



**Gaylord Rockies Resort & Convention Center
Aurora, Colorado
July 15th - 19th, 2026**

Sessions marked with a camera will be Livestreamed to the Virtual Conference.
Sessions marked with a red dot will be Recorded & available at a later date.
All times are in Mountain Daylight time (MT).

Time	Session	Room	Speaker(s)
Wednesday, 7/15/26			
All Day	Gaylord Activities	On your own	
	Enjoy the beautiful Colorado views at the Gaylord Rockies.		
8:00 AM - 9:00 AM	PMSF Planning Team Meeting	Homestead 3	Carla D'Imperio; Amanda Bergen
	For members of the Conference Planning Committee only.		
12:00 PM - 5:00 PM	Registration OPEN	Red Rock Pre-Function	
	Come pick up your registration packet, including the conference guide and your name badges.		
2:30 PM - 4:30 PM	Board of Directors Meeting	Homestead 3	Denise Croden; Ben Holocher, CPA
	For members of the Board of Directors only.		
6:00 PM - 8:00 PM	Community Welcome Reception	Colorado A	
	Kick off the conference by joining us for our Welcome Reception! This casual gathering is a chance to connect with fellow families, self-advocates, clinicians, researchers, and community partners in a relaxed and welcoming environment. Enjoy a selection of hors d'oeuvres and refreshments, with a cash bar available, as we come together to reconnect, meet new friends, and begin the climb together.		
	<i>*Additional sessions to be added. Agenda subject to change.</i>		
Thursday, 7/16/26			
8:00 AM - 5:00 PM	Registration OPEN	Red Rock Pre-Function	
	Come pick up your registration packet, including the conference guide and your name badges.		
8:30 AM - 9:30 AM	Together at Basecamp: Opening Session & Keynote Speaker	Colorado A	Robbie Baker, CEO; Command Sergeant Major Gretchen Evans
	PMSF CEO Robbie Baker will welcome attendees and open the conference with reflections on the strength and resilience of the Phelan-McDermid syndrome community. He will share his vision for the future of PMSF and the importance of connection, collaboration, and hope as families, clinicians, researchers, and advocates come together to advance support and progress for individuals living with Phelan-McDermid syndrome. For our keynote, decorated Army veteran and motivational speaker Gretchen Evans will deliver an inspiring keynote on resilience, perseverance, and the power of community. Through her personal story of overcoming life-changing injuries sustained during military service, Gretchen will encourage attendees to face challenges with courage, determination, and the support of those around them. Her message of hope and connection will resonate deeply with families and caregivers navigating the rare disease journey.		
9:45 AM - 12:00 PM	Looking to the Summit: Advances in Industry-Sponsored Therapeutics (NNZ-2591, JAG201, and PYC-002)	Colorado A	Neuren, PYC, & Jaguar
	This session offers a comprehensive overview and the latest updates from three leading industry partners actively engaged in therapeutic development for Phelan-McDermid syndrome. Each company will present an overview and updates on their respective programs. Neuren will present progress on its NNZ-2591 Phast 3 trial; Jaguar will share on its AAV9 gene therapy Phase 1/2 trial; and PYC will highlight its RNA-based approach using antisense oligonucleotides to upregulate SHANK3 expression. Together, these updates showcase diverse therapeutic strategies advancing toward clinical impact.		
9:45 AM - 12:00 PM	Live Stream Room: Looking to the Summit: Advances in Industry-Sponsored Therapeutics (NNZ-2591, JAG201, and PYC-002)	Colorado B-C	Neuren, PYC, & Jaguar
	Whether you're looking to watch the session but be removed from the room with the speaker or the room with the speaker was too full, feel free to watch the session live from the next room over!		
10:30 AM - 11:00 AM	BREAK		
9:45 AM - 10:45 AM	Siblings Session Support Group (Ages TBD)	Colorado D	
	Siblings, these sessions are designed just for you! Participants will have the opportunity to play games, create a special keepsake, and take part in a supportive group discussion with other Phelan-McDermid syndrome siblings. Sessions are divided by age group to help create meaningful connections and conversations. These sessions are intended for siblings under the age of 18.		
11:00 AM - 12:00 PM	Siblings Session Support Group (Ages TBD)	Colorado D	
	Siblings, these sessions are designed just for you! Participants will have the opportunity to play games, create a special keepsake, and take part in a supportive group discussion with other Phelan-McDermid syndrome siblings. Sessions are divided by age group to help create meaningful connections and conversations. These sessions are intended for siblings under the age of 18.		
12:00 PM - 1:30 PM	Neuren Sponsored Buffet LUNCH Q&A	Colorado A & Pre-Function	
	Sit face-to-face with representatives from Neuren Pharmaceuticals for a Question & Answer session over a buffet lunch provided by Neuren.		
1:30 PM - 2:30 PM	Making the Ascent: Progress Updates from the Natural History Study	Colorado A	Alex Kolevzon, MD; Audrey Thurm, PhD; Sid Srivastava, MD; Tess Levy, CGC
	This session will present new research findings from the Developmental Synaptopathies Consortium (aka the "Natural History Study"), including insights into cognitive and adaptive behavior as well as genotype-phenotype relationships in Phelan-McDermid syndrome. Speakers will also share priorities and planned initiatives for the Consortium's third funding cycle. The session will highlight progress toward deeper phenotyping and improved clinical trial readiness.		
1:30 PM - 2:30 PM	VIEWING ROOM: Making the Ascent: Progress Updates from the Natural History Study	Colorado B-C	Alex Kolevzon, MD; Audrey Thurm, PhD; Sid Srivastava, MD; Tess Levy, CGC
	Whether you're looking to watch the session but be removed from the room with the speaker or the room with the speaker was too full, feel free to watch the session live from the next room over!		
TBD	Various Meet-Ups and One-on-Ones	Homestead 3 & 4	TBD
	TBD		

