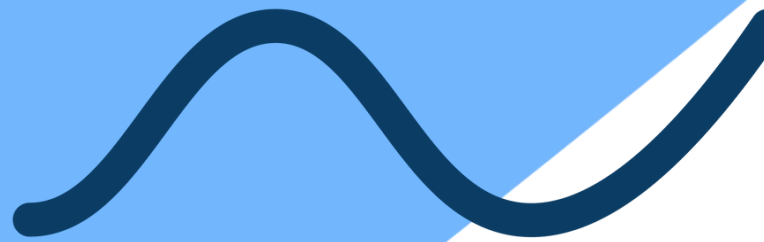




The Ehlers-Danlos Society Learning & Education Director

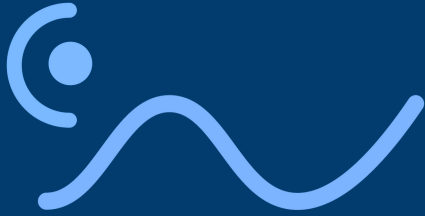
**Candidate pack
December 2025**



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The
**Ehlers
Danlos**
Society



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Introduction

Thank you for your interest in joining The Ehlers-Danlos Society. This role sits at the centre of our mission: improving understanding, advancing care, and ensuring people living with EDS and HSD receive the support they need - wherever they are in the world.

Education is one of our strongest drivers of change. Through programmes like EDS ECHO, our global conferences, online learning, and clinical resources, we reach thousands of clinicians, researchers, and community members each year. As research accelerates - through the HEDGE study, Biobank, and the Criteria Review - the need for clear, accessible, and inclusive education has never been greater.

As our Learning & Education Director, you will shape The Society's educational strategy for the years ahead. You will lead innovative learning programmes, and ensure our content reflects both scientific rigour and the lived experience of our community.



Your leadership will play a vital role in bridging knowledge gaps and raising the standard of care worldwide.

We are a supportive, inclusive, collaborative, and accountable team. You will join colleagues who are deeply committed to creating high-quality education that truly makes a difference.

Thank you for considering bringing your expertise to this work. I hope you find this pack helpful, and I look forward to the possibility of welcoming you to our team.

Lara Bloom
CEO & President
The Ehlers-Danlos Society

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About us



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The Ehlers-Danlos Society

The Ehlers-Danlos Society is a global organisation dedicated to advancing and accelerating research and education in [Ehlers-Danlos syndromes \(EDS\)](#) and [hypermobility spectrum disorders \(HSD\)](#). Our mission is support the development of effective and equitable EDS and HSD therapies and work collaboratively to improve the lives of individuals affected by EDS and HSD.

Originally established as a non-profit in the USA in 1985 by Nancy Hanna Rogowski (1957–1995), the Ehlers-Danlos National Foundation (EDNF) filled a deep void for patients living with one of the most misunderstood and underdiagnosed syndromes in history. EDNF grew from one woman's tireless efforts to find others with whom to share emotional support, into a vital information link to and from the medical community.

From the industriousness of Nancy Rogowski's quest to learn more and to spark hope in others - to the volunteer efforts, initiative, and support of thousands to transform our understanding of Ehlers-Danlos in its many forms - The Ehlers-Danlos Society emerged in May 2016 as the very first truly international organisation devoted entirely to global research and the support and advocacy for patients, caregivers, and medical professionals.

What is EDS?

The Ehlers-Danlos syndromes (EDS) are a group of 13 heritable connective tissue disorders. The conditions are caused by genetic changes that affect connective tissue. Each type of EDS has its own set of features with distinct diagnostic criteria. Some features are seen across all types of EDS, including joint hypermobility, skin hyperextensibility, and tissue fragility.

What is HSD?

Hypermobility spectrum disorders (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.

Our vision

To create a world in which each person living with EDS and HSD has the right treatment and care at the right time for their specific needs.

Click here for further information on [impact reports and financials](#).

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About Us



Our values

Supportive

Our value of “Supportive” embodies our commitment to creating an environment where every individual feels heard, valued, and supported. We prioritise empathy and kindness, ensuring that our interactions are guided by warmth and understanding, and that we collectively grow stronger through shared experiences. We promote a healthy work-life balance, respecting personal time and well-being, and creating an environment where personal and professional lives are consistently aligned.

