthen support networks.



Emergency Care Summit: A UK-Focused 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



"Thank you so much for all the hard work you put into running EDS ECHO — it's outstanding and the highlight of my week."

- UK EDS ECHO participant



"There was so much information that I will now take time to go over again, session by session. I know it will help my clients immensely."

- UK Allied Health Professional



"The sessions were hugely informative, and it was so valuable to see UK-specific healthcare insights. Thank you!"



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 (including the UK)

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
- Optimising diet and nutrition for neurodivergent individuals
- Understanding supplementation

Lorna Ryan, UK-based 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.



EDUCATION



GLOBAL LEARNING CONFERENCE 2025
TEAMWORK
 The Ehlers-Danlos Society

2024 Global Learning Conference: A Global Event with UK Voices

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. The hybrid format enabled participants from the UK to join live from home, removing travel barriers and supporting greater inclusion.

Programme Highlights:

- 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

All sessions were recorded and made available on-demand, with CME/CEU credits offered for live participation.

“It’s wonderful to be part of such a global and welcoming event. The sessions on neurodivergence and gastrointestinal care were incredibly relevant to my patients.”

- UK Physiotherapist, virtual attendee

“Thank you for making the conference accessible virtually. It’s a lifeline for people like me who can’t travel but want to stay informed.”

- UK Community Member



EDUCATION

Junior Zebras Take the Spotlight

We hosted our largest-ever Junior Zebras programme, **welcoming 75 children and teens**. Led by Camp Joy, the youth programme 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.

Louize's Half Marathon for Awareness

Diagnosed with hEDS in childhood, **Louize** completed the **Manchester Half Marathon**, raising **£155** and sharing her lived experience to help others better understand the challenges of life with EDS.

“So many people don't understand what these conditions really mean. I wanted to help change that, and raise money for better care and research.”

Matthew's Mission: Running for a Loved One

Matthew Chapple raised **£286** in support of his partner, sharing his fundraising story to raise awareness of EDS and the strength of caregivers.

“Watching someone you love go through this journey and not be able to take the pain away is difficult. This was one small way I could support her—and others like her.”

Toyin's Instagram Fundraiser for Research

Living with hEDS herself, **Toyin** raised **£128.16** through an Instagram fundraiser, sharing daily posts and educational content throughout the month.

“This community has given me knowledge, strength, and belonging. I wanted to give something back.”

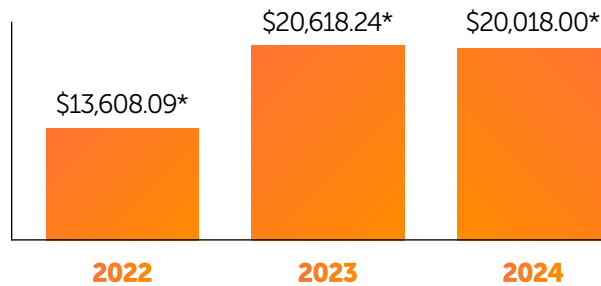


FUNDRAISING

Giving Tuesday: Doubling Impact

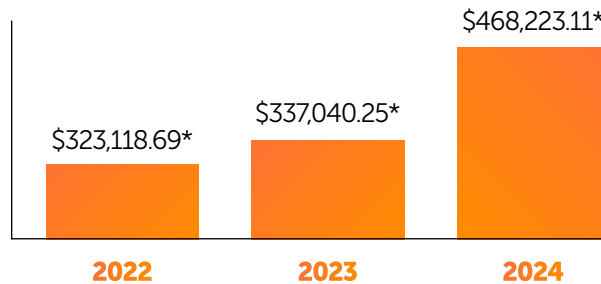
On Giving Tuesday, our supporters stepped up, and thanks to an anonymous match donation of up to \$400,000*, your generosity meant double the impact.

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 programmes 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

★ Where the financial impact of a programme is spread across our US and UK organisations, consolidated amounts are used.



