



The
**Ehlers
Danlos**
Society

UK IMPACT REPORT

1st May, 2023 - 30th April, 2024



Registered Charity Number:
1180984

Letter From the President and Chair of the Board of Directors

Dear Friends and Supporters,

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

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

One of the most significant milestones this year was the growth of our EDS ECHO programme, which now supports a global network of healthcare professionals and advocates. With over 350 new health professionals joining our programmes in 2023, we are more equipped than ever to ensure that individuals with EDS and HSD receive the specialised care they deserve. We are grateful to now have 215 UK alumni in our EDS ECHO programme!

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

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

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

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

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

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

With gratitude,

*Professor
Lara Bloom*

President and CEO
The Ehlers-Danlos Society



Susan Hawkins

Chair of Trustees
The Ehlers-Danlos Society

Helpline

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

Demand for the helpline grew year-on-year, and in 2023 we increased our global Community Education team count to three. Together, the team answered over 530 calls and 2,600 emails, offering potentially life-changing advice.

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

Access to Expert Knowledge and Guidance

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

Emotional Support and Validation

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

Resource Navigation

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

Education and Advocacy

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

Ongoing Research and Updates

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



"I just wanted to say **THANK YOU for this thoughtful and detailed response!**

I was able to use the information provided to secure an appointment with our hospital's paediatric team to work on getting a wheelchair for longer outings. We are also using some of the resources provided to craft better accommodations for my daughter's school day. Really appreciate the support and community while we work to figure out what's happening with our daughter."



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



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

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

CARE

Virtual Support Groups

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

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

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

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

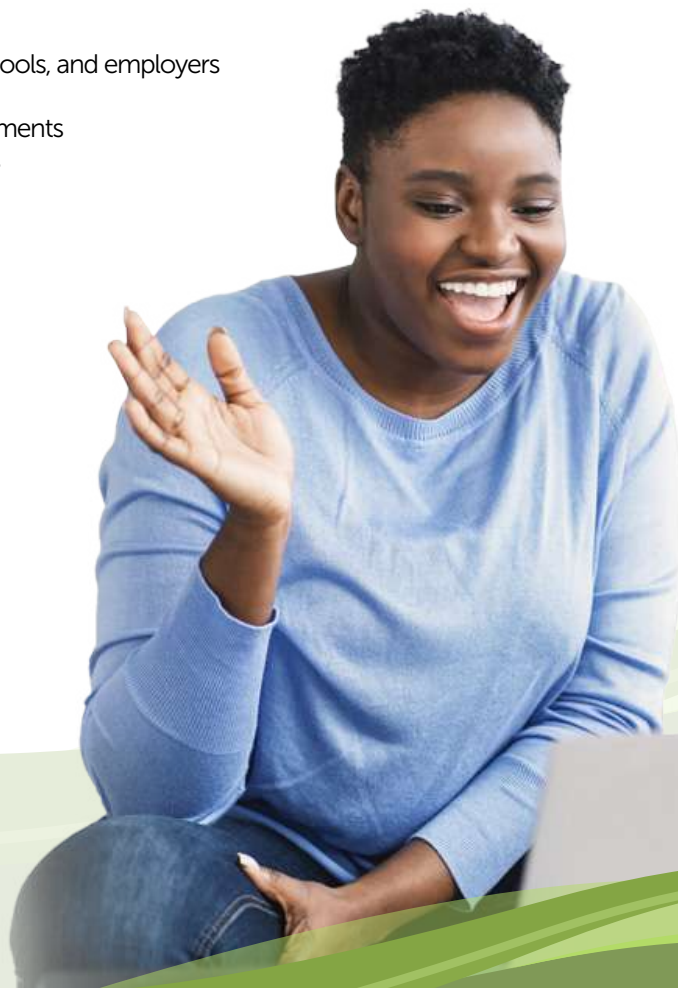
- Individuals impacted by all types of EDS and HSD
- Adults who have vascular Ehlers-Danlos syndrome (vEDS) and/or those who have a child with vEDS
- Parents with EDS or HSD or parents of children with EDS or HSD
- Partners and spouses
- Men
- LGBTQIA+ individuals
- Teens

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

Commonly discussed topics included:

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

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



Community Connections

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

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

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



“

“OMG!!! 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 organisations like yours that explain everything so clearly!”

”

“

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

”

Supporting Our Junior Zebras

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

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

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

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

Let's Chat: Teens Support Groups

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

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

Junior Zebras Programme

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

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

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

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

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



CARE

Expanding Access to Information, Care, and Resources

In 2023, The Ehlers-Danlos Society's website was accessed by over 1.9 million users around the world, with over 164,000 from the UK. The website serves as a vital hub, connecting individuals with EDS and HSD, their caregivers, healthcare professionals, and researchers to essential resources and information tailored to their needs.