Wednesday, 7/15/26

Thursday, 7/16/26

Friday, 7/17/26

TBD	Various Support Groups	Homestead 3 & 4	TBD
	TBD		
5:30 PM - 8:30 PM	"The Climb We Make Together" Community Dinner	Colorado A	
	Join us for "The Climb We Make Together" Community Dinner, an evening dedicated to connection, reflection, and community. This plated dinner for families offers an opportunity to gather with others navigating the Phelan-McDermid syndrome journey, celebrate the strength of the community, and enjoy meaningful time together in a warm and supportive setting.		
	<i>*Additional sessions to be added. Agenda subject to change.</i>		
Friday, 7/17/26			
8:00 AM - 8:45 AM	PYC Sponsored Breakfast Q&A <small>(food available 7:30 AM - 9:30 AM)</small>	Colorado A & Pre-Function	
	Sit face-to-face with representatives from PYC Therapeutics for a Question & Answer session over a breakfast provided by PYC.		
9:00 AM - 11:00 AM	Symptom Deep Dive: Loss of Skills & Regression	Colorado A	Audrey Thurm, PhD; Alex Kolevzon, MD; Jon Santoro, MD
	This session will provide an overview of current knowledge on loss of skills and regression in Phelan-McDermid syndrome. Topics will include early and late-onset regression, assessment approaches, potential autoimmune contributions, brain imaging findings, and emerging treatment strategies.		
9:00 AM - 9:45 AM	Emerging Biomarkers in Phelan-McDermid Syndrome	Colorado D	April Levin; Tobias Böckers
	This session will highlight exciting progress in identifying emerging biomarkers for Phelan-McDermid syndrome, including those found in blood and brain activity (EEG). Researchers will explain how these biomarkers may help us track changes in the brain and body and maybe even guide future treatments.		
9:00 AM - 10:00 AM	Service Dogs with 4Paws	Colorado C	4Paws TBD
	Learn the basics about service dogs and the mission of 4 Paws for Ability through a virtual presentation led by a 4 Paws volunteer. Attendees will also have the opportunity to meet service dogs in person and connect with local 4 Paws families and their dogs.		
10:00 AM - 11:00 AM	Knowledge for the Climb: Genetics and Gene Therapy in Phelan-McDermid Syndrome	Colorado D	Arne Shillington, DO; Guoping Feng, PhD
	This session will provide overview of the genetics of Phelan-McDermid syndrome as well as emerging therapeutic strategies in Phelan-McDermid syndrome. Dr. Guoping Feng will present cutting-edge basic and translational research, including insights from advanced animal models, while Dr. Arne Shillington will provide clinical context and how this research translates into gene therapy approaches.		
10:15 AM - 11:45 AM	Phelan-McDermid Moms Session <small>(repeat session offered in the afternoon)</small>	Colorado C	Phelan-McDermid Syndrome Moms
	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.		
10:15 AM - 12:15 PM	Exploring Therapies! Mini Fair	Colorado B	TBD
	Learn about a variety of therapies, programs, and supportive services available to individuals with Phelan-McDermid syndrome and their families. Attendees will have the opportunity to meet therapy providers, explore resources, ask questions, and connect with organizations offering support across a range of developmental and therapeutic needs.		
11:15 AM - 12:15 PM	Symptom in Focus: Treatment Approaches for Challenging Behaviors	Colorado A	Latha Soorya, PhD, BCBA; Pilar Trelles, MD
	This session will focus on the management of challenging behaviors in individuals with Phelan-McDermid syndrome, including aggression, self-injury, and elopement. Experts will present evidence-informed strategies combining behavioral interventions and pharmacological approaches tailored to the unique needs of the Phelan-McDermid syndrome population. The session will highlight practical tools and emerging research to support families and care teams.		
11:15 AM - 12:15 PM	SAC Spotlight: Research Updates from Our Experts	Colorado D	Alex Shcheglovitov, PhD; Luigi Boccutto, MD