The Ehlers-Danlos Society

Trustee Report 2024-2025

Report Of The Trustees

The Trustees herewith present their report and the unaudited financial statements of the company for the year ended 30th April, 2025.

Structure, Governance and Management

The Ehlers-Danlos Society is a charity and a company limited by guarantee. The governing documents are the company's memorandum and articles of association. The Charity is organised so that the Trustees meet quarterly to review results and manage its affairs. In this way the Trustees gather information needed to make decisions and plan for the future. New trustees are recruited by personal approach or recommendation by a current trustee.

The Trustees have appointed a CEO, Lara Bloom, who leads the day-to-day management of the charity.

The trustees are satisfied that systems are in place to mitigate exposure to any major risks to which the charity could be exposed.

The UK and US organisations are two separate legal entities; however, we share a global mission, governance, financial and administrative structures, some staff, website, social media platforms, and volunteer resources; all of which ensures we are as efficient as possible and maximise the impact we can have on our UK community. Our Trustees also serve on our US Board of Directors.

Reference and Administrative Details

As set out under the relevant sections herein.

Exemptions from disclosure

None.

Financial Review

As a relatively new and expanding charity, our income from this financial year has been influenced by the COVID pandemic and subsequent economic turmoil but has predominantly come from public donations, fundraising events in memory of those who have passed away and a grant from The Ehlers-Danlos Society (US Charitable Society). Our administrative expenditure is kept as low as possible in order to ensure maximum benefit to the beneficiaries, and as described we continue to work closely by sharing common services with The Ehlers-Danlos Society, USA.

Our Statement of Financial Activities shows a net movement In funds of £143,285 for the fiscal year ending on 30th April, 2025. The resulted In an Increase In total funds at the balance sheet date to £200,179.

Total income for the year increased by £386,456 compared to the prior fiscal year as a result of an increase in donations related to the HEDGE project as well as grants from EDS US.

Total expenses for the year increased by £268,578 compared to the prior fiscal year. A decrease in expenses related to the HEDGE study was offset by increases in labour costs as well as travel costs for events.

Going forward, we aim to increase our income in the same ways and to apply for potential grant opportunities in the UK and the USA. We also intend to focus on growing our UK-based community giving. We do not have any debts, and at this time we do not have a reserves policy but we aim to create one in the next few years as our income allows. We continuously review the financial performance of our activities and programmes to ensure they allocate resources to their best effect.

We currently employ eighteen full-time staff, three part-time staff, and one full-time consultant/contractor. All of our staff work remotely as part of our effort to reduce unnecessary overhead expenditures and reduce our impact on the environment.

Statement of Trustees Responsibilities for Preparing the Financial Statements

The Trustees are responsible for preparing the Trustee's Report and the Accounts in accordance with applicable law and regulations. Company law requires the Trustees to prepare Accounts for each financial year.

Under the law, the Trustees have elected to prepare the Accounts in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law).

Under company law, the Trustees must not approve the Accounts unless they are satisfied that they give a true and fair view of the state of affairs of the Company and of the profit or loss of the Company for that period.

In preparing these Accounts, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and estimates that are reasonable and prudent;
- prepare the Financial Statements on the going concern basis unless it is inappropriate to presume that the Company will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the Company's transactions and disclose with reasonable accuracy at any time the financial position of the Company and enable them to ensure that the Accounts comply with the Companies Act 2006. The Trustees are also responsible for safeguarding the assets of the Company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Amounts are presented within items in the profit and loss account and balance sheet, the Trustees have had regard to the substance of the reported transaction or arrangement, in accordance with generally accepted accounting principles or practice. In the case of each of the persons who are Trustees at the time when the Trustees' report is approved: so far as the Trustee is aware, there is no relevant audit information (information needed by the charity's auditors in connection with preparing their report) of which the charity's auditors are unaware, and each Trustee has taken all steps that they ought and themselves aware to have taken as a Trustee in order to make himself aware of any relevant audit information and to establish that the charity's auditors are aware of that information.