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

Access to Essential Information

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

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

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

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

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



ACCESS

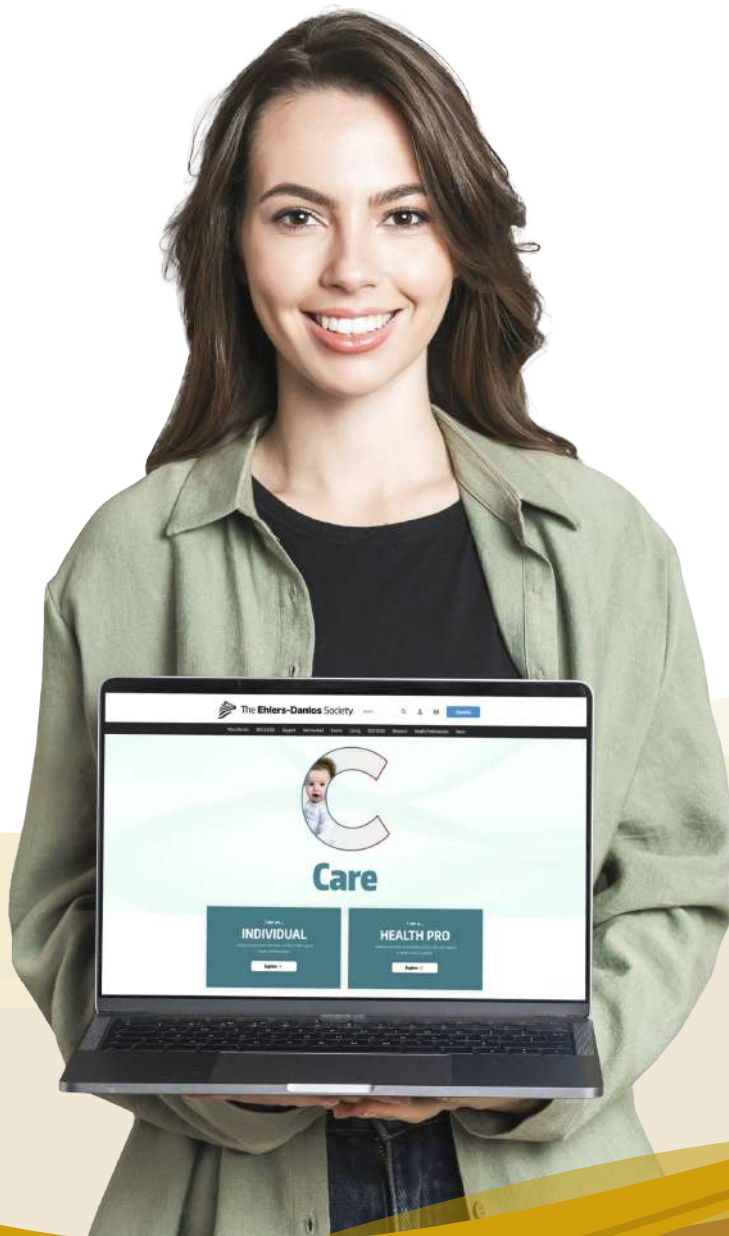
Expanding Access to Information, Care, and Resources

Access to Expert Care Healthcare Professionals Directory

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

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

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



ACCESS

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



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

We know that around the world, what is desperately needed is early diagnosis, validation, and effective multidisciplinary care. We look forward to making this a reality. Our aim is that no matter where you live, you have access to a multidisciplinary team approach.

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

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



Australia

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



Canada

SickKids Foundation [cohort 2]



France

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



Germany

Universität zu Köln [cohort 1]



Italy

Casa Sollievo della Sofferenza [cohort 1]



Kuwait

Alsiri Hypermobility Clinic [cohort 2]



United Kingdom

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



USA

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

ACCESS



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

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

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

COHORT 3

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

Support Group and Charity Directory

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

Our Support Group and Charity Directory helps individuals with EDS or HSD find local support groups and organisations so they can better access care and resources within their own communities. This frequently shared resource now lists 112 support groups and charities supporting people with EDS and HSD around the world, including 6 listings in the UK.

Global Affiliation Programme

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

Five fantastic organisations have joined the Global Affiliate programme from the UK, committed to working together to support people all around the UK and further research and education with GPs and health professionals.



ACCESS

Funded Research

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

Research Grant Programme

The Research Grant programme has continued to support promising researchers and investigators in their pursuit of scientific advancements in EDS and HSD. By providing financial assistance and mentorship, we have fostered a vibrant research community focused on unraveling the complexities of these disorders.

In 2023's \$50,000 microgrant round, The Ehlers-Danlos Society awarded ten microgrants of up to \$5,000 each to researchers worldwide*. Three of the incredible researchers are from the UK, committing to progress in understanding these complex conditions.

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



Genotype and Phenotype

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



Time to Diagnosis Reduction

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



Centers of Excellence and Pathways

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



Therapies and Management

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



RESEARCH

Microgrant Awardees: UK Spotlight

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

Jane Simmonds

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

University College London
London, England



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

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

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



RESEARCH

Jessica Eccles

Variant Connective Tissue: A Risk Factor for Long COVID

Brighton and Sussex Medical School
Hove, England



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

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

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

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

Qasim Aziz

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

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



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

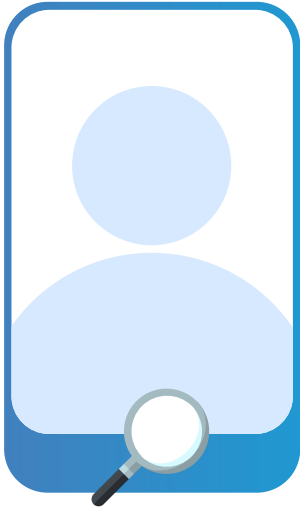
People with hEDS/HSD often have to travel long distances to find healthcare professionals who understand their gastrointestinal issues, leading to high costs and long wait times. The lack of high-quality, evidence-based information on the internet further complicates their search for reliable guidance,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

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

Tessa Hulburt

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

Emory University School of Medicine



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

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

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



RESEARCH

Open Access Funding

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

Increased Accessibility:

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

Faster Dissemination of Knowledge:

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

Increased Impact and Citations:

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

Supporting Patient Advocacy and Education:

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

Global Reach:

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

Transparency and Trust:

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



RESEARCH

The Ehlers-Danlos Society funded \$12,254 for three research papers to be open access in 2023*. Two of these papers were led by researchers from the UK.

