



2024 Family Conference

Session Descriptions

Wednesday 7/17/24

Mall of America Activities On Your Own | Scavenger Hunt

Take part in a fun Mall of America scavenger hunt designed with the help of our Minnesota Moms! You will find the Scavenger Hunt forms at Registration.

Registration & Information | Graffiti Hallway

Check in with us when you arrive. Pick up your Registration Packet with information and lanyards. Select your stickers, ribbons to decorate your badge. You will find your dinner room assignment for Thursday Evening in your badge holder.

Daycare Meet & Greet | Plus One

The Caregiver Meet & Greet is a time for participants to meet their caregivers. This will help prepare the caregivers and familiarize the participants with the space and their caregiver, which will all help drop-off the following day to run more smoothly and help everyone feel more comfortable.

Sensory Room | Harriet AB | PMSF/Plus One

The sensory Room is an unsupervised play room for children attending the conference. This room will be in the conference center and filled with toys, games, and arts and crafts. Children under the age of 10 must be accompanied by an adult. There will be scheduled activities available as well as "open play" times. Please note: this is not a drop off program.

PMSF Store | Graffiti Hallway | Patty O'Boyle, Colleen Wirth

Show off your PMSF pride with merchandise from our store.

Volunteer Orientation | Isles Boardroom | Patty O'Boyle, Diane Linnehan

For all conference volunteers, check in to receive your assignments.

New Member Meet & Greet | Lakes Ballroom A-D | Carla D'Imperio; Ronni Blumenthal, CEO; Diane Linnehan, Sr. Dir. of Operations; and The Founders

Join our Family Support Specialist, Carla D'Imperio, as well as CEO Ronni Blumenthal, Sr. Dir. of Operations Diane Linnehan, and the founders of PMSF, to meet other families who have joined the PMSF in the past year. There will be a short introduction from Carla followed by time to mingle.

Welcome Reception | Lakes Ballroom A-D | Ronni Blumenthal, CEO; Co-hosted by Neuren Pharmaceuticals; Performance by Elim Brookshire. Friends old and new will come together for an evening of fun, laughter, and community connection. (Included with your conference registration.) Enjoy entertainment by one of our talented siblings, Elim Brookshire.

Thursday 7/18/24

Deb Graham Siblings Session (1st - 4th Grade) | Minnetonka BC | Kiley Richards, LISW, Carla D'Imperio, & Stacey Brandjord, PhD, NCSP, CCC-SLP

Siblings, these sessions are just for you. You will have the chance to play some games and make a keepsake, as well as have a group discussion with other Phelan-McDermid sibs. These groups are broken out by age.

Opening Session & Keynote Speech | Lakes Ballroom A-D | Ronni Blumenthal, CEO & Liza Squires, MD Neuren Pharmaceuticals; Rick Guidotti

Join us in kicking off our conference! Keynote speaker Rick Guidotti from Positive Exposure will ring in the 2024 Family Conference.

Scientific Welcome & Overview | Lakes Ballroom A-D | Kate Still, PhD

Join us in kicking off the CURE and CARE sessions of the conference, as Dr. Still summarizes the content of upcoming presentations, the intention behind them, and PMSF's strategic priorities in research.

Finding & Testing New Cutting Edge Therapies | Lakes Ballroom A-D | Hala Harony-Nicolas, PhD; Guoping Feng, PhD; & Xian Gao, PhD

In order to find new treatments for a disorder, the disorder is usually studied in the laboratory in cell or animal "models" which mimic the disease. These studies increase understanding of the disorder, potential ways to treat the disorder, and give a simple way to test the impact of a new therapy before testing in humans. In this session, Dr. Harony-Nicolas, Dr. Feng, and Dr. Gao will discuss real-world examples of studying Phelan-McDermid syndrome in the lab and testing new therapies. PMSF funds this type of research alongside clinical research through our Research Grants Program.

