



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

Sessions marked with a **(M)** will be livestreamed to the Virtual Conference.

Sessions marked with an **(R)** be Recorded & available at a later date.

All times are in Mountain Daylight time (MT).

Wednesday, 7/15/26

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.		
12:00 PM - 8:00 PM	Registration OPEN	Colorado Pre-Function	
	Come pick up your registration packet, including the conference guide and your name badges.		
3:00 PM - 5:00 PM	Board of Directors Meeting	Willow Lake 4	Denise Croden; Ben Holocher, CPA
	For members of the Board of Directors only.		
5:00 PM - 6:00 PM	Daycare Meet & Greet	Red Rock 8 & 9	
	Join us for a brief meet and greet to tour the daycare room, meet the Plus One Meetings team, review important information, and help your loved one become comfortable before the conference. We look forward to welcoming your family!		
6:30 PM - 8:30 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>Agenda is subject to change.</i>			

Thursday, 7/16/26			
7:30 AM - 9:00 AM	Breakfast	On Your Own	
8:00 AM - 5:00 PM	Registration OPEN	Colorado Pre-Function	
	Come pick up your registration packet, including the conference guide and your name badges.		
9:00 AM - 10:00 AM	Together at Basecamp: Opening Session & Keynote Speaker (V)(R)	Colorado A	Robbie Baker, CEO; Command Sergeant Major Gretchen Evans; Jon Pilcher, CEO, Neuren Pharmaceuticals
	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.		
9:15 AM - 10:45 AM	Siblings Session (Ages 6-11)	Colorado B	Kiley Richards, LISW
	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. This session is for siblings ages six years to 11 years.		
10:00 AM - 12:00 PM	Looking to the Summit: Advances in Industry-Sponsored Therapeutics (NNZ-2591, PYC-002, and JAG201) (V)(R)	Colorado A	Lauren Schmitt, PhD; Neuren (Liza Squires, MD), PYC (Janya Grainok, PhD), Jaguar (Daniel Gallo, PhD)
	With an introduction from Lauren Schmitt, PhD, PMSF Chief Science officer, this session offers a comprehensive overview and the latest updates from three leading industry partners actively engaged in therapeutic development for Phelan-McDermid syndrome. Neuren will present progress on its NNZ-2591 Phase 3 trial; while Jaguar will share on its AAV9 gene therapy Phase 1/2 trial JAG201; and PYC will highlight its PYC-002 RNA-based approach using antisense oligonucleotides (ASO). Together, these updates showcase diverse therapeutic strategies advancing toward clinical impact.		
10:00 AM - 12:00 PM	Livestream Viewing: Looking to the Summit: Advances in Industry-Sponsored Therapeutics (NNZ-2591, PYC-002, and JAG201)	Colorado D	Neuren, PYC, & Jaguar
	A livestream viewing space designed for anyone who may need extra flexibility during conference sessions. Attendees are welcome to relax, move around, and participate comfortably while still staying connected to conference programming.		
10:00 AM-10:45 AM	Meeting the Challenge of Rare Disease in the Family (R)	Colorado C	Al Freedman, PhD
	Join Al Freedman, PhD, a rare disease parent and psychologist, for a compelling session exploring how lived experience and professional expertise come together to help families navigate the challenges of rare disease. Drawing on 30 years of lessons learned, Dr. Freedman will share insights on resilience, coping, advocacy, and finding hope along the journey.		
10:45 AM - 11:00 AM	BREAK	On Your Own	
11:00 AM - 12:30 PM	Siblings Session (Ages 12-18)	Colorado B	Kiley Richards, LISW