1. [Extracutaneous features and complications of the Ehlers-Danlos syndromes: A systematic review](#)

Brent J. Doolan et al.

School of Basic and Medical Biosciences, St. John's Institute of Dermatology, King's College London, London, United Kingdom.

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

2. [Dermatologic manifestations and diagnostic assessments of the Ehlers-Danlos syndromes: A clinical review](#)

Brent J. Doolan et al.

School of Basic and Medical Biosciences, St. John's Institute of Dermatology, King's College London, London, United Kingdom.

The paper in the Journal of the American Academy of Dermatology was led by Brent J Doolan from the School of Basic and Medical Biosciences, St. John's Institute of Dermatology, King's College London, London, United Kingdom. This paper examines the prevalence and clinical features of the EDS types in dermatology practice. It highlights the importance of recognising skin and soft tissue manifestations in EDS for early diagnosis and management. The study emphasises the role of dermatologists in identifying EDS-related complications and improving patient outcomes through timely referrals and appropriate care. The findings underscore the need for increased awareness of EDS among dermatologists to better serve this patient population.



RESEARCH

Pregnancy, Childbirth, and Postnatal Care in EDS and HSD.



 **The International Consortium
on Ehlers-Danlos Syndromes (EDS)
& Hypermobility Spectrum Disorders (HSD)**
Facilitated by The Ehlers-Danlos Society

"I AM IMMENSELY PROUD TO BE LEADING THE INTERNATIONAL CONSORTIUM ON EDS AND HSD, IN CO-CREATING INTERNATIONAL CONSENSUS GUIDELINES IN RELATION TO CHILDBEARING WITH HYPERMOBILE EDS (hEDS) AND VASCULAR EDS (vEDS).

"IN PURSUIT OF IMPROVING OUTCOMES AND EXPERIENCES, I AM KEEN TO ENSURE THAT THE BEST AVAILABLE EVIDENCE IS USED TO INFORM BOTH DECISION-MAKING AND PRACTICE IN THESE AREAS."

DR. SALLY PEZARO

FELLOW OF THE ROYAL COLLEGE OF MIDWIVES (FRCM)

A small number of studies have looked at the challenges EDS and HSD can present in pregnancy, childbirth, and postnatal care, and yet there are currently no international guidelines.

The Ehlers-Danlos Society is supporting a team of international experts, led by Dr. Sally Pezaro who are producing much-needed guidelines in this area. Dr. Pezaro is an academic midwife based at Coventry University in the United Kingdom, a Fellow of the Royal College of Midwives (FRCM), and an editorial board member of the British Journal of Midwifery, Evidence-Based Midwifery, MIDIRS, and the International Journal of Childbirth. She is also the lead midwife for hedstogether, a project which has enabled many networking and awareness-raising activities, building up a team of people with a range of experiences to co-create tools in relation to childbearing, hEDS, and HSD.

Dr. Pezaro is leading the Pelvic Floor and Bladder Disorders Working Group along with many other expert members of The International Consortium on EDS and HSD, to produce guidelines for the management of pregnancy, birth, and post-natal recovery in the context of hypermobile Ehlers-Danlos syndrome (hEDS), hypermobility spectrum disorders (HSD), and vascular Ehlers-Danlos syndrome (vEDS).

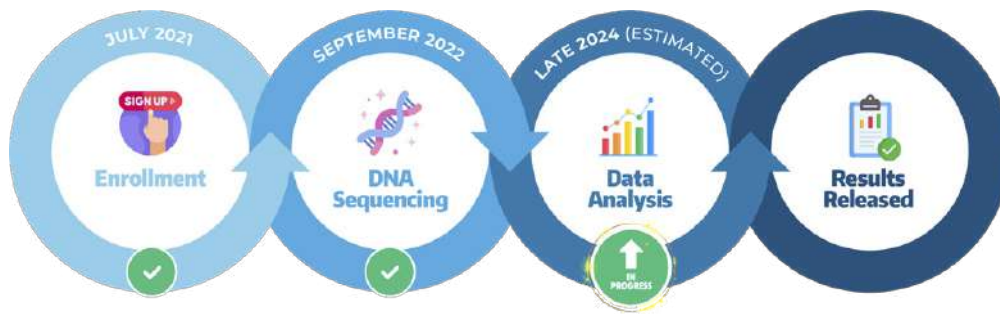
While clinical care considerations for hEDS and HSD through pregnancy, birth, and beyond have been published (Blagowidow, 2021; Pezaro et al, 2018, 2021), no uniform international guidelines for the management of hEDS and HSD during the prenatal (antenatal), intrapartum, and postnatal period exist.

Individuals with hEDS and HSD may encounter pregnancy-related problems such as ineffective anesthetic, unusually fast labors and births, problematic bleeding, and/or poor wound healing.

Pregnant individuals with vEDS have an increased risk of pregnancy complications and mortality. Major complications can occur during pregnancy, labor, birth, and in the weeks and months following. Thus, close monitoring by specialists throughout pregnancy is essential for those with vEDS.

While this project will focus on developing two sets of guidelines (one for hEDS and HSD, and one for vEDS) it will also consider and include the other rare and ultra-rare types of EDS as they may have similar concerns and require similar management.