Appointment of Auditors

The auditors, Jeffrey Altman & Company, will be proposed for re-appointment at the forthcoming Annual General Meeting.

This Report has been prepared in accordance with the small companies regime of the Companies Act, 2006.



Sue Haskell

Director & Trustee

The Ehlers-Danlos Society

(A Company Limited By Guarantee)

Statement of Financial Activities (including income and expenditure account) for the year ended 30th April, 2025.

Incoming Resources	Notes	2025 Unrestricted Funds (£)	2025 Restricted Funds (£)	2025 Total (£)	2024 Unrestricted Funds (£)	2024 Restricted Funds (£)	2024 Total (£)
Incoming & endowments from: Donations & legacies		831,462	721,064	1,552,526	656,413	509,657	1,166,070
Charitable Activities: Conference Income		-	-	-	-	-	-
Investments: Bank Interest		-	-	-	-	-	-
TOTAL	3	831,462	721,064	1,552,526	656,413	509,657	1,166,070

Expenditure On: Cost of Generating Funds	Notes	2025 Unrestricted Funds (£)	2025 Restricted Funds (£)	2025 Total (£)	2024 Unrestricted Funds (£)	2024 Restricted Funds (£)	2024 Total (£)
Charitable activities	4	179,366	1,218,857	1,398,223	113,402	1,016,689	1,130,091
Other	4	11,018	-	11,018	10,572	-	10,572
TOTAL EXPENDITURE		190,384	1,218,857	1,409,241	123,974	1,016,689	1,140,663

Net Income/Expenditure before Taxation		641,078	(497,793)	143,285	532,439	(507,032)	25,407
Tax Payable		-	-	-	-	-	-
TOTAL		641,078	(497,793)	143,285	532,439	(507,032)	25,407

Net Incoming/(Expenditure)	Notes	2025 Unrestricted Funds (£)	2025 Restricted Funds (£)	2025 Total (£)	2024 Unrestricted Funds (£)	2024 Restricted Funds (£)	2024 Total (£)
Transfers between funds		(642,132) (1,054)	642,132 144,339	- 143,285	(469,553) 62,886	469,553 (37,479)	- 25,407

Net Movement in Funds: Reconciliation of Funds	Notes	2025 Unrestricted Funds (£)	2025 Restricted Funds (£)	2025 Total (£)	2024 Unrestricted Funds (£)	2024 Restricted Funds (£)	2024 Total (£)
Fund balances at 1 st May, 2024		56,894	-	56,894	(5,992)	37,479	31,487
Fund balances at 30 th April, 2025		55,840	144,339	200,179	56,894	-	56,894

Continuing Operations

None of the Charity's activities were acquired or discontinued during the above financial period.
The statement of financial activities includes all gains and losses recognised in the year.

The Ehlers-Danlos Society

(A Company Limited By Guarantee)

Legal & Administrative Information

Charity N°:

1180984

Company N°:

10722868

Directors & Trustees:

W. Gandy, Esq
Mrs S.Haskel
Mrs S Hawkins
Dr M.J. Macleod
Mr R Rubin
Mr J Zonarich

Registered Office:

Wayman House
141 Wickham Road
Shirley
Croydon
Surrey CR0 8TE

Auditors:

Messrs. Jeffrey Altman & Company
Chartered Accountants
Wayman House
141 Wickham Road
Shirley
Croydon
Surrey CR0 8TE

Bankers:

Virgin Money Bank
154-158 Kensington High Street
London
W8 7RL

The Ehlers-Danlos Society

(A Company Limited By Guarantee)

