



## 2024 PMSF International Family Conference Sessions

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.

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](mailto:diane@pmsf.org) or Ronni Blumenthal, CEO, at [ronni@pmsf.org](mailto:ronni@pmsf.org)

### Conference Sessions (subject to change)

**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 family activities:

#### Family Support

Navigating Legal Issues  
Communication Enhancement  
Transition Strategies for adulthood  
Adult Residential Options  
Navigating Public & Private Education  
Waiver Services  
Public Policy & Advocacy  
Caregiver Support & Coping Strategies  
Moms, Dads & Sibling Sessions

#### Family Activities include:

- Sibling Field Trip
- Club 22 for older siblings
- Sensory Room for all
- Small group meetups
- New Family Reception
- Family Dinner Party
- Dance Party
- PALs Mentors
- Movie Night

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. The topics are rooted in current knowledge and what can be done now. They are also focused on efforts to increase visibility among clinicians about Phelan-McDermid syndrome.

Some topics we plan to cover include:

- Genetics underlying Phelan-McDermid syndrome & follow-up testing
- Genetic counseling resource for families
- International clinical consensus guidelines in Phelan-McDermid syndrome
- Spotlight on specific symptoms and their management (some but not all will be covered):

Neuropsychiatric illness	Alternative medicines and treatments
Regression	Puberty & OB/GYN
Communication	Complex care
Challenging behaviors	Epilepsy and EEG abnormalities
Hypotonia/motor challenges	Dentistry
Gastrointestinal disorders	Kidney & urologic disorders
Sleep	Lymphedema

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. We will cover from start to finish how new findings are discovered in labs around the world, tested in models of Phelan-McDermid syndrome, and make their way to clinical trials.

Some topics we plan to cover include:

- At the bench - laboratory studies to find and test new therapies
- Families' roles in research (Natural History, PMS DataHub, and other clinical research)
- Selected Scientific Advisory Committee research successes
- PMSF's Grant Program - updates from researchers who have received funding
- Pharmaceutical company updates testing drugs for Phelan-McDermid syndrome
- Clinical trials - past, current, and future