	This session will showcase cutting-edge research from members of the PMSF Scientific Advisory Committee, highlighting their ongoing efforts to advance understanding and treatment of Phelan-McDermid syndrome. Presentations will cover a range of topics, from basic science to clinical studies, reflecting the depth and breadth of expertise within the committee. Attendees will gain insight into key research priorities and emerging directions in the field.		
12:00 PM - 1:30 PM	LUNCH <small>(on your own)</small>	On Your Own	
1:30 PM - 3:45 PM	Posters Session	Colorado Foyer	TBD
	Come view various scientific and family posters at your leisure - and even chat with some of the poster presenters!		
1:30 PM - 3:00 PM	Symptom Deep Dive: Gastrointestinal Issues	Colorado A	William (Billy) Bennett, MD, MS; Julia Dallman, PhD
	This session will explore the presentation and management of gastrointestinal (GI) issues in individuals with Phelan-McDermid syndrome, including constipation, diarrhea, reflux, and feeding difficulties. Presenters will share emerging research on underlying mechanisms as well as evidence-based management and treatment approaches. The session aims to improve awareness of GI symptoms and promote comprehensive, multidisciplinary care.		
1:30 PM - 3:00 PM	Phelan-McDermid Dads Session	Colorado B-C	Phelan-McDermid Syndrome Dads
	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.		
1:30 PM - 2:30 PM	Research in Progress: Updates from PMSF Grant Awardees	Colorado D	Pilar Trelles, MD; Tess Levy, CGC; Kristy Johnson, PhD
	This session will provide updates from two projects funded through the PMSF Research Grants Program. These studies focus on improving how we understand and track neuropsychiatric symptoms and communication in Phelan-McDermid syndrome, using caregiver-informed tools and real-world data collection. Together, this work aims to better capture both symptoms and meaningful changes over time, advancing clinical care and strengthening tools for future research and clinical trials.		
3:15 PM - 3:45 PM	SNACK BREAK	Colorado Pre-Function	
4:00 PM - 5:00 PM	Many Ways to Communicate: Speech, AAC, Sign and More!	Colorado A	Kailey Medlock, SLP, ATP
	Explore the many ways individuals with Phelan-McDermid syndrome communicate in this interactive session facilitated by Kailey Medlock. From spoken language and sign language to AAC (Augmentative and Alternative Communication) and other communication methods, attendees will learn about tools, strategies, and approaches that support meaningful connection and self-expression for individuals with a wide range of communication needs.		
4:00 PM - 5:30 PM	Phelan-McDermid Moms Session	Colorado B-C	Phelan-McDermid Syndrome Moms
	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.		
4:00 PM - 5:00 PM	Understanding the Immune System's Role in Phelan-McDermid Syndrome	Colorado D	Milena Andzelm, MD, PhD; Jon Santoro, MD
	This session will explore the emerging role of neuroimmunology in Phelan-McDermid syndrome, including how the immune system may impact brain function and behavior. Topics will include blood-based immune markers, autoimmune neuropsychiatric symptoms, and the potential use of treatments like intravenous immunoglobulin (IVIg). Speakers will also discuss how lessons from other neurodevelopmental disorders may help inform research and treatment approaches in PMS.		
5:15 PM - 6:15 PM	Meet-Up: Individuals with Phelan-McDermid syndrome	Colorado D	TBD
	Join us for a fun and relaxed Game Night created especially for individuals with Phelan-McDermid syndrome. This casual evening is all about spending time together, making connections, enjoying games and activities, and building friendships within the community in a welcoming and supportive environment.		
6:30 PM - 9:30 PM	"Our Journey to the Summit" Dance Party	Colorado A	