Inclusive

“Inclusive” represents our dedication to celebrating diversity, enabling a sense of belonging, and ensuring that every individual, regardless of background or location, feels included and valued within our organisation. Grounded in principles of equity and inclusion, we advocate for personal growth, embrace curiosity, and value diverse perspectives, creating an environment where unique contributions are recognised and appreciated.

Collaborative

“Collaborative” defines our emphasis on leveraging diverse skills and perspectives to achieve collective goals, promoting a spirit of togetherness that transcends geographical boundaries. We champion employee engagement, ensuring a balance between work and fun to promote a positive and fulfilling workplace experience. We are dedicated to collectively driving innovation and encouraging creativity to effect positive change.

Accountable

Our value of “Accountable” underscores our commitment to transparency, trust, and ethical conduct within our community. Embracing the principles of ESG (Environmental, Social, and Governance), we prioritise efficiency and process improvement, with every team member taking ownership of their actions and decisions. We promote a culture where learning and growth from setbacks is encouraged, and individuals have the confidence to ask questions and challenge situations that don't align with our values or mission. We lead by example, demonstrating the highest standards of accountability and integrity in all that we do.

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About Us



Our programs

Many around the world face a diagnostic odyssey: years, sometimes lifetimes, fighting for recognition, diagnosis, and care. The Ehlers-Danlos Society is working towards a time when geography and wealth no longer determine your quality of life.

At The Ehlers-Danlos Society, we CARE – We are driving forward Care, Access, Research, and Education, and are committed to changing the lives of people impacted by EDS and HSD.

Care — Providing life-changing support services

We provide support, guidance, and resources to anyone affected by EDS and HSD - wherever they are in the world. Our dedicated global helpline team supports individuals, families, and caregivers through phone and email. Healthcare professionals also reach out to our team for advice and patient resources, now making up over 10 - 15% of all inquiries.

We also host a wide range of virtual support groups, providing welcoming, inclusive spaces where people can connect, share experiences, and find community.

Access — Promoting equity and inclusion

We are committed to reducing barriers to care and shortening the diagnostic journey for people with EDS and HSD.

In response to the global need for accessible, multidisciplinary care, we created the CORE Network of Excellence - a program rooted in Collaboration, Outreach, Research, and Education. The CORE Network is a growing international community of healthcare professionals dedicated to improving clinical outcomes through peer-to-peer learning, global collaboration, and research.

We also have a Healthcare Professionals Directory, which connects individuals and families find clinicians who are familiar with diagnosing or managing EDS and HSD, and run the the [EDS and HSD Global Alliance](#). The Alliance brings together patient organisations, charities, and non-profit groups from across the world, all committed to advancing care, education, support, and research for EDS and HSD. Together, we are building strong collaborations that share resources and tools, increase awareness, and ensure that knowledge and education are available in multiple languages and formats - wherever they are needed.



Research — Fostering collaboration & advancing understanding

Since 2016, The Ehlers-Danlos Society has raised over \$14 million to fund research into the types of EDS, HSD, and associated conditions. Our goal is to ensure a consistent pipeline of [ground-breaking research](#), with a focus on earlier diagnosis, more effective treatment, and better outcomes for people worldwide. Through our [Research Grant Program](#), we aim to fund at least \$1 million in research annually - supporting basic science, translational research, and clinical studies across a range of disciplines.

At the heart of our research infrastructure is the DICE Global Registry - a worldwide research platform designed to collect data on all types of EDS and HSD and the wide range of associated symptoms and comorbidities. DICE allows individuals living with EDS and HSD to contribute their lived experience and medical history securely and anonymously, helping researchers identify trends, patterns, and new opportunities for clinical trials, treatment development, and precision medicine.

The DICE Registry already supports major studies, including the HEDGE Study, the largest-ever whole genome sequencing effort to identify the genetic basis of hypermobile EDS. With over 1,000 participants from 86 countries, early findings from HEDGE were presented in 2024 at the American Society of Human Genetics, with publications underway.