Deb Graham Siblings Session (5th - 8th Grade) | Minnetonka B | Kiley Richards, LISW, Carla D'Imperio, & Stacey Brandjord, PhD, NCSP, CCC-SLP

Siblings, these sessions are just for you. You will have the chance to play some games and make a keepsake, as well as have a group discussion with other Phelan-McDermid sibs. These groups are broken out by age.

Deb Graham Siblings Session (9th - 12th Grade) | Minnetonka C | Kiley Richards, LISW, Carla D'Imperio, & Stacey Brandjord, PhD, NCSP, CCC-SLP

Siblings, these sessions are just for you. You will have the chance to play some games and make a keepsake, as well as have a group discussion with other Phelan-McDermid sibs. These groups are broken out by age.

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**you must sign up for the caregiver sessions*

Your Role in Research: Phelan-McDermid syndrome Natural History Study Results & DataHub and Other Research Studies | Lakes Ballroom A-D | Alex Kolevzon, MD & Kate Still, PhD; Intro by Liza Squires, MD Neuren Pharmaceuticals

Family participation in clinical research offers direct insights into how Phelan-McDermid progresses, is best managed, and can be measured. Dr. Kolevzon will share highlights from his leadership in the 9+ year Natural History Study and its impact on medical research. Dr. Still will cover the impact of family participation in external research studies circulated by the PMSF, and internal studies, such as the PMSF-run genetic registry, the DataHub.

Overview of Clinical Trials | Lakes Ballroom A-D | Elizabeth Berry-Kravis, MD, PhD

The number and types of clinical trials in Phelan-McDermid syndrome is increasing over time. These categories include: repurposed drugs, drugs which aim to improve brain signaling, specific symptom-management drugs, drugs which target genetics, and others. Dr. Berry-Kravis will give an overview of current treatment strategies being tested in clinical trials for Phelan-McDermid syndrome, and similar neurodevelopmental disorders. She will also cover the phases of trials, general trial design, and what to consider for participation.

Grandparents & Extended Family Support Group | Minnetonka A | Kiley Richards, LISW

The Support Group For the Phelan-McDermid Syndrome Caregiver is an open group for grandparents and extended family members of Phelan-McDermid syndrome individuals. Participants will be able to process, understand, and cope with the mental health symptoms that can accompany the ongoing and complex trauma and loss that comes with a Phelan-McDermid syndrome diagnosis.

Emerging Clinical Trials for New Therapies | Lakes Ballroom A-D | Neuren Pharmaceuticals & Jaguar Gene Therapy

Some emerging clinical trials in Phelan-McDermid syndrome are testing new drugs which are not yet approved by the FDA for any other conditions. In this session, representatives from two companies, Jaguar Gene Therapy, and Neuren Pharmaceuticals, will cover updates on their current programs for Phelan-McDermid syndrome which have reached the clinical trials stage of development.

Phelan-McDermid Dads Session | Minnetonka ABC | Mike Cento & Mike Riley

Join our Dads session to get together with other Phelan-McDermid syndrome dads to get to know one another and share your experience of being a father to an individual with Phelan-McDermid syndrome.

Phelan-McDermid Moms Session | Minnetonka ABC | Cathy Bottini, Andrea Papageorgiou, Kris Graff, & Jamie Vande Hey

Join our Moms session for a unique opportunity to build meaningful connections with fellow moms. Moms will get to know one another and leave this session with a feeling of connection and a sense of belonging.

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Posters Session | Lakes Foyer | Various Presenters

View various scientific posters and meet the minds behind them.

Scientific Summit | MOA Lounge | Researchers, Clinicians, & Scientists

A meeting of the minds for our researchers, clinicians, and scientists to exclusively mingle and chat.

Community Dinner | Lakes Ballroom A-D & Minnetonka ABC | Ronni Blumenthal, CEO

Join us for an unforgettable evening at our Community Dinner! Begin the night with a family-style dinner among families, researchers, clinicians, sponsors, industry professionals, PMSF staff and PMSF board members that will foster connections. Enjoy a family video and great conversation with others in the Phelan-McDermid community.

