

The Influential Role of Patient Advocacy Groups in Registry Data Efforts



We are excited to invite you to our upcoming webinar, “The Influential Role of Patient Advocacy Groups in Registry Data Efforts,” hosted by the Mitochondrial and Inherited Metabolic Diseases Task Force. This event will take place on Thursday, July 18, at 12 p.m. ET.

Patient advocacy groups play a crucial role in leading registry data efforts for mitochondrial and inherited metabolic diseases. Their work ensures that patient experiences and outcomes are central to research and regulatory decision-making, ultimately leading to more effective and patient-centered healthcare solutions.

Meet Our Presenters:

Sophia Zilber, Board Member and Patient Registry Director, Cure Mito Foundation

Sophia Zilber leverages her professional background and personal story to create meaningful contributions to the rare disease community. With over 20 years of experience in drug development, clinical data analysis, and managing statistical programming teams, Sophia is deeply involved with raising awareness and ensuring high-quality data collection for research and drug development. She leads a global Leigh syndrome patient registry at the Cure Mito Foundation.

Elizabeth Reynolds, PhD, Co-Founder and Executive Director, The Champ Foundation

Dr. Elizabeth Reynolds is dedicated to supporting research for Single Large-scale mtDNA Deletion Syndromes (SLSMDS), like Pearson syndrome. Under her leadership, The Champ Foundation has deployed over \$2 million in research grants. Dr. Reynolds is the co-Principal Investigator on a multi-site Natural History Study and patient-registry. Professionally, she is a public health research analyst at RTI International, focusing on newborn screening, rare diseases, and patient registries. She is also the mother of a Pearson syndrome champ, William Reynolds.

Amanda Klein, PharmD, Executive Director, Critical Path for Lysosomal Diseases (CPLD) and Alpha-1 Antitrypsin Deficiency (CPA-1) Consortia, Critical Path Institute.

Dr. Amanda Klein leads pre-competitive collaboration among stakeholders to accelerate the drug development process for mitochondrial and inherited metabolic diseases. She is instrumental in the RDCA-DAP initiative, establishing an aggregated database and developing regulatory-grade solutions derived from its data.

This webinar is an excellent opportunity to learn from these experts about the impactful role of patient advocacy groups in advancing research and improving healthcare outcomes.

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