HEDGE Study



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

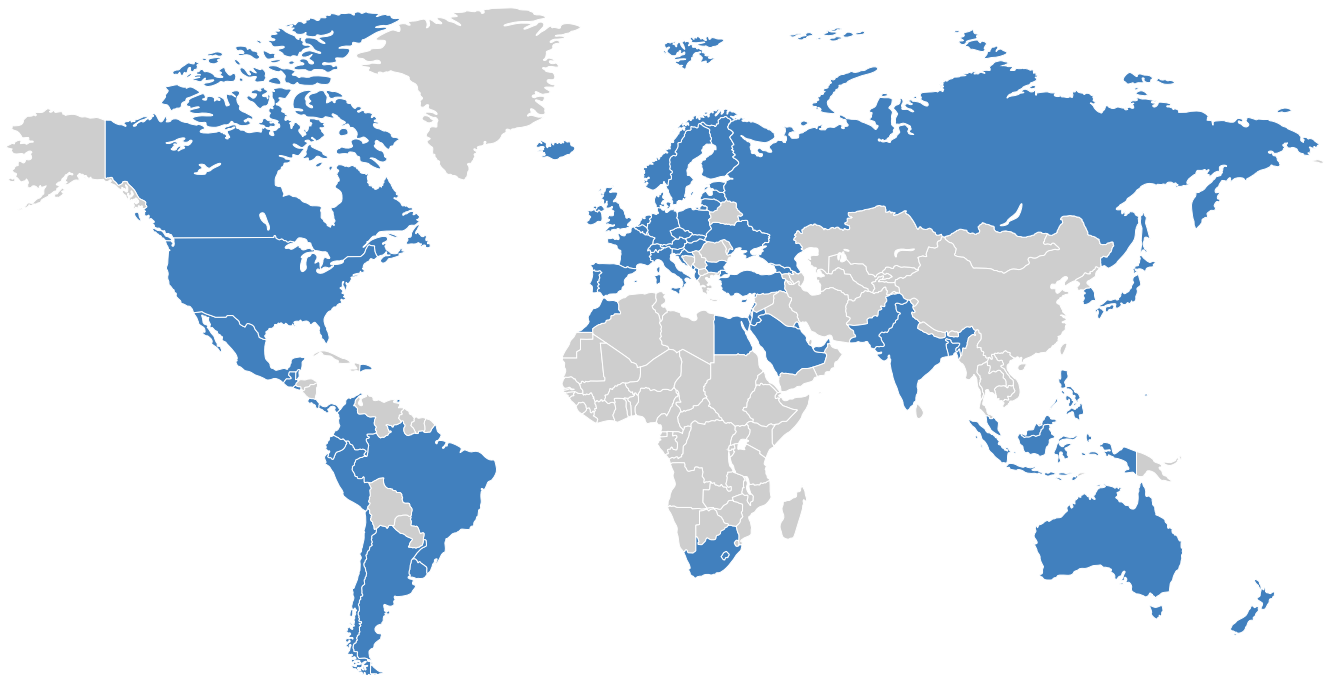
The HEDGE Study analysis team is currently analysing **1,021** whole-genome sequences from individuals who have hypermobile Ehlers-Danlos syndrome (hEDS) by the 2017 clinical diagnostic criteria.

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

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

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

 **1,021 blood samples**
Participants from 86 countries



RESEARCH

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

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

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



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

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

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

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

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

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



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

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

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

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

RESEARCH

Global Registry

Help Progress Research, Treatment, and Understanding

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

DICE – Data, Inclusion, Collaboration, and Excellence

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

Each person who joins will help:

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

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

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



DATA • INCLUSION • COLLABORATION • EXCELLENCE

RESEARCH



EDS ECHO: An Evolution in Medical Education and Care Delivery

What is Project ECHO®

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

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

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

EDS ECHO

EDS ECHO is a series of programmes and courses for healthcare professionals across all disciplines who want to improve their ability to care for people with EDS, HSD, and associated symptoms and conditions. Enhancing care for people with all types of EDS and HSD through case-based discussions, sharing knowledge, and expert updates is at the heart of what we do. EDS ECHO also runs programmes on advocacy and other topics for community leaders and educators, exploring ways participants can better teach and support those living with EDS or HSD.

Participants in our programmes share their cases and questions in the sessions and are guided to further educational materials and support. After taking part in a healthcare professional programme, participants are invited to join us at any future EDS ECHO sessions and continue to take advantage of and support our ever-growing network of knowledgeable clinicians. We also help local and regional groups start a programme for the care of their patients, expanding the EDS ECHO network, bringing care closer to home.

In 2023, we saw participation grow in the number of participants and the breadth of healthcare specialists. We have had 1,880 individual healthcare professionals and community advocates participate in our programmes and courses to date, with 350 new health professionals joining our programmes this year! Of those, 184 health professionals practice in the UK, and 31 advocates are committed to support people living with EDS and HSD in the UK.

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

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

137
Sessions

196
Teaching/Learning
Hours

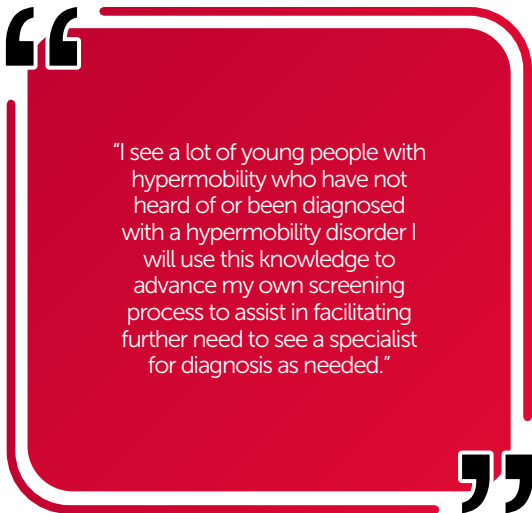
147
Continuing Educational
Credits Available

EDUCATION

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

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

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



EDS ECHO awarded ECHO Excellence Award at MetaECHO® 2023

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

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

"Second, all the teams at The Ehlers-Danlos Society and our generous donors and sponsors; to everyone, thank you for the amazing support.