6:30 PM - 9:30 PM	Bingo Night	Colorado B-C	
	Get ready to celebrate at our conference Dance Party! This year's theme invites attendees to come dressed to represent where they are from, whether it is their hometown, state, country, or culture, and join together in celebrating the strength and diversity of the Phelan-McDermid syndrome community. Enjoy an evening of music, dancing, and connection, and be ready to "plant your flag on the mountain" as we celebrate the journey we climb together.		
	Looking for a quieter way to spend the evening? Join us for Bingo Night, a relaxed and welcoming activity for attendees who prefer a calmer environment. Enjoy games, prizes, laughter, and time together with members of the Phelan-McDermid syndrome community while taking a break from the louder evening festivities.		
	<i>*Additional sessions to be added. Agenda subject to change.</i>		
Saturday, 7/18/26			
8:00 AM - 8:30 AM	Breakfast <i>(on your own)</i>		
8:30 AM - 10:45 AM	Symptom Deep Dive: Neuropsychiatric Illness	Colorado A	Teresa (Tesi) Kohlenberg, MD; Alex Kolevzon, MD
	This session will focus on understanding neuropsychiatric illness in Phelan-McDermid syndrome, including mood changes and other mental health challenges that can emerge in adolescence and adulthood. Experts will discuss how these symptoms present in individuals with Phelan-McDermid syndrome and share current treatment approaches. The session will also include practical tips on helping families access improved diagnosis, care, and outcomes for their loved ones experiencing these symptoms.		
8:30 AM - 9:30 AM	Handling Insurance Denials	Colorado B	Michael D'Imperio, JD
	Navigating insurance denials can be overwhelming for families managing complex medical needs. This session will provide practical guidance on understanding denial letters, appealing coverage decisions, advocating for medically necessary services and equipment, and accessing helpful resources. Attendees will gain tools and strategies to help navigate the insurance process with greater confidence and persistence.		
8:30 AM - 9:30 AM	Feeding Challenges in Phelan-McDermid Syndrome	Colorado C	Chardell Buchanan, MA, RDN
	Feeding challenges are common for individuals with Phelan-McDermid syndrome and can impact nutrition, growth, health, and daily life. This session will explore common feeding difficulties, including oral motor challenges, sensory sensitivities, selective eating, reflux, and tube feeding. Attendees will gain practical strategies, resources, and insights to help support safe, positive, and individualized feeding experiences across all ages.		
8:30 AM - 9:30 AM	Toward the Summit: New Frontiers in Treatment Research	Colorado D	Boaz Barak, PhD; Haitham Amal, PhD
	This session will highlight promising new directions in the search for treatments for Phelan-McDermid syndrome. Leading researchers will share early-stage findings and innovative therapeutic approaches aimed at targeting the underlying biology of Phelan-McDermid syndrome.		
9:30 AM - 10:00 AM	BREAK		
10:00 AM - 11:00 AM	Symptom in Focus: Sleep Issues	Colorado B	Jimmy Holder, MD, PhD
	This session will focus on sleep disturbances in individuals with Phelan-McDermid syndrome, and how they can significantly impact daily functioning and family wellbeing. In this session, Dr. Jimmy Holder will review underlying causes and share practical strategies to support healthier sleep as well as discuss other neurological factors impacted in Phelan-McDermid syndrome like seizures and epilepsy.		
10:00 AM - 11:00 AM	PMSF Abstract Award Winners	Colorado D	Minquin Jiang, Lidia Garcia Pradas, Amanda Fath, Shen-Nan Qiao
	This session will feature the 2026 PMSF Conference Abstract Winners, showcasing innovative research from early career investigators. Topics span across brain and behavior and focus on everything from sensory processing to gastrointestinal biology to inflammation in Phelan-McDermid syndrome. Drawing from basic science in the lab, animal models, and human clinical research, these presentations offer new insights into the biology of Phelan-McDermid syndrome and pathways toward future therapies.		
11:15 AM - 12:15 PM	How to Get What You Need: Lessons from a Trial Attorney	Colorado A	Michael D'Imperio, JD