Education — Educating & mentoring healthcare professionals & individuals

The average time to diagnosis of an EDS or HSD is 10-12 years: for some, it can take decades. Early diagnosis is crucial to positive patient health. As these conditions are multi-systemic, the problems often go unconnected for many years. Many in our community report being told their symptoms “are all in their head” or that they cannot possibly be experiencing the pain or other symptoms they say they are. Misdiagnosis is common, delaying treatment, or resulting in unnecessary surgeries or unsuitable treatments. Barriers to access and wait times persist. Once diagnosed, there is often little or no follow-up care, with patients not given information on their condition, how to self-manage aspects of their care, adaptations that can be made to improve quality of life, or where to find support for a lifelong, chronic condition.

This needs to change, and education is key, hence EDS ECHO – An Evolution in Medical Education and Care Delivery.

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About Us



EDS ECHO

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 increasing independence as skills, confidence, and self-efficacy. For more information about Project ECHO® visit echo.unm.edu.

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

About EDS ECHO

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

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

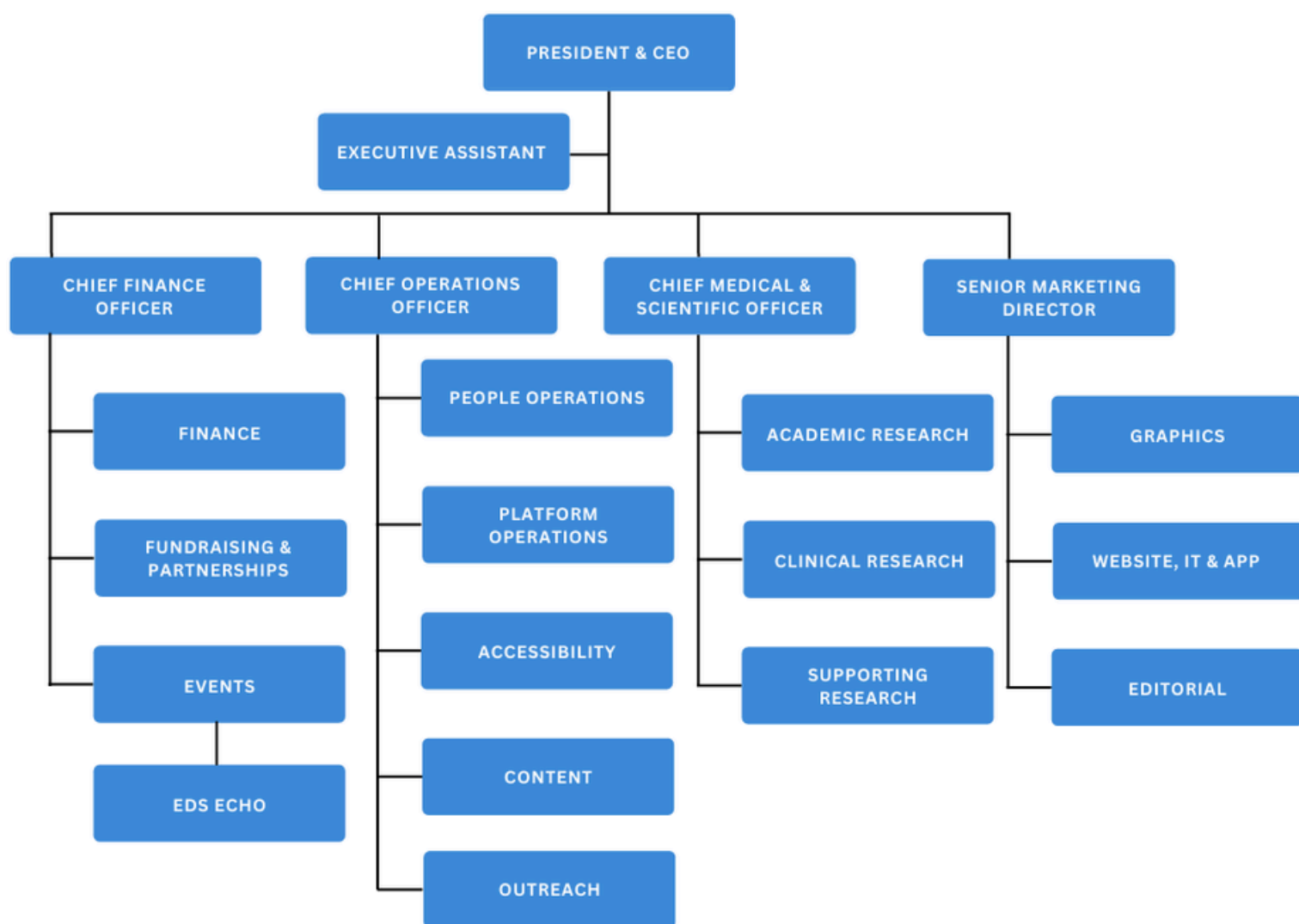
After taking part in a healthcare professional program, participants are invited to join us at any future EDS ECHO sessions and continue to take advantage of and support our ever-growing network of knowledgeable clinicians. We also help local and regional groups to start a program for the care of their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