"Finally, there are two members of the team we'd like to give a loud shout-out to for their incredible dedication and hard work — Stacey Simmonds, Events Director, and Paul Gardener, EDS ECHO Manager from our UK team.

"We're looking forward to another wonderful and busy year next year that will also be our 5th anniversary. This award is a fabulous gift towards that."

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

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



EDUCATION

Five Years of EDS ECHO



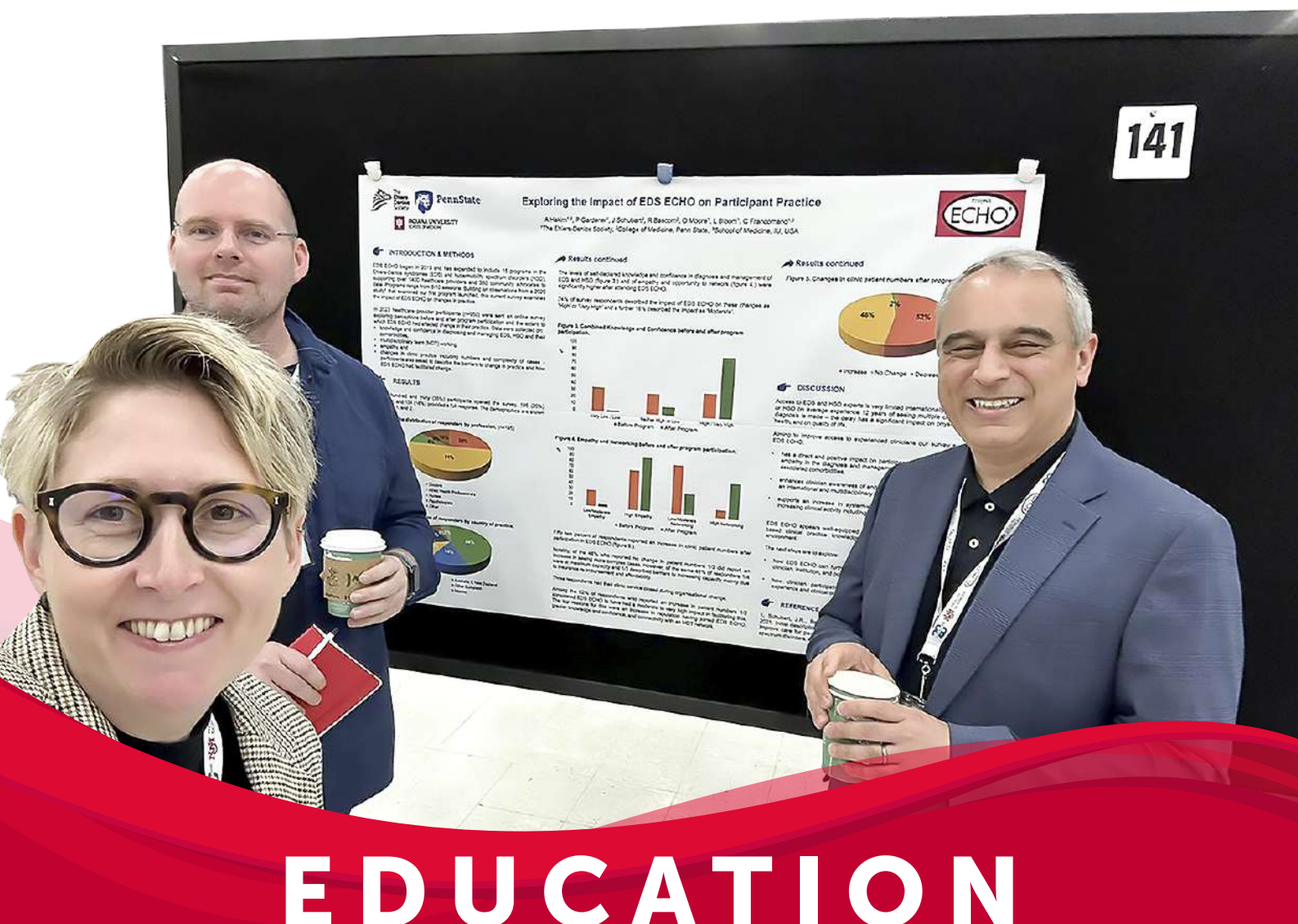
5 CELEBRATING YEARS OF EDS ECHO

Educating, Empowering, and Expanding Horizons

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

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

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



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

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

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

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

Healthcare Professional Attendees



Virtual EDS ECHO Summits

The EDS ECHO Summits are virtual events that share the latest research and knowledge with community members and health professionals globally, through the traditional Project ECHO® all-teach, all-learn format, and are CME-accredited. The Ehlers-Danlos Society's [EDS ECHO](#) programme supports clinicians by increasing their knowledge; helps clinicians network with each other to discuss management strategies; improves access to care by increasing the number of experienced clinicians; and supports community advocates in raising awareness of EDS and HSD.

EDUCATION



EDS ECHO Summit: Hypermobility Spectrum Disorders (HSD)

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

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

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

The event covered topics including:

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

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

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

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

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



Global Learning Conference 2023, Dublin, Ireland

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

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

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

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

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



EDUCATION



Global Learning Conference 2023, Dublin, Ireland

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

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

”

“

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

”

“

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

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

”

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



EDUCATION



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

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

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

The discussion was opened with an overview by Ms Micks, supported by Assoc. Prof. Alan Hakim, CMO, Research Director and Education Director at The Ehlers-Danlos Society; Lara Bloom, President and CEO at The Ehlers-Danlos Society; and medical genetic specialist Dr. Anand Saggar. It was attended by community members in person and virtually.