Independent Auditors' Report to the Members of The Ehlers-Danlos Society

Opinion

We have audited the financial statements of the Ehlers-Danlos Society (the "Charity") for the year ended 30th April, 2025 which comprise of the Statement of Financial Activities, Balance sheet, cash flow statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the Charity's affairs as at 30th April, 2025 and of its incoming resources and application of resources for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice;
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and the provisions available for small entities, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that individually or collectively may cast significant doubt on the Charity's ability to continue as a going concern for a period of at least 12 months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- The information given in the trustees' report (incorporating the strategic report and the directors' report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- The trustees' report (incorporating the strategic report and the directors' report) have been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the Charity and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- Adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us;
- The financial statements are not in agreement with the accounting records and returns;
- Certain disclosures of trustees' remuneration specified by law are not made; or
- We have not obtained all the information and explanations necessary for the purposes of our audit.

Responsibilities of the trustees

As explained more fully in the trustees' responsibilities statement, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as they determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the Charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

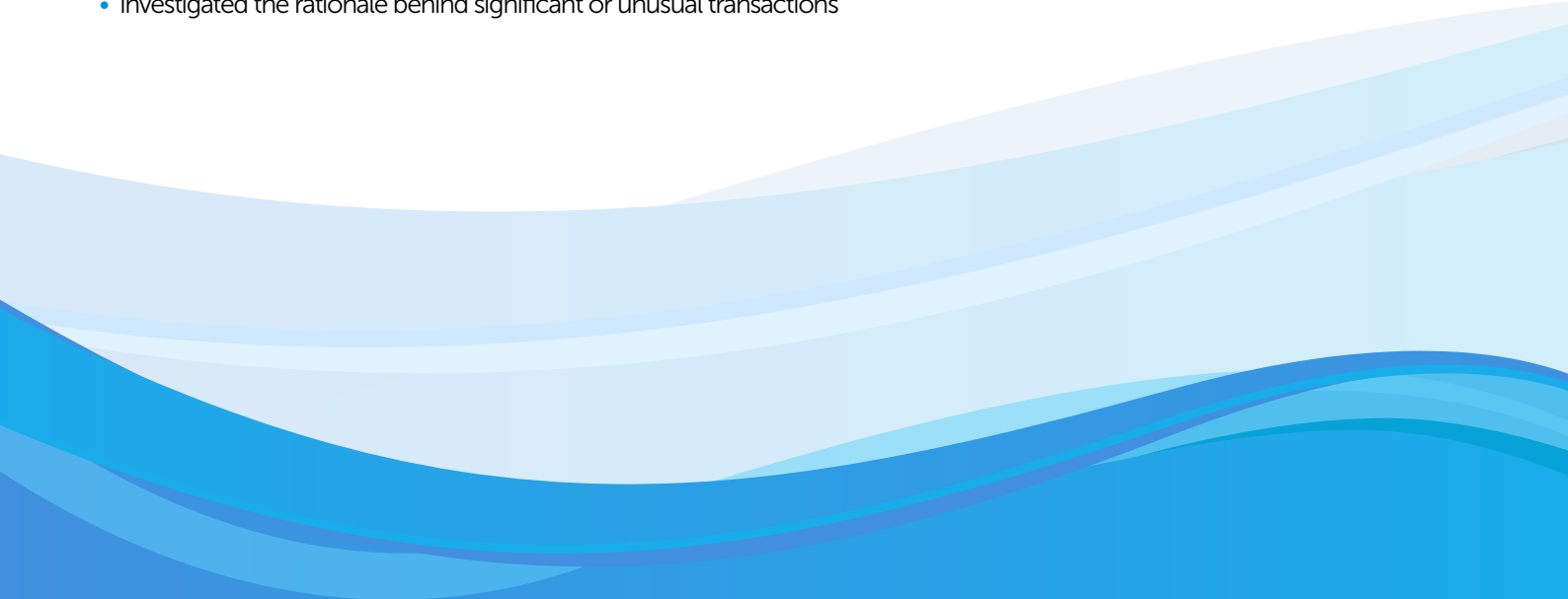
Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below.