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About Us

Organisation charts

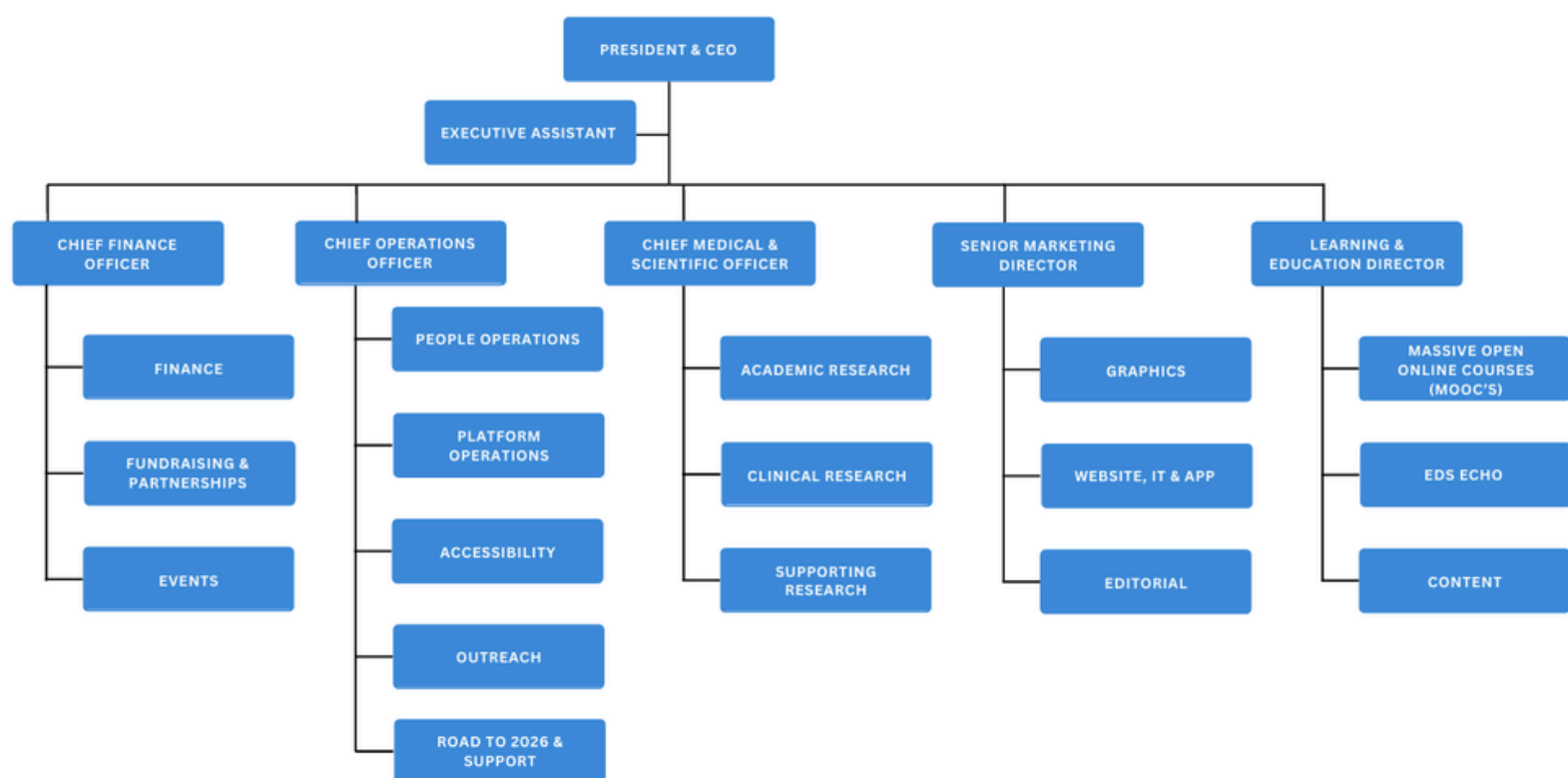
A high level overview of the current organisation chart



