FORUM SPEAKER BIOGRAPHIES - PARENTS AND PATIENTS

Çağdaş Canbolat, ISMRD Board Member, Galactosialidosis Network Founder

Mr Çağdaş Canbolat is a patient advocate at Galactosialidosis Network and Board Member of The International Society of Mannosidosis & Related Diseases, (ISMRD), London, UK.

Çağdaş is delighted to be joining the conference to talk about the work the patient advocacy community has done to progress treatment options for the rare metabolic disorder, Galactosialidosis.

Initially, Çağdaş established The Galactosialidosis Network in the UK as a source of support and advocacy for individuals grappling with this ultra-rare inherited metabolic disorder. His interest in patient advocacy was born out of a deeply personal journey with his daughter, Clara, who battled this condition and sadly passed away on 6 March 2024.

During his and his wife's fight to save Clara's life, The Galactosialidosis Network gained global reach, fueled by the collaboration of devoted parents, clinicians, and their partnership with ISMRD and Metabolic Support UK.

It was challenging to garner interest from pharmaceutical companies for various reasons. Nevertheless, their mission swiftly expanded to embrace all children confronting Galactosialidosis. They were able to highlight the prevalence of rare diseases on a global scale, raising awareness and offering support to families in need.

Their vision extended far beyond this, driving meaningful change by fostering collaboration between families, clinicians, and the scientific community. By leveraging his professional experience, they empowered the parent community to actively contribute to the pursuit of approved, enduring therapies for this rare disease.

In less than a year, with a well-planned communication strategy and a focus on relationship building, they successfully brought together all key stakeholders, including scientists and parents in this field. They equipped them with knowledge and advocated for groundbreaking scientific advancements. During this time, they earned the trust of both the scientific and patient communities, gaining the confidence to champion the needs of the rare disease community effectively. This was made possible because they led and mobilised key individuals and organisations worldwide. Their goal is to initiate a clinical trial and achieve an effective treatment for Galactosialidosis.

Sarah Forsman, ISMRD Communications Officer

Sarah Forsman is the Communications Officer at ISMRD, bringing her Marketing expertise and a deep personal understanding to her role.

With passions for the brain and anatomy, she is a dedicated advocate for the rare disease Alpha Mannosidosis—a condition she has personally navigated since birth, including a 2003 bone marrow transplant and recovery from a 2015 car accident.

She inspires others through her blog, "Achieve the Impossible Today," and her new podcast, "It's a Rare Story," launched in 2025, fostering a supportive community for those with rare diseases and disabilities. Sarah champions resilience, sharing stories of overcoming challenges and highlighting the impact of brain health.

Laurel Gregier, ISMRD Board Member,

The Lost Enzyme Project Founding Member

Laurel is a licensed mental health therapist who lives in Montana with her husband and her 2 sons.

Her eldest son Oliver was diagnosed with Beta-mannosidosis in 2014. Oliver was the first patient diagnosed with Beta-mannosidosis in the United States.

In 2015, Laurel and Oliver moved to Minneapolis, MN, where Oliver underwent an experimental bone marrow transplant. This was the first HSCT for Beta-mannosidosis in history.

Since that time, Laurel has dedicated herself to promoting Beta-mannosidosis awareness, inclusion, and advocacy.

She was elected to the board of the International Society for Mannosidosis and Related Diseases (ISMRD) in 2022. She has been helping connect rare patients and families around the world.

Laurel Gregier, cont'd

Laurel is arranging the inclusion of Beta-mannosidosis into the National Organization for Rare Disease (NORD) Disease Database.

In 2023, she co-founded The Lost Enzyme Project, a campaign and a foundation devoted to the creation of disease specific treatment and support for those affected by Beta-mannosidosis.

She is a member of the newly formed LSD Global Collaborative. Laurel is a co-host on the podcast, *These Kids Can't Wait: Discovering the World of Rare Disease,* giving a voice to this ultra-rare group and interviewing key individuals in the rare disease medical and research fields.

Jackie James, Cure Mucolipidosis President

Jackie James is the mother of Anna (30), who lives with Mucolipidosis III alpha/beta.

Her journey into rare disease advocacy began in 2012 when she joined the board of ISMRD.
By 2015, she had stepped into the role of board president, where she spent several years championing awareness, research, and community support for Mucolipidosis and other ultra-rare disorders.

In 2021, Jackie transitioned from her leadership role at ISMRD to co-found *Cure ML* alongside fellow mom/advocate Jenny Noble. This nonprofit organization is solely dedicated to advancing research and science toward effective treatments and, ultimately, a cure for Mucolipidosis.

She remains deeply committed to driving the mission forward and is excited to support the progress of science that will one day bring meaningful therapies—and hope—to the Mucolipidosis community.

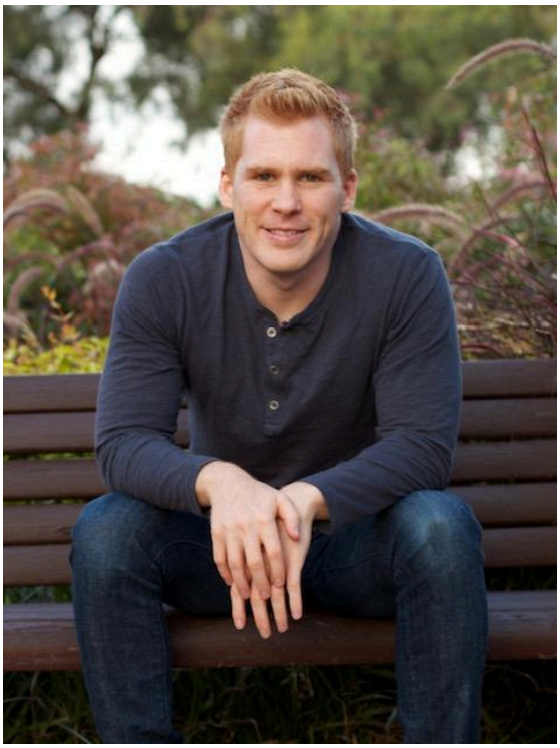
Carolyn Paisley-Dew, ISMRD President

A tireless advocate and leader in the rare disease community, Carolyn has dedicated nearly two decades to the International Society for Mannosidosis and Related Diseases (ISMRD), serving as its President for the last four years. Her commitment is deeply personal, inspired by the memory of her son, Matthew, who passed away from Fucosidosis in 2006 at the age of 10.

Based in Canberra, Australia, where she lives with her husband Chris, Carolyn brings a wealth of professional experience to her advocacy work. She spent 28 years in the Australian Public Service and holds an Honours degree in French, with sub-majors in Mathematics and Psychology, as well as a Graduate Diploma in Management.

Her dedication extends to research and collaboration; she is a co-author of the paper, “International online survey of Fucosidosis: key symptoms and the family experience,” presented at WORLDSymposium 2023, and a founding member of the Global LSD Collaborative. Ultimately, her dream is to see newborn screening and effective treatments for all the Glycoproteinoses, ensuring that other families do not have to endure the same journey.

Dan Peach, Cure Mucolipidosis Research Lead, New Zealand



Dan Peach is deeply committed to advancing a cure for Sialidosis. Following his own diagnosis and the loss of his brother to the disease, Dan has become a driving force in a global community of researchers, clinicians, patients, and families working together to find meaningful treatments that target the root causes of Sialidosis.

With over 15 years of hands-on experience in managing Sialidosis, Dan brings a unique and invaluable perspective to the field. He collaborates closely with leading scientists and medical experts to ensure the Sialidosis community remains at the forefront of emerging research and innovation.