Our approach to identifying and assessing the risks of material misstatement in respect of irregularities, including fraud and non compliance with laws and regulations, was as follows:

The engagement partner ensured that the engagement team collectively has the appropriate competence, capabilities and skills to identify or recognised non compliance with applicable laws and regulations:

- We identified the laws and regulations applicable to the Charity through discussions with Trustees and other management, and from our knowledge and experience of the Charity sector.
- We focused on specific laws and regulations which we considered may have a direct material effect on the financial statements or operations of the Charity.
- We assessed the extent of compliance with the laws and regulations identified above through making enquiries of management and inspecting legal documents and
- Identified laws and regulations were communicated within the audit team regularly and the team remained alert to instances of non-compliance throughout the audit.
- We assessed the susceptibility of the Charity's financial statements to material misstatement including obtaining an understanding of how fraud might occur, by:
- Making enquiries of management as to where they considered there was susceptibility to fraud, their knowledge of actual, suspected and alleged fraud: and
- Considering the internal controls in place to mitigate risks of fraud and non compliance with laws and regulations

To address the risk of fraud through management bias and override of controls, we:

- performed analytical procedures to identify any unusual or unexpected relationship:
 - tested journal entries to identify unusual transactions:
 - assessed whether judgements and assumptions were made in determining the accounting estimates were indicative of potential bias: and
 - investigated the rationale behind significant or unusual transactions
- 

In response to the risk of irregularities and non compliance with laws and regulations, we designed procedures which included, but were not limited to:

- agreeing financial statement disclosures to underlying supporting documentation;
- reading the minutes of meetings of those charged with governance
- enquiring of management as to actual and potential litigation and claims; and
- reviewing correspondence with HMRC, relevant regulators and the Charity's legal advisors.

There are inherent limitations in our audit procedures described above. The more removed that laws and regulations are from financial transactions, the less likely it is that we would become aware of non-compliance. Auditing standards also limit the audit procedures required to identify non-compliance with laws and regulations to enquiry of the Trustees and other management and the inspection of regulatory and legal correspondence, if any.

Material misstatements that arise due to fraud can be harder to detect than those that arise from error as they may involve deliberate concealment or collusion.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities]. This description forms part of our auditor's report.

Use of our Report

This report is made solely to the Charity's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the Charity's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity's members as a body, for our audit work, for this report, or for the opinions we have formed.



Mikaela Altman F.C.A.

Senior Statutory Auditor

*for and on behalf of Jeffrey Altman & Company
Statutory Auditors and Chartered Accountants*

Wayman House
141 Wickham Road
Shirley
Croydon
Surrey
CR0 8TE

10th October 2025

Date

The Ehlers-Danlos Society

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Statement of Cash Flows for the year ended 30th April 2025

Cash Flow from Operating Activities	2025 (£)	2024 (£)
Operating profit/(loss) for the financial year	143,285	25,407
(Increase)/decrease in debtors	(199,452)	37,299
Increase/(decrease) in creditors	20,223	11,504
Cash from Operations	(35,944)	74,210
Net cash from operating activities	(35,944)	74,210
Net (decrease)/increase in cash and cash equivalents	(35,944)	74,210
Cash and cash equivalents at 1 st May, 2024	78,083	3,873
Cash and cash equivalents at 30 th April, 2025	42,139	78,083

Unaudited Balance Sheet as at 30th April, 2025

Current Assets	Notes	2025 (£)	2025 (£)	2024 (£)	2024 (£)
Debtors	7	211,160	-	11,708	-
Cash at Bank and in Hand		42,139	-	78,083	-
TOTAL		253,299	-	89,791	-

Current Liabilities	Notes	2025 (£)	2025 (£)	2024 (£)	2024 (£)
Creditors - amounts falling due within one year	8	53,120	-	32,897	-
Net Current Assets		-	200,179	-	56,894
Total Assets Less Current Liabilities		-	200,179	-	56,894
Net Assets		-	200,179	-	56,894
Reserves		-	-	-	-
Unrestricted Funds		-	-	-	-
General funds	9	-	55,840	-	119,780
Restricted funds	9	-	144,339	-	(37,479)
TOTAL		-	200,179	-	82,301

These accounts are prepared in accordance with the provisions applicable to Companies subject to the small companies regime of Companies Act 2006.