Friday 7/19/24

Immersive Genetics 101 | Lakes Ballroom A-D | Tess Levy, MSc

Genetic testing is a powerful tool which leads to the diagnosis of Phelan-McDermid syndrome, but the implications can be confusing to decipher for families. In this session, Tess Levy will cover an introduction to genetics, the genetic causes of Phelan-McDermid syndrome, and how to read a genetic report. She will cover types of testing and follow-up testing, information about how genotypes can be associated with specific features of Phelan-McDermid, and introduce a genetic consult program available through PMSF.

Neuropsychiatric Meet-Up | Minnetonka A | Teresa "Tesi" Kohlenberg, MD

Dr. Tesi Kohlenberg will be offering an informal meet-up for families whose children or adult children are going through or have gone through episodes of neuropsychiatric illness. If you have met with Dr. Kohlenberg about your child's psychiatric health; if you have participated in our "Coping With Neuropsychiatric Episodes" Support Group; or if your child has been diagnosed with catatonia, depression, psychosis, anxiety, or mania, then this meet-up would be a great opportunity for you to connect with others.

Caregiver Support Group | Isles Boardroom | Kiley Richards, LISW

The Support Group For the Phelan-McDermid Syndrome Caregiver is an open group for parents, guardians, and primary caregivers of Phelan-McDermid syndrome individuals. Participants will be able to process, understand, and cope with the mental health symptoms that can accompany the ongoing and complex trauma and loss that comes with a Phelan-McDermid syndrome diagnosis.

Nickelodeon Universe | Sibling Field Trip | Carla D'Imperio

Siblings will share an unforgettable day as they enjoy thrilling rides, playful characters, and endless laughter. This chaperoned trip is for siblings only.

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U.S. & International Clinical Care Guidelines | Lakes Ballroom A-D | Sid Srivastava, MD & Michael Schön

Two sets of international clinical guidelines were released in 2023 for the monitoring, management, and treatment of symptoms in Phelan-McDermid syndrome. Dr. Srivastava and Dr. Schön will summarize these guidelines, including categories like genetics, communication, sleep, GI disorders, behavioral interventions, neuropsychiatric illness, seizures, lymphedema and more. They will give an overview of the process for devising these guidelines, explain how families can use these guidelines, and where to find these current resources.

Augmentative and Alternative Communication - Supporting Communication and Connection for All | Minnetonka ABC | Kate Ahern, MEd (Virtual)

This session addresses implementing augmentative and alternative communication, regardless of which device or system the child uses or how old the user is. We will consider the purpose of AAC, some options and examine using the Motivate, Model, Move Out of the Way framework.

Posters Session | Lakes Foyer | Various Presenters

View various scientific posters and meet the minds behind them.

4 Paws for Ability Service Dogs | Minnetonka BC | Meredith Koerner

Learn all the basics about service dogs and 4 Paws For Ability with a virtual presentation from a 4 Paws volunteer. Then meet the service dogs in-person!

Neuropsychiatric Illness, Regression, & Challenging Behaviors | Lakes Ballroom A-D | Teresa "Tesi" Kohlenberg, MD

A subset of people with PMS develop new and serious psychiatric illness during their teen or young adult years, sometimes accompanied by loss of skills (regression). Dr. Kohlenberg will share videos showing what these problems can look like, review what we have learned about how to manage these problems, and share ideas about prevention. She will also speak about the supports available through the Foundation, including the Neuropsychiatric Consult Group.

Epilepsy & EEG Abnormalities | Lakes Ballroom A-D | Jimmy Holder, MD

Approximately one-third of people with Phelan-McDermid syndrome have a diagnosis of epilepsy. In this session, Dr. Holder will share background information on the types of seizures, review the most current research and EEG findings, discuss genetics associated with epilepsy, current knowledge of best treatments, and clinical lessons learned at the Texas Children's Hospital.

Caregiver Support Group* | Isles Boardroom | Kiley Richards, LISW

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Understanding Behaviors & Underlying Health Issues | Minnetonka A | Ann Neumeyer, MD

Join Dr. Neumeyer as she discusses how new behaviors or regressions can signal underlying medical issues in children and adults with Phelan-McDermid syndrome. This session will provide insights into the clinical evaluation process, helping to identify and address the potential medical causes of these behavioral changes.

