

Lara Bloom

Language Undefined



Lara Bloom

CEO and President, The Ehlers-Danlos Society

United Kingdom

Why would you like to be on the NCDA Board of Directors?

I would be honoured to serve on the NCDA Board of Directors to advance inclusive, patient-driven responses to the global NCD crisis. As someone living with a complex, chronic condition, I understand first-hand the barriers faced by millions navigating fragmented health systems — particularly those with under-recognised or multisystemic diseases.

Through my work as CEO of The Ehlers-Danlos Society, Vice-Chair of IAPO, and Board Member of GA UK, I have led global efforts to elevate the voice of the patient across research, policy, and education. I am also a Professor of Practice at Penn State College of Medicine, specialising in patient engagement and global collaboration. These roles have shown me the urgent need to integrate lived experience at the heart of decision-making — not as a token gesture, but as a strategic imperative.

NCDA's mission resonates deeply with me. The organisation's commitment to equity, accountability, and meaningful participation aligns with my own values and professional track record. I believe I can contribute both governance experience and grassroots insight, particularly in championing underrepresented and intersectional patient communities.

If elected, I will work to strengthen NCDA's civil society partnerships, ensure that PROMs and patient-reported outcomes help shape system-level accountability, and advocate for health systems that enable true social participation. My vision is a world where people living with NCDs lead the change — and where health is defined not only by survival, but by dignity, autonomy, and quality of life.

What makes you a good candidate for the NCDA Board of Directors?

I bring a unique blend of lived experience, strategic leadership, and global advocacy that aligns with NCDA's mission and priorities. Having worked across sectors, I understand the importance of uniting patient communities, policymakers, clinicians, and researchers to drive sustainable, equitable change in NCD care and prevention.

As CEO of a global patient organisation, I lead international programmes focused on education, research, and policy influencing. I've built cross-border coalitions, engaged with WHO and UN agencies, and driven impactful campaigns that centre the voices of people living with chronic and multisystemic conditions.

My governance experience includes serving as Vice-Chair of the International Alliance of Patients' Organizations and Board Member of GA UK, where I have contributed to strategy development, risk management, and accountability frameworks. Additionally, as Professor of Practice at Penn State College of Medicine, I support initiatives that build capacity in patient engagement and global collaboration.

I have a track record of fostering partnerships across cultures and disciplines, ensuring inclusion of underserved and underrepresented communities. My approach is always collaborative, values-driven, and impact-focused.

I believe that a strong Board must reflect the diversity and reality of the NCD community. I offer not only professional expertise but deep empathy, resilience, and an unwavering commitment to equity and meaningful participation. I'm ready to contribute actively to NCDA's strategic goals and help shape a future where people living with NCDs are at the centre of every solution.

Biography

Lara Bloom is a global advocate and leader in the rare disease community, with over 15 years of experience advancing the rights and recognition of people living with chronic and complex conditions. As CEO of The Ehlers-Danlos Society, she leads international efforts in research, education, and advocacy for those affected by Ehlers-Danlos syndromes and related disorders.

Diagnosed with EDS at age 24, Lara brings lived experience to her leadership, driving equity, awareness, and systemic change. She serves as Vice-Chair of the International Alliance of Patients' Organizations (IAPO) and as a Board Member of GA UK, contributing to global strategy, governance, and patient representation.

Lara has built strong cross-sector alliances and influenced policy on a global scale. In 2020, she was appointed Professor of Practice in Patient Engagement and Global Collaboration at Penn State College of Medicine. Her work continues to shape more inclusive, participatory, and person-centred health systems worldwide.

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