	Advocating for needed services, supports, and accommodations can feel overwhelming, especially when facing systems that say "no." In this session, a trial attorney will share practical strategies for effective advocacy, negotiation, and communication when working with schools, healthcare providers, insurance companies, and support systems. Attendees will gain tools and confidence to ask the right questions, present their case clearly, and persist in getting the resources their loved ones need.		
11:15 AM - 12:15 PM	An Introduction to Palliative Care	Colorado B	Brittany Gummere, MSW, LSW; Peter Baenziger, MD, MS
	This session explores how palliative care can support individuals with Phelan-McDermid Syndrome and their families across the lifespan - not just at the end of life. Led by an interdisciplinary team, it will dispel common myths, highlight practical ways palliative care enhances quality of life, and offer tools for navigating complex medical, emotional, and caregiver needs. Attendees will leave with a clearer understanding how early, integrated palliative care can be a meaningful layer of support alongside ongoing treatment.		
11:15 AM - 12:15 PM	Workshop: Managing Challenging Behaviors	Colorado C	Latha Valluripalli Soorya, PhD, BCBA
	This interactive workshop will build on strategies introduced in the "Symptom in Focus: Treatment Approaches for Challenging Behaviors" session. Led by Dr. Valluripalli Soorya, a clinical psychologist, this workshop will help families work through case examples and guided discussion to practice evidence-based approaches. Families will leave with practical tools and greater confidence to use these strategies at home.		
11:15 AM - 12:15 PM	Tracking the Climb: Measuring Symptoms and Progress in Phelan-McDermid Syndrome	Colorado D	Cristan Farmer, PhD; Megan Abbot; Anne Wheeler, PhD
	This session will help families understand how clinicians and researchers measure symptoms and track meaningful change in Phelan-McDermid syndrome. Presenters will highlight both emerging tools designed specifically for Phelan-McDermid syndrome as well as cross-disorder measures. Attendees will gain insight into why measurement matters, especially in the context of clinical trials.		
12:15 PM - 1:30 PM	Get Involved with PMSF Buffet LUNCH & Giveaway	Colorado A	
	Learn how to get involved with the Foundation with a buffet lunch provided by PMSF. Plus: free giveaways!		
1:30 PM - 3:45 PM	Transition to Adulthood	Colorado A	
	Transitioning to adulthood brings new opportunities, challenges, and important decisions for individuals with Phelan-McDermid syndrome and their families. In this panel discussion, attendees will hear practical insights and personal experiences related to independence, programs and services, healthcare transition, legal planning, and building meaningful adult lives.		
1:30 PM - 2:30 PM	Understanding ECT: Myths, Facts, and Care in Phelan-McDermid Syndrome	Colorado B	Kelli Dominick
	This session will focus on the management of neuropsychiatric symptoms in Phelan-McDermid syndrome. A key component will be a clear, evidence-informed discussion of electroconvulsive therapy (ECT), addressing common misconceptions and outlining when it may be considered as a safe and effective treatment option in specific situations. The presenter also will review pharmacologic approaches and practical guidance to support clinical decision-making and individualized care.		
1:30 PM - 2:30 PM	Lymphedema Q&A	Colorado C	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.		
1:30 PM - 3:30 PM	Special Needs Estate Planning Workshop	Colorado D	Rick Wood, JD
	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.		
2:45 PM - 3:45 PM	Autism Diagnosis in Phelan-McDermid Syndrome	Colorado B	Somer Bishop
	TBD		
2:45 PM - 3:45 PM	Epilepsy Update	Colorado C	Jimmy Holder, MD, PhD

	TBD		
4:00 PM - 5:00 PM	Back Together at Basecamp: Closing out the Conference	Colorado A	Robbie Baker, CEO
	Join us for our Closing Session as we come together one final time to celebrate the connections, memories, and progress shared throughout the conference. This special gathering will include community recognition, awards, giveaways, and reflections on the weekend as we honor the strength and spirit of the Phelan-McDermid syndrome community before heading home.		
6:00 PM - 9:00 PM	Caregivers' Evening Out	Red Rock 8-9	
	Treat yourself to a caregivers' night out with our special evening care!		
	<i>*Additional sessions to be added. Agenda subject to change.</i>		
PMSF 8 Sorrento Dr, Osprey, FL 34229 pmsf.org Agenda as of 5/11/26			