Communications Mini Fair | Minnetonka BC | Carla D'Imperio

Come and visit our first-ever communications mini fair. You will have the opportunity for hands-on learning at six different tables featuring: low-tech AAC, high-tech AAC, PROMPT method, sign language, speech therapy, spelling, and Eye Gaze.

Gastrointestinal Disorders | Lakes Ballroom A-D | William "Billy" Bennett, Jr., MD, MS

Many people with Phelan-McDermid syndrome experience gastrointestinal disorders such as constipation, diarrhea, cyclic vomiting, reflux, gastroparesis, trouble with feeding, and others. Dr. Bennett will cover the current state of the research for GI disorders in Phelan-McDermid syndrome and other neurodevelopmental disorders, diagnosis and treatment avenues, and resources. Dr. Bennett will also cover a collaborative initiative led in part by the Foundation, called CANDID - the Consortium for Autism, Neurodevelopmental Disorders and Digestive Diseases.

Everyday Advocacy Panel | Minnetonka A | Priscilla Hackstadt, Laraleigh Windom, Chrissy Hood & Janet Wilson

Hear first-hand from some of the most powerful advocates there are: Phelan-McDermid syndrome moms. Learn about how to be an advocate everyday in your home, community, and state.

Sleep | Lakes Ballroom A-D | Ann Neumeyer, MD

Sleep problems occur at high rates in Phelan-McDermid syndrome, such as falling asleep, staying asleep, sleep duration, parasomnias, and others. In this session, Dr. Neumeyer will both discuss her current research in sleep in Phelan-McDermid syndrome and autism, and she will share resources and tools for managing sleep disorders.

Phelan-McDermid Peer Connection Meet-Up | Minnetonka A | Cynthia Schauss

This meet-up is for you, our community of individuals with Phelan-McDermid syndrome who want to hang out, play games, and interact with your peers!

How It All Began: The Founders | Minnetonka BC | Dr. Katy Phelan, Sue Lomas, Curtis Rogers, MD, & Nick Assendelft

Come listen to the folks who started it all!

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Phelan Lucky Photo Op | Minnetonka ABC | Kelsie Adams & Devin Wilber

Throw on your "Phelan Lucky" T-shirt and meet us for a giant photo! Say cheese!

Summer Camp Dance Party | Lakes Ballroom A-D

Gather with us for a delightful family event at our Summer Camp-themed party. Bring your best summer camp looks and let's dance together with our Phelan-McDermid community.

Saturday 7/20/24

Sensory Room; Plus One

The sensory Room is an unsupervised play room for children attending the conference. This room will be in the conference center and filled with toys, games, and arts and crafts. Children under the age of 10 must be accompanied by an adult. There will be scheduled activities available as well as "open play" times. Please note: this is not a drop off program.

Caregiver Coping Toolkit; Kiley Richards, LISW

Join Kiley Richards, LISW, for a hands-on session where you will learn coping strategies to help you manage the day-to-day mental health challenges that caring for a child or adult with Phelan-McDermid syndrome can present. Be ready for activities to practice and discuss!

Nutrition & the Immune System for Individuals with Phelan-McDermid; Chardell Buchanan, MA, RDN

Join us to learn how nutrition can strengthen your child's immune system, focusing on the gut microbiota's vital role in health. Discover practical guidelines for a high-fiber, plant-rich diet that supports immunity. We'll cover key vitamins, minerals, and when supplements might be necessary, providing you with straightforward, actionable steps to boost your child's immune health now.

Clinical, Genetic, and Therapy Insights from Research at the Univ. of Modena, Italy; Antonio Persico, MD

The Phelan-McDermid Syndrome Foundation has several global partners - and research, including clinical trials, are rapidly advancing internationally. In this session, Dr. Persico will describe current research at the University of Modena in Italy, focused on 1) results from a clinical trial for a metabolic support therapy, 2) clinical characterization of a large cohort of people with Phelan-McDermid, and 3) linking of genetics to symptoms. He will also describe his work and advisory role at the Italian Association for Phelan-McDermid syndrome (AISPHEM).

