



2024 PMSF International Family Conference

We are thrilled to invite you to our most anticipated event, where we will convene for an extraordinary week filled with connection, camaraderie, education, and sharing for everyone. Since our last meeting in 2018, the Phelan-McDermid Syndrome Foundation (PMSF) family membership has grown significantly, with hundreds of new families joining us. We expect over 650 people from 12 countries to attend. This event stands as the world's preeminent gathering for Phelan-McDermid families, offering a unique opportunity for direct networking and engaging with pioneering researchers, social interactions, and attending informative sessions with esteemed guest speakers to discuss the pressing concerns and challenges within our community. Visit our website for more information <https://pmsf.org/conference>.

Conference Location

Join us at the Radisson Blu, Mall of America in Bloomington, MN, USA, from July 17-20, 2024. This contemporary hotel offers a seamless connection to a plethora of activities within the Mall of America, ensuring comfort and convenience, including indoor walking spaces, air conditioning, and complimentary airport shuttle services.

Who Should Attend?

Whether it's your first or tenth time, the PMSF International Family Conference is designed for everyone whose life is affected by Phelan-McDermid syndrome. We encourage everyone touched by Phelan-McDermid syndrome to come and experience the growth, connection, and lifelong friendships that this conference fosters. We welcome families, caregivers, researchers, therapists, medical professionals, educators and other professionals who want to learn or share more about Phelan-McDermid syndrome.

Why Attend?

Our aim is to provide a warm, inclusive environment for the entire Phelan McDermid community. For caregivers, this is a pivotal chance to connect with leading researchers and peers, empowering them to meet the daily challenges of caring for someone with Phelan-McDermid syndrome. For researchers and medical professionals, this is a chance to meet the people your work impacts and to get a first-hand understanding of the Phelan-McDermid syndrome lived experience. Together, we hope to find strength and optimism in the advancements of Phelan-McDermid research, clinical care, support and advocacy efforts.

Educational Insights

The conference will host a series of educational sessions and interactive workshops throughout Thursday, Friday, and Saturday.

Is This Event for the Whole Family?

Absolutely! Family Fun Day will feature a variety of activities, including complimentary family photos, service dog demonstrations, music therapy, and games. New families will be welcomed in a special session, followed by an evening reception for all. There will be social events including field trips for siblings, a reception on Wednesday night, a group dinner on Thursday, and a chance to dance the night away on Friday. Plus, there will be specially designed sessions for mothers, fathers, siblings, and extended family members.

We will delve into essential subjects like the latest scientific developments, clinical practices, and how to manage the complex aspects of treating and living with Phelan-McDermid syndrome. Three agenda tracks will be offered:

CONNECT: These sessions provide opportunities to meet others who live with Phelan-McDermid syndrome to share, learn from and support one another. Sessions will be a combination of expert panelists, interactive family networking, and social meetings: Family Support, Navigating Legal Issues, Communication Enhancement, Transition Strategies for adulthood, Mastering State Systems, Adult Residential Options, Navigating Public & Private Education, Waiver Services, Mental Health, Moms, Dads & Sibling Activities, Sibling Field Trip, Club 22 for older siblings, Sensory Room, Small group meetups.

CARE: Care sessions have a clinical focus - from diagnosis to symptom management. These sessions will be a mix of oral presentations, panel Q&A, and poster presentations including: *Families' roles in research (Natural History, PMS DataHub), Medical Care, Understanding Regression, Managing Care, Exploring Therapeutic Models, Gastrointestinal Issues, Seizure Management, Neuropsychiatric Concerns, Clinical Care Guidelines, Altered Sensory Functions, Dentistry, Urology, and Lymphedema, Sleep Management*

CURE: These sessions will cover the cutting edge research that informs therapeutics. CURE sessions will be a mix of oral presentations, panel Q&A, and poster presentations including: *Research Updates, Clinical Trials, Loss of Skills, Genetics of PMS, Advanced Research Panels, Genotype-Phenotype Correlations, Progress in Research over Two Decades, Involving Caregivers in Research*

We look forward to seeing you at what promises to be an enriching and memorable experience for the entire Phelan-McDermid Syndrome community!

If you have questions, contact conference co-chairs, Diane Linnehan, Director of Operations at diane@pmsf.org or Ronni Blumenthal, CEO, at ronni@pmsf.org