Ms Micks began by highlighting the importance of raising awareness about EDS and HSD among Irish patients, as the population affected by these conditions is steadily growing. While some improvements have been made in recent years, the progress has not been sufficient to meet the needs of the community.

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

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

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

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



EDUCATION



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

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

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

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

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

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



EDUCATION



Genetically-Defined EDS: Strategies and Solutions for Unmet Needs

Scientific Chair:

Fransiska Malfait, MD, PhD, Ghent University Belgium

Scientific Committee:

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

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

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

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

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



EDUCATION

Genetically-Defined EDS: Strategies and Solutions for Unmet Needs

This networking event had four main objectives:

- (1) to share knowledge on the genetically defined EDS types among healthcare professionals, researchers, and patients, taking advantage of bringing together and expanding different European and international networks involved in EDS (including participants from underrepresented countries);
- (2) to develop new research hypotheses, priorities, and strategies;
- (3) to encourage new interdisciplinary international collaborations; and
- (4) to provide international resources for clinical and molecular diagnosis and care.

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

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

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

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

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

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

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



EDS ECHO Summit: Fatigue - Causes and Management

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

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

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

A comprehensive event programme included presentations on topics including:

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

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

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

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

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

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

EDUCATION



Amplifying Voices During May Awareness Month

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

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

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



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

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

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

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

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

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

Raising spirits with our fitness fundraiser

A big thank you to Amy Attree and friends in the UK for fundraising to support our shared mission!

"We ran a full day of fitness classes that included yoga, Pilates, Zumba, dance fit, seated exercise, salsa, and heeled dance.

We raised a grand total of **£832.00 (+ Giftaid!)** which we are super pleased with and hope this helps The Ehlers-Danlos Society as much as possible!"

Baking for good

Thank you to Courtney Stoker in the UK who raised **£740** in support of The Ehlers-Danlos Society.

"I set up a fundraising event where people entered their baking creations! We made zebra print scrunchies and zebra print ribbons to sell, and we also sold homemade jam and did face painting. It was a very good day!"

Alex's Awareness Talks

"I was diagnosed with Ehlers-Danlos syndrome 8 years ago. I, unfortunately, experience autonomic dysfunction causing loss of consciousness. This was life-changing and is a constant daily challenge.

I also have mast cell activation syndrome and severe migraines that at times have caused paralysis and affect my speech. I am in constant pain in my joints due to the frequent fainting.

I spent the past three weeks of May raising awareness of Ehlers-Danlos syndrome and invisible disabilities as I experience prejudice constantly when using disabled facilities.

Over the last two weeks, I have delivered face-to-face awareness briefings to approximately 250 colleagues across the company I work for - and their support has been phenomenal!

I also delivered my presentation via Teams today to 70 members of the LoWEG. I plan further briefings and will continue on this journey until awareness is everywhere and perceptions change.

I am blessed with a supportive family and work colleagues that have helped me to continue working over the past 8 years, I am so thankful to all of them. I have given myself this challenge to stand up and make others understand."

Special thanks to Alexandra Akitici in the UK!



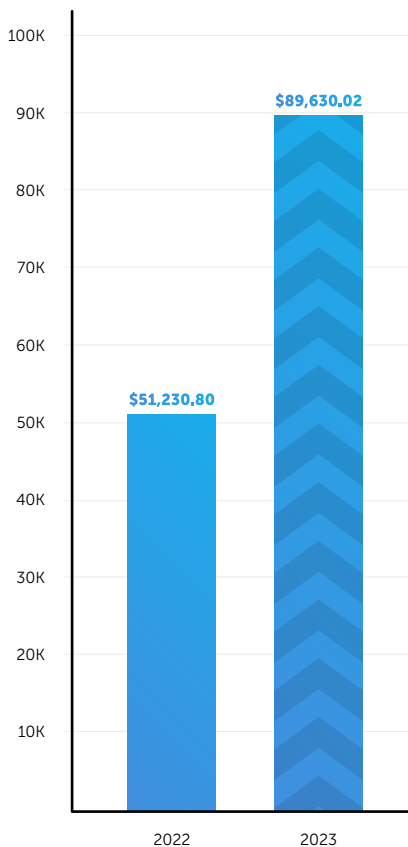
The Power of Community: Our End of Year Campaign

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

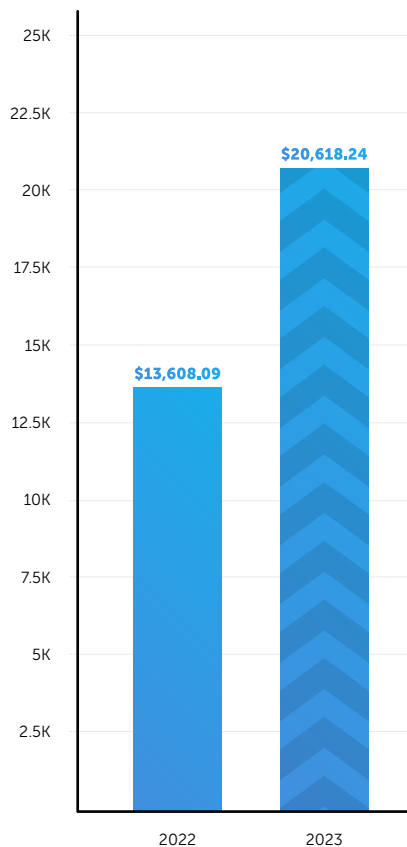
In 2023, we witnessed incredible generosity from our supporters, who helped us raise an outstanding **\$337,040.25***. These funds are not just numbers; they represent hope, progress, and a shared commitment to transforming lives. Each donation, big or small, directly impacts our ability to advance research,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