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About Us

A high level overview of the future organisation chart for the next 12 months



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Role description



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Role details

Position:	Learning & Education Director
Reports to:	President & CEO
Location:	UK / Remote based
Working Hours:	Full time: 09:00 - 17:00
Contract:	Fixed-Term - 12 months (reviewed annually)
Salary:	£60,000 per annum
Benefits:	<ul style="list-style-type: none">• 28 days annual leave plus bank holidays• Cashback healthcare scheme (Medicash)• Life insurance (2x times annual salary)• Employee Assistance Program (EAP)• Time in lieu• Monthly broadband payments• An annual home office contribution• Access to a pooled annual learning & development budget• Sabbatical leave after 10 years of service• Additional 5 days of annual leave after 5 years of service• Pet bereavement leave,• "Chill Friday" - finishing at 1pm on the last Friday of every month, or every Friday in two summer months or after the Global Learning Conference.

Work environment

This role is a fully remote position, working from home. However, due to the international nature of the Society's work, staff may be required to travel to company events, including the one annual UK-based retreat, meetings, and conferences as well as some weekend work. Travel and accommodation expenses are paid.



Role purpose

The Learning & Education Director is a senior leadership role responsible for the strategic direction, development, oversight, and project support of all educational initiatives across The Ehlers-Danlos Society. This role ensures the organisation delivers high-quality, evidence-based learning opportunities for healthcare professionals, advocates, caregivers, and the broader community.

The Director will provide visionary leadership, integrate learning strategies across departments, and ensure programs are evidence-based, relevant, and aligned with the Society's mission. Where required, they will also manage day-to-day delivery of EDS ECHO projects. They will collaborate with internal and external stakeholders, including universities and other educational institutions and bodies, healthcare networks, and patient advocacy communities, to expand The Society's reach and impact. This role requires a combination of strategic planning, program management, expertise in educational design and implementation, as well as strong leadership skills to manage, mentor, and inspire multidisciplinary teams.

Key responsibilities

This role has 5 core areas of ownership, the responsibilities include, but are not limited to:

Departmental strategy & program oversight

- Lead the strategic planning and concept development for all educational initiatives, including Content, MOOCs, and EDS ECHO, ensuring that all learning materials and public education resources are integrated within a unified education framework aligned with The Society's mission, vision, and values.
- Translate high-level strategic priorities into actionable plans with clear objectives, timelines, and accountability measures.
- Develop, execute, and monitor departmental strategies to achieve program goals and organisational impact.
- Integrate best practices and emerging trends in medical education and community-based learning to continuously improve service delivery.



Team & program leadership

- Oversee and actively support the EDS ECHO program's strategic and operational delivery, ensuring quality, compliance, and alignment with organisational goals.
- Provide leadership, mentorship, and guidance to departmental leads, fostering a high performing, collaborative culture.
- Ensure interdepartmental collaboration across the Society, promoting seamless execution of programs and equitable participation.
- Oversee line management responsibilities, including PTO/TIL planning, annual appraisals, and development plans, ensuring alignment with strategic goals.

Compliance, risk & resource management

- Oversee compliance with Continuing Medical Education (CME) requirements and other relevant guidelines, ensuring all programs meet regulatory standards.
- Take overall accountability for project milestones, program efficiency, and operational risk mitigation.
- Allocate resources effectively, manage departmental budgets, and ensure efficient use to maximise program outcomes.

Stakeholder engagement & representation

- Build and maintain strategic partnerships with universities and other educational institutions and bodies, healthcare networks, research institutions, and advocacy organisations.
- Represent The Society externally, promoting its educational programs and advancing its credibility in the EDS/HSD community.
- Collaborate with internal and external stakeholders to ensure programs are evidence-based and community-relevant.