Crayola Experience | Group Activity | Carla D'Imperio

Kids can unleash their imagination through vibrant activities, hands-on crafts, and more. Pre-purchased tickets and sign-up are required.

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Climb Zone | Group Activity | Carla D'Imperio

Kids will reach new heights as they conquer themed climbing walls. Pre-purchased tickets and sign-up are required.

Understanding and Managing Lymphedema Symptoms | Minnetonka A | Dana Winrow, PT, CT-LANA

This session will focus on lymphedema in Phelan-McDermid syndrome. Learn about what lymphedema is and how you can relieve symptoms of lymphedema at home.

Decoding State Systems Panel | Lakes Ballroom A-D | Ali Niemi, Rick Wood, & Janet Wilson

Come hear our panelists untangle the mysteries of accessing state supports like SSI, Waivers, Medicaid, and ABLE accounts. Here from local Minnesota experts about topics that will transfer to navigating supports in other states as well.

Transitions Across the Life Course | Minnetonka BC | Lynda Anderson & Renata Ticha of UMN Institute on Community Integration

Come join experts from the Institute on Community Integration at the University of Minnesota as we explore "Life Course Theory". You will learn about life stages and transitions (ie transition to adulthood) and how caregivers and guardians can make choices within the constraints of the system.

Pay It Forward: Help PMSF Continue Its Mission | Minnetonka A | Shira Johnson

Join us to learn ways to help PMSF support & connect families, improve medical care, and drive research breakthroughs. This fun session will include door prizes and awards.

Cross-Disorder Research Efforts | Lakes Ballroom A-D | Audrey Thurm, PhD

Phelan-McDermid syndrome shares features with other neurodevelopmental disorders, such as symptoms, assessments, and treatment strategies. PMSF frequently collaborates with other advocacy groups to make shared progress. In this session, Dr. Thurm will share takeaways from a few of these cross-disorder research efforts, such as the Inchstone Project, AGENDA, and others.

Navigating Legal Processes | Minnetonka BC | Rick Wood

Please join estate planning and family law attorney and Phelan-McDermid syndrome dad, Rick Wood, as he shares valuable information about planning for your child's future with various milestones and legal processes in mind. From guardianship to estate planning, this session will give a high-level overview of how to navigate legal processes as a parent of a child or adult with Phelan-McDermid syndrome. Special emphasis will be on special needs trusts, presented in plain language, ABLE accounts, Medicaid eligibility, and self-determination programs.

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Residential Options Panel | Lakes Ballroom A-D | Pamela Kurtz; Brandon Barnett; Cindy Barnett, LCSW; Rebecca Remberg; & Amy O'Donnell

It's tricky to know what's out there in terms of residential living options for your child as their child gets older. Hear from our panel of Phelan-McDermid Syndrome parents discuss their experience of choosing and placing their children into alternative housing.

Caregiver Support Group* | Isles Boardroom | Kiley Richards, LISW

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Healthy Eating for Caregivers | Lakes Ballroom A-D | Chardell Buchanan, MA, RDN

We've all heard about self-care, but the hectic pace of day-to-day life often hinders things like spa days and massages. Join this session to learn some concrete ways to take better care of yourself through diet and nutrition. You're going to learn to use a tool to make sure all your meals are healthy. We'll plan some healthy dinners to get you through the next few days, complete with a shopping list. Life is busy, but healthy eating can be easy and enjoyable.

Closing Session & Awards | Lakes Ballroom A-D | Ronni Blumenthal, CEO

Join us to celebrate a wonderful time together and honor some special community members!

Caregivers' Evening Out | Cedar & Nokomis A-C | Plus One

Enjoy a night on the town when you drop off your children and/or individuals with Phelan-McDermid syndrome for a fee with our extended evening care.

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