Approved by the Trustees on 10th Oct, 2025 and signed on their behalf by:



Sue Haskel
Director & Trustee

The Ehlers-Danlos Society

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Notes to the Unaudited Accounts for the year ended 30th April, 2025

1. Accounting Policies

The accounting policies set out below have been applied consistently by the Charity in the preparation of its Accounts.

(a) Basis of Accounting

The Accounts have been prepared in accordance with FRS 102 and the Charities SORP (FRS 102) (effective 1st January, 2015) and the Companies Act 2006 and under the Historical Cost Convention and on a going concern basis.

(b) Charitable Income

Voluntary income is received by way of donations and gifts and is included in full in the Statement of Financial Activities when receivable. The value of services provided by volunteers has not been included. Credit is taken in the Accounts for donations, legacies and grants only when they are actually received by the Charity.

(c) Public Benefit Entity

The Charity is a public benefit entity under FRS 102 and has been incorporated in England and Wales and is registered with The Charity Commission in England and Wales. The principal place of business being that of Office 7, 35-37 Ludgate Hill, London, EC4M 7JN.

(d) Taxation

As a registered Charity, the company is not liable to taxation on its income.

(e) Funds Accounting

Funds held by the Charity are either:

Unrestricted general funds - these are funds which can be used in accordance with the charitable objects at the discretion of the Trustees.

Designated funds - these are funds set aside by the Trustees out of unrestricted general funds for specific future purposes or projects.

Restricted funds - these are funds that can only be used for particular restricted purposes within the objects of the Charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

(f) Resources Expended

Resources expended are included in the Statement of Financial Activities on an accruals basis, inclusive of any VAT which cannot be recovered.

Certain expenditure is directly attributable to specific activities and has been included in those cost categories. Certain other costs which are attributable to more than one activity, are apportioned across cost categories on the basis of an estimation of the proportion of time spent on those activities. Government costs include those incurred in the governance of the charity and its assets are primarily associated with constitutional and statutory requirements.

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Notes to the Unaudited Accounts for the year ended 30th April, 2025.

Legal Status of the Charity

The Charity is a Company limited by guarantee and has no share capital. The liability of each member in the event of winding up is limited to £1.

Income from Charitable Activities

	2025 Unrestricted Funds (£)	2025 Restricted Funds (£)	2025 Total (£)	2024 Unrestricted Funds (£)	2024 Restricted Funds (£)	2024 Total (£)
Conference Income	-	-	-	-	-	-
Donations & Grants	831,462	721,064	1,552,526	656,413	509,657	1,166,070
Interest on Investments	-	-	-	-	-	-
TOTAL	831,462	721,064	1,552,526	656,413	509,657	1,166,070