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

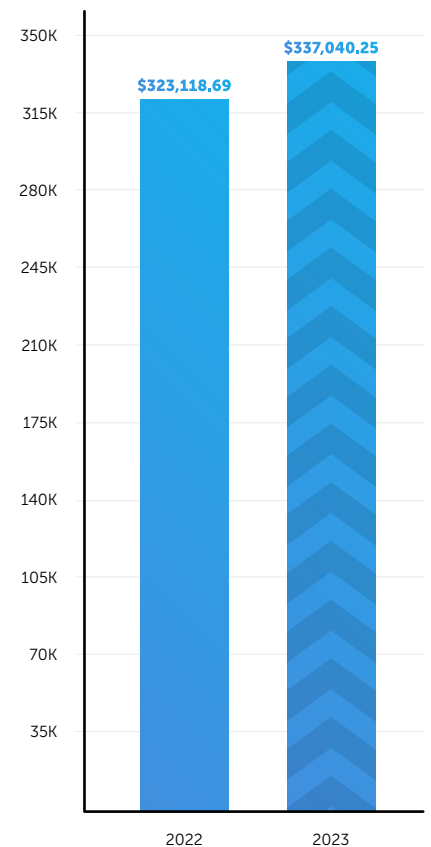
May Awareness



Giving Tuesday



End Of Year



Join Us in Funding Our Shared Mission

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

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

Let's continue to make an impact together.

Together, we dazzle.

Donate today at: ehlers-danlos.com/donate

* Where the financial impact of a program is spread across our US and UK organizations, consolidated amounts are used.



The Ehlers-Danlos Society

(A Company Limited By Guarantee)

Company N°: 10722868

Charity N°: 292280

Audited Accounts For The Year Ended 30th April, 2024

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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
Ms E Herndon
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)

Report Of The Trustees & Directors

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 £25,407 for the fiscal year ending on 30th April, 2024. This resulted in an increase in total funds at the balance sheet date to £56,894.

Total income for the year decreased by £51,501 compared to the prior fiscal year. A decrease in donations related to the HEDGE study was partially offset by increases in donations from the US organisation and individual donors, as well as the addition of income from the Gift Aid scheme.

Total expenses for the year decreased by £76,400 compared to the prior fiscal year. A decrease in expenses related to the HEDGE study was partially offset by increases in labour costs.

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 programs to ensure they allocate resources to their best effect.

We currently employ 15 full-time staff, 3 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.

The Ehlers-Danlos Society

(A Company Limited By Guarantee)

Report Of The Trustees & Directors

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.



Mrs Susan Haskel
Director & Trustee

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, 2024 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, 2024 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.

The Ehlers-Danlos Society

(A Company Limited By Guarantee)

Independent Auditors' Report To The Members Of The Ehlers-Danlos Society

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.

The Ehlers-Danlos Society

(A Company Limited By Guarantee)

Independent Auditors' Report To The Members Of The Ehlers-Danlos Society

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.

The Ehlers-Danlos Society

(A Company Limited By Guarantee)

Independent Auditors' Report To The Members Of The Ehlers-Danlos Society

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

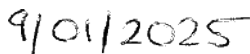
This report is made solely to the Charities members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the Charities members those matters we are required to state to them in an auditors report and for no other purpose.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



Date

Statement Of Cash Flows For The Year Ended 30th April, 2024

Cash Flow From Operating Activities	2024 (£)	2023 (£)
Operating profit/(loss) for the financial year	25,407	508
(Increase)/decrease in debtors	37,299	(1,682)
Increase/(decrease) in creditors	11,504	(514)
Cash from Operations	74,210	(1,688)
Net cash from operating activities	74,210	(1,688)
Net (decrease)/increase in cash and cash equivalents	74,210	(1,688)
Cash and cash equivalents at 1st May, 2023	3,873	5,561
Cash and cash equivalents at 30th April, 2024	78,083	3,873



Statement Of Financial Activities For The Year Ended 30th April 2024

(Including Income & Expenditure Account)

	Notes	Unrestricted Funds (£)	2024 Restricted Funds (£)	Total (£)	Unrestricted Funds (£)	2023 Restricted Funds (£)	Total (£)
Incoming Resources							
Incoming and endowments from: Donations and legacies		656,413	509,657	1,166,070	475,496	733,225	1,208,721
Charitable Activities: Conference Income		-	-	-	8,850	-	8,850
Investments: Bank Interest		-	-	-	-	-	-
Total	3	656,413	509,657	1,160,070	484,346	733,225	1,217,571

Expenditure On:

Cost of Generating Funds: Charitable activities	4	113,402	1,016,689	1,130,091	142,696	1,065,967	1,208,663
Other	4	10,572	-	10,572	8,400	-	8,400
Total Expenditure		123,974	1,016,689	1,140,663	151,096	1,065,967	1,217,063
Net Income/Expenditure Before Taxation		532,439	(507,032)	25,407	333,250	(332,742)	508
Tax Payable		-	-	-	-	-	-
		532,439	(507,032)	25,407	333,250	(332,742)	508

Net Income/(Expenditure)

Transfers between funds		(469,553)	469,553	-	(332,742)	332,742	-
		62,886	(37,479)	25,407	508	-	508

Net Movement In Funds

Reconciliation Of Funds: Fund balances at 1st May, 2023		(5,992)	37,479	31,487	(6,500)	37,479	30,979
Fund balances at 30th April, 2024		56,894	-	56,894	(5,992)	37,479	31,487

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.