Evaluation, quality assurance & policy oversight

- Establish metrics to assess program impact, reach, and effectiveness, implementing continuous improvement strategies.
- Ensure programs are inclusive, accessible, and aligned with the needs of both healthcare professionals and the EDS/HSD community.
- Approve policies and guidelines related to educational initiatives, ensuring compliance with internal standards and external regulations.

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Person specification



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Person specification



Who are we looking for...

Education & knowledge

- Bachelor's degree (required) and advanced degree or diploma (PGCE, Master's or PhD (preferred) in Education, Healthcare, Public Health, Instructional Design, or related field.
- Deep understanding of healthcare education, adult learning principles, and evidence-based instructional design.
- Proven experience leading multi-program educational initiatives in healthcare, non-profit, or academic settings.
- Familiarity with accreditation standards for medical education and online learning programs (e.g., CME compliance).
- Knowledge of Ehlers-Danlos syndromes (EDS), hypermobility spectrum disorders (HSD), or rare diseases is highly desirable.

Communication & interpersonal skills

- Exceptional written and verbal communication skills, with the ability to convey complex medical or educational concepts to diverse audiences.
- Strong stakeholder engagement skills; able to build partnerships with healthcare providers, academic institutions, and advocacy organisations.
- Highly collaborative, with the ability to lead cross-functional teams and foster interdepartmental cooperation.
- Skilled in mentoring, coaching, and developing managers and senior coordinators.

Professional experience

- Familiarity with HIPAA and GDPR is preferred (training provided).
- Proficiency in MS Office Suite (Outlook, Word, Excel, PowerPoint), Teams, Zoom, Slack, Monday.com, and Zoho (training provided).
- Experience in strategic program planning, resource allocation, budget oversight, and risk management.

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Person specification



Workstyle & flexibility

- Strong organisational and time management skills, with the ability to prioritize workload effectively.
- Ability to work independently in a fully remote team environment, while collaborating across global time zones.
- Flexibility to occasionally work evenings, weekends, or early mornings to accommodate international stakeholders.
- Comfortable managing multiple priorities, projects, and deadlines simultaneously.

Environment & travel requirements

- Must be eligible to work in the UK without sponsorship.
- Reliable internet connection for video calls and cloud-based services, as this is a fully remote role.
- Ability to attend one in-person retreat annually (UK).
- Ability to travel to other in-person meetings and events as required.

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How to Apply



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How to apply



The Ehlers-Danlos Society is working exclusively with Charisma Charity Recruitment.

Expressions of interest should be submitted through the [Charisma website](#), and include:

- A comprehensive CV
- A supporting statement, explaining how you believe you match the requirements of the role.

For an informal and confidential discussion about the role, please contact: Katherine Anderson-Scott, Executive Director of Charisma Charity Recruitment on 01962 813300 or email info@charismarecruitment.co.uk

Closing date: 19 January 2026

Charisma vetting interviews will need to be completed by close of play on the 27 January in preparation for shortlist submission on the 28 January.

Interviews with The Ehlers-Danlos Society:

- **1st stage interviews: w/c 9 February 2026**
- **2nd stage interviews: w/c 16 February 2026**

Please note: the chosen candidate will need to be available to attend the annual retreat on 16th March 2025 (this can be attended while the candidate is serving notice. All expenses will be paid, however, if the chosen candidate subsequently withdraws and doesn't join The Society, the candidate will be expected to reimburse the organisation).

The Ehlers-Danlos Society's commitment to diversity and inclusion is driven by the four pillars of our mission: C.A.R.E. - providing care, access, research and education in all that we do. We are a global, multicultural organisation. As such, we seek to increase opportunities for individuals from diversified backgrounds and are committed to building an inclusive culture that celebrates the diverse voices in our team and community. The Ehlers-Danlos Society actively recruits, employs, trains, compensates, and promotes opportunities regardless of race, nationality, ethnicity, gender, marital or civil partner status, caring responsibilities, disability, gender identity, age, social class, sexual orientation, religion, and other protected status as required by applicable law.



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