	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. This session is for siblings who are children ages 12 and up.		
11:00 AM - 12:15 PM	Neuropsychiatric Illness Caregiver Support Group (option 1 of 2) **	Homestead 1	Al Freedman, PhD
	The "Coping With Neuropsychiatric Episodes" Support Group is a closed group for caregivers whose child is going through or has gone through a period of neuropsychiatric illness. Caregivers will have the opportunity to process the trauma and stress of caring for a person who is dealing with intense neuropsychiatric episodes. You can read about what those episodes can look like here if you scroll down to "Information For PMS Parents."		
12:00 PM - 1:30 PM	Neuren Sponsored Buffet Lunch - Q&A Panel: Industry Sponsored Therapeutics (V)(R)	Colorado A & Pre-Function	Neuren (Liza Squires, MD; Rachel Groth, PhD); PYC (Janya Grainok, PhD; Donna Bezner); Jaguar (Daniel Gallo, PhD; Tessa Clarkson, PhD)
	Buffet lunch sponsored by Neuren Pharmaceuticals. Join representatives from Neuren (Liza Squires, MD; Rachel Groth, PhD); PYC (Janya Grainok, PhD; Donna Bezner); Jaguar (Daniel Gallo, PhD; Tessa Clarkson, PhD) for a live Q&A panel following their therapeutic updates for Phelan-McDermid syndrome. This interactive session offers attendees the opportunity to ask questions about progress, and explore future directions.		
1:30 PM - 2:30 PM	Making the Ascent: Progress Updates from the Natural History Study (V)(R)	Colorado A	Alex Kolevzon, MD; Audrey Thurm, PhD; Sid Srivastava, MD; Tess Levy, CGC
	This session will present new research findings from the NIH-funded Developmental Synaptopathies Consortium (also known as the "Natural History Study"), including insights into cognitive and adaptive behavior, genotype–phenotype relationships, and updated prevalence in Phelan-McDermid syndrome. Plans for the third funding cycle (DSC-III) also will be shared.		
1:30 PM - 2:30 PM	Livestream Viewing: Making the Ascent: Progress Updates from the Natural History Study	Colorado D	Alex Kolevzon, MD; Audrey Thurm, PhD; Sid Srivastava, MD; Tess Levy, CGC
	A livestream viewing space designed for anyone who may need extra flexibility during conference sessions. Attendees are welcome to relax, move around, and participate comfortably while still staying connected to conference programming.		
1:30 PM - 2:30 PM	Adult Sibling Support Group	Homestead 1	Kiley Richards, LISW
	We are excited to invite our adult siblings of individuals with Phelan-McDermid syndrome to a new support group just for them! This group is a place where you can come together to talk about the challenges of being a Phelan-McDermid syndrome sibling with others who "get it." This group is open to all adult siblings, not just caregivers.		
2:40 PM - 3:55 PM	Neuropsychiatric Illness Caregiver Support Group (option 2 of 2)	Homestead 1	Al Freedman, PhD
	The "Coping With Neuropsychiatric Episodes" Support Group is a closed group for caregivers whose child is going through or has gone through a period of neuropsychiatric illness. Caregivers will have the opportunity to process the trauma and stress of caring for a person who is dealing with intense neuropsychiatric episodes. You can read about what those episodes can look like here if you scroll down to "Information For PMS Parents."		
2:45 PM - 3:45 PM	Finding Your Way (R)	Colorado C	
	Day One can be a lot to take in. This welcoming session is an opportunity to pause, process, and connect with others. Learn more about PMSF, explore conference opportunities that match your interests and needs, ask questions, and discover resources available to support you and your family. Whether you're newly diagnosed, new to the community, or just looking for a place to start, we're here to help you find your way.		
4:00 PM - 5:15 PM	Transition to Adulthood Family Panel (R)	Colorado C	Barbara Tobias, Heidi Sommer, Diane Linnehan
	Transitioning to adulthood brings new opportunities and challenges for individuals with Phelan-McDermid syndrome and their families. Join this panel discussion to hear practical advice on planning for adulthood, navigating adult services, fostering independence, and building meaningful lives. Learn how understanding supports in your state, strengthening advocacy skills, and building strong relationships can make the journey easier.		
4:05 PM - 5:20 PM	Newly Diagnosed Support Group	Homestead 1	Al Freedman, PhD
	The months following a Phelan-McDermid syndrome diagnosis can be very difficult for parents and caregivers. The "Support Group For the Newly Diagnosed Phelan-McDermid Syndrome Caregiver" is a closed support group for parents, guardians, and primary caregivers of Phelan-McDermid syndrome individuals who were diagnosed within the last twelve months. This group is intended to support our new families with the unique challenges associated with coping with a new Phelan-McDermid syndrome diagnosis.		
5:30 PM - 7:30 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.		
*Agenda subject to change.			
Friday, 7/17/26			
8:00 AM - 8:45 AM	PYC Sponsored Breakfast Q&A (food available 7:30 AM - 9:30 AM)	Colorado A & Pre-Function	Janya Grainok, PhD; Dulce Vargas-Landin, PhD; Abbie Francis, PhD; Fern Utama, PhD
	Over breakfast, listen to a brief presentation then sit face-to-face with representatives from PYC for a Question & Answer session about PYC-002, their RNA-based approach using ASO.		
9:00 AM - 10:00 AM	Symptom Expedition: Loss of Skills and Regression in Phelan-McDermid Syndrome (V)(R)	Colorado A	Audrey Thurm, PhD; Alex Kolevzon, MD; Jonathan Santoro, MD
	This session will provide an overview of current knowledge on loss of skills and regression in Phelan-McDermid syndrome with the goal of sharing research, clinical understanding, and care strategies for individuals with loved ones who has been affected by regression. Topics will include early and late-onset regression, relation to neuropsychiatric illness, and potential autoimmune contributions.		
10:00 AM - 11:00 AM	Symptom Expedition: Q&A Panel: Loss of Skills and Regression in Phelan-McDermid Syndrome (V)(R)	Colorado A	Audrey Thurm, PhD; Alex Kolevzon, MD; Jonathan Santoro, MD; Milena Andzelm, MD, PhD; Sid Srivastava, MD
	Join a live Q&A panel with leading experts to explore the complex issue of skill loss and regression. Panelists will engage in open dialogue and respond to audience questions.		
9:00 AM - 10:00 AM	Service Dogs with 4Paws (R)	Colorado C	Meredith Koerner
	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.		
9:00 AM - 9:45 AM	Emerging Biomarkers in Phelan-McDermid Syndrome (R)	Colorado D	April Levin, PhD; Tobias Böckers, MD, PhD
	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 may be useful clinical trial endpoints.		
9:00 AM - 10:00 AM	Workshop: Transition to Adulthood	Homestead 1	Diane Linnehan, Heidi Sommer, Chad Hale M.Ed, Brittany Gummere, MSW, LSW; Peter Baenziger, MD, MS
	Bring your