Unaudited Balance Sheet

As At 30th April 2024

Current Assets	Notes	2024 (£)		2023 (£)	
Debtors	7	11,708		49,007	
Cash At Bank & In-Hand		78,083		3,873	
		89,791	-	52,880	-

Current Liabilities

Creditors - Amounts falling due within one year)	8	32,897		21,393	
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Net Current Assets			56,894		31,487
Total Assets Less Current Liabilities			56,894		31,487
Net Assets			56,894		31,487
Reserves					

Unrestricted Funds

General Funds	9		56,894		(5,484)
Restricted Funds	9		-		37,479
			56,894	-	31,995

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 09.01.2025 and signed on their behalf by:



Mrs Susan Haskell
Director & Trustee

Notes To The Unaudited Accounts For The Year Ended 30th April 2024

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.

2. 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.

Notes To The Unaudited Accounts For The Year Ended 30th April 2024

3. Income From Charitable Activities

	2024			2023		
	Unrestricted Funds (£)	Restricted Funds (£)	Total (£)	Unrestricted Funds (£)	Restricted Funds (£)	Total (£)
Conference Income	-	-	-	8,850	-	8,850
Donations & Grants	656,413	509,657	1,166,070	475,496	733,225	1,208,721
Interest On Investments	-	-	-	-	-	-
	656,413	509,657	1,166,070	484,346	733,225	1,217,571

4. Analysis Of Total Resources Expended

	2024				2023			
	Unrestricted Funds Direct Costs (£)	Support Costs (£)	Restricted Funds Direct Costs (£)	Total (£)	Unrestricted Funds Direct Costs (£)	Support Costs (£)	Restricted Funds Direct Costs (£)	Total (£)
Charitable Activities								
Wages & Salaries	59,541	-	694,153	753,694	80,978	-	418,385	499,363
National Insurance	-	-	-	-	30,211	-	7,042	37,253
Grants Awarded	-	-	176,500	176,500	-	-	473,818	473,818
Pension Costs	-	-	-	-	10,557	-	-	10,557
Staff Benefits	14,087	-	-	14,087	-	-	-	-
Advertising & Promotional Expenses	-	-	-	-	-	-	-	-
Training	-	-	-	-	-	-	-	-
Insurance	1,224	-	-	1,224	1,100	-	-	1,100
Telephone	9,172	-	3,213	12,385	3,670	-	1,190	4,860
Auditor's Fees	-	10,572	-	10,572	-	8,400	-	8,400
Printing, Postage & Stationery	394	-	3,505	3,899	381	-	605	986
Professional Fees	2,160	-	103,250	105,410	9,258	-	159,987	169,245
Computer Costs	4,071	-	-	4,071	558	-	-	558
Conference Costs	-	-	3,628	3,628	-	-	-	-
Donations & Subscriptions	3,846	-	1,051	4,897	1,077	-	323	1,400
Finance Costs	19	-	424	443	70	-	376	446
Sundry Expenses	356	-	189	545	1,315	-	-	1,315
Travel Costs	18,532	-	30,776	49,308	3,521	-	4,241	7,762
	113,402	10,572	1,016,689	1,140,663	142,696	8,400	1,065,967	1,217,063

Notes To The Unaudited Accounts For The Year Ended 30th April 2024

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:

	2024	2023
Between £60,000-£70,000	2	-
Between £80,000-£90,000	1	-
Between £110,000-£120,000	-	1
Between £140,000-£150,000	1	-

The total remuneration of key management personnel during the year was £143,688 (2023: £118,073)

6. Staff Numbers

	2024	2023
Administration	14	12

7. Debtors

	2024 (£)	2023 (£)
Donations	-	37,013
Taxation & Social Security	-	-
Prepaid Expenses	11,708	11,994
	11,708	49,007

8. Creditors

Amounts falling due within one year

	2024 (£)	2023 (£)
Deferred Conference Revenues	-	-
Taxation & Social Security	22,325	12,993
Accruals	10,572	8,400
	32,897	21,393

Notes To The Unaudited Accounts For The Year Ended 30th April 2024

9. Movement Of Funds In The Year

	2024							2023		
	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, 2023	(5,992)	-	37,479	-	-	-	31,487	(6,500)	37,479	30,979
Income In The Year	656,413	37,013	36,000	176,500	19,925	240,219	1,166,070	484,346	733,225	1,217,571
	650,421	37,013	73,479	176,500	19,925	240,219	1,197,557	477,846	770,704	1,248,550
Expenditure In The Year	123,974	37,013	107,048	176,525	448,523	247,580	1,140,663	151,096	1,065,967	1,217,063
	526,447	-	(33,569)	(25)	(428,598)	(7,361)	58,894	326,750	(295,263)	31,487
Transfers	(469,553)	-	33,569	25	428,598	7,361	-	(332,742)	332,742	-
At 30th April, 2024	56,894	-	-	-	-	-	56,894	(5,992)	37,479	31,487

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, 2024.

12. Related Party Transactions

During the year, the Charity received a £20,000 donation (2023: £15,000) from a Charity controlled by one of the Trustee. The charity also received £256,507 (2023: £659,052) in donations from a Charity controlled by a second Trustee. The charity also received £747,233 (2023: £459,978) in donations during the year from a Charity under common control. £176,500 (2023: £473,818) was granted during the year to the Charity under common control.