

INTERNATIONAL SPONSORSHIP PROPOSAL

EUCROF27 – 10th Annual European Clinical Research Conference

BRIDGING THE GAP BETWEEN PATIENTS, RESEARCH AND HEALTHCARE

Living beyond survival

The need to listen to patients with Ehlers-Danlos Syndrome

Conference	EUCROF27
Dates	14·16 February 2027
Location	Prague, Czech Republic
Speaker	Debbie Hellenbrand · Plenary Speaker
Organisation	ZebraLife4Us

Together, we are stronger than alone.

SPONSORSHIP TARGET | ?8,500

Who We Are

ZebraLife4Us is an independent initiative in the process of becoming an officially established foundation. We are dedicated to improving awareness, understanding and collaboration around rare and complex medical conditions.

Our primary areas of focus are the Ehlers-Danlos Syndromes (EDS) and Addison's disease. However, our mission extends beyond individual diagnoses.

ZebraLife4Us was born out of personal experiences within our own family. These experiences have shown us how life-changing it can be when symptoms are overlooked, patients are not sufficiently heard and diagnoses take years to establish. Our family is the starting point of our mission, but our ambition reaches much further.

Our Mission: Building Bridges

Important work takes place every day behind the scenes of healthcare. Researchers develop new insights. Biopharmaceutical companies invest in scientific discoveries and treatments. Clinical Research Organisations (CROs) facilitate clinical trials. Hospitals and healthcare professionals work to translate scientific knowledge into everyday patient care.

But how does this knowledge ultimately reach the people it is intended to help? And how can we ensure that patients' experiences and perspectives are genuinely considered in research, diagnostics and treatment decisions?

ZebraLife4Us aims to build bridges between:

- Patients and their families
- Researchers and scientific institutions
- Biopharmaceutical companies
- Clinical Research Organisations (CROs)
- Healthcare professionals and hospitals

Our goal is not to replace existing organisations, but to connect them, make knowledge more accessible and encourage meaningful collaboration. We believe research becomes stronger when patients are heard, understood and involved throughout the process.

Why Listening to Patients Matters

Rare diseases often present significant diagnostic challenges. Patients may spend years searching for answers, experiencing unexplained symptoms, multiple consultations and delayed diagnoses. The Ehlers-Danlos Syndromes are an important example.

We want to contribute to earlier recognition and diagnosis, greater awareness among healthcare professionals, meaningful patient involvement in research, better communication between researchers, clinicians and patients, and treatment approaches that genuinely consider the patient's experience.

Patients are not simply the people research is conducted for. They are also an essential source of knowledge and experience that can help shape better research.

EUCROF27: An Opportunity to Connect

From 14–16 February 2027, the 10th Annual European Clinical Research Conference will bring together professionals from across the clinical research community in Prague. The conference offers an opportunity for researchers, CROs, pharmaceutical companies, healthcare professionals and other stakeholders to exchange knowledge and discuss the future of clinical research.

Debbie Hellenbrand will participate as a Plenary Speaker, representing ZebraLife4Us.

Living beyond survival: The need to listen to patients with Ehlers-Danlos Syndrome

Through personal experiences within her own family, Debbie will explore the importance of listening to patients, recognising symptoms earlier and developing more appropriate treatment plans. Her contribution brings an essential perspective to the international clinical research community: the lived reality of people navigating complex and often misunderstood medical conditions.

For ZebraLife4Us, EUCROF27 is also an opportunity to establish new connections between patient communities, clinical researchers and the biopharmaceutical industry. We see this as an important step towards long-term international collaboration.

What We Want to Achieve

1. Develop an informative magazine
A professionally designed and printed magazine combining personal experiences, medical insights and the societal impact of delayed diagnosis. An important element will be an evidence-based exploration of the healthcare and societal costs associated with missed or delayed diagnoses.

2. Increase awareness and knowledge
Extend the message of the presentation beyond the conference and encourage greater understanding of the importance of patient involvement.

3. Create connections for the future
Establish relationships with researchers, CROs, pharmaceutical companies and healthcare organisations to explore opportunities for future collaboration.

4. Establish ZebraLife4Us
Create a solid organisational foundation for ZebraLife4Us, enabling us to continue building bridges between patients, research and healthcare.

Our Sponsorship Request

To make these objectives possible, we are seeking financial partners who share our vision. Our fundraising target is **€8,500**. Contributions will support travel and conference related expenses, the magazine, project preparation and coordination, the establishment of ZebraLife4Us and a limited contingency budget.

The project budget includes dedicated working hours for content development, coordination, editorial work and sponsor relations. We believe sustainable initiatives require realistic financial planning and transparent recognition of the work involved.

Partnership, Transparency and Independence

We invite pharmaceutical companies, CROs and other organisations to become partners in this initiative. Support may take the form of a financial contribution, support for the magazine, or collaboration on future educational and awareness initiatives.

ZebraLife4Us remains independent. Sponsorship will not determine the scientific content, the message of our presentations or the perspectives we represent. All collaborations will be based on transparency, mutual respect and shared objectives.

We are committed to providing clear information about financial contributions, project expenditure and any compensation for professional activities. Every contribution will be accounted for and allocated transparently to its agreed purpose.

Project Budget

Budget item	Amount
Travel to Prague	€600.00
Conference and accommodation package	€1,161.60
Magazine design and printing	€600.00
Foundation establishment and notary	€800.00
Project work (80 hours × €60)	€4,800.00
Contingency	€500.00
Total estimated project budget	**€8,461.60**
Fundraising target (rounded)	**€8,500.00**

The project-work allocation is a proposed budget for 80 hours of project coordination, content development, editorial work and sponsor relations. Any compensation will be subject to appropriate governance, approval and applicable legal and tax requirements.

Together, We Can Make a Difference

Behind every diagnosis is a person. Behind every patient is a story. And behind every advancement in healthcare are people working every day to create new possibilities. We want to bring these worlds closer together, not in opposition, but alongside one another.

Together, we can make rare conditions more visible, patient experiences more meaningful and scientific knowledge more accessible.

Debbie Hellenbrand
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Plenary Speaker – EUCROF27

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