Analysis of Total Resources Expended

Charitable Activities	2025 Unrestricted Funds Direct Costs (£)	2025 Support Costs (£)	2025 Restricted Funds Direct Costs (£)	2025 Total (£)	2024 Unrestricted Funds Direct Costs (£)	2024 Support Costs (£)	2024 Restricted Funds Direct Costs (£)	2024 Total (£)
Wages & salaries	111,828	-	873,521	985,349	52,146	-	627,930	680,076
National insurance	12,552	-	97,604	110,156	6,908	-	66,223	73,131
Grants awarded	-	-	93,952	93,952	-	-	176,500	176,500
Pension costs	16,473	-	-	16,473	14,087	-	-	14,087
Staff benefits	4,090	-	-	4,090	487	-	-	487
Advertising & Promotional Expenses	640	-	2,220	2,860	-	-	-	-
Training	290	-	-	290	-	-	-	-
Insurance	1,432	-	-	1,432	1,224	-	-	1,224
Telephone	9,960	-	7,867	17,827	9,172	-	3,213	12,385
Auditor's Fees	-	11,018	-	11,018	-	10,572	-	10,572
Printing, Postage & Stationery	174	-	2,515	2,689	394	-	3,505	3,899
Professional Fees	1,680	-	117,008	118,688	2,160	-	103,250	105,410
Computer costs	-	-	-	-	4,071	-	-	4,071
Conference costs	-	-	229	229	-	-	3,628	3,628
Donations & subscriptions	4,473	-	1,665	6,138	3,846	-	1,051	4,897
Finance costs	49	-	431	480	19	-	424	443
Sundry Expenses	84	-	116	200	356	-	189	545
Travel costs	15,641	-	21,729	37,370	18,532	-	30,776	49,308
TOTAL	179,366	11,018	1,218,857	1,409,241	113,402	10,572	1,016,689	1,140,663

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5. Staff Costs & Trustees Remuneration

The Trustees were not paid or reimbursed for expenses during the period.
The number of staff receiving a salary of over £60,000 was:

	2025	2024
Between £60,000-£70,000	-	2
Between £70,000-£80,000	2	-
Between £80,000-£90,000	-	1
Between £100,000-£110,000	1	-
Between £110,000-£120,000	-	-
Between £140,000-£150,000	-	1
Between £170,000-£180,000	1	-

The total remuneration of key management personnel during the year was £171,788 (2024: £143,688).

6. Staff Numbers

	2025	2024
Administration	24	14

7. Debtors

	2025 (£)	2024 (£)
Donations	201,463	-
Taxation and social security	-	-
Prepaid Expenses	9,697	11,708
TOTAL	211,160	11,708

8. Creditors - Amounts Falling Due Within One Year

	2025 (£)	2024 (£)
Deferred conference revenues	-	-
Taxation and social security	39,941	22,325
Accruals and Other Creditors	13,179	10,572
TOTAL	53,120	32,897

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9. Movement Of Funds In The Year

	2025							2024		
	Unrestricted Funds	Restricted Funds						Unrestricted Funds	Restricted Funds	
	General Fund (£)	Administrative Assistant (£)	ECHO (£)	HEDGE (£)	Education & Events (£)	Scientific & Research (£)	Total (£)	General Fund (£)	Total (£)	Total (£)
At 1st May, 2024	56,894	-	-	-	-	-	56,894	-5,992	37,479	31,487
Income in the year	831,462	-	52,104	235,334	59,669	373,963	1,552,526	656,413	509,657	1,166,070
	888,356	-	52,104	235,334	59,663	373,963	1,609,420	650,421	547,136	1,197,557
Expenditure in the year	190,384	-	128,229	94,465	625,670	370,493	1,409,241	123,974	1,106,689	1,140,663
	697,972	-	-76,125	140,869	-566,007	3,470	200,179	526,447	-469,553	56,894
Transfers	-642,132	-	76,125	-	566,007	-	-	-469,553	469,553	-
At 30th April, 2025	55,840	-	-	140,869	-	3,470	200,179	56,894	-	56,894

10. Going Concern

The financial statements have been prepared on a going concern basis. The trustees consider that the Charity holds sufficient reserves to deem the going concern basis appropriate for at least 12 months from the date of this report.

11. Contingent Liabilities

There were no contingent liabilities as at 30th April, 2025.

12. Related Party Transactions

During the year, the Charity received a £20,000 donation (2024: £20,000) from a Charity controlled by one of the Trustees. The charity also received £143,312 (2024: £256,507) in donations from a Charity controlled by a second Trustee and £164,350 (2024: £nil) in donations from the Trustee. The charity also received £1,113,826 (2024: £747,233) in donations during the year from a Charity under common control. £93,952 (2024: £176,500) was granted during the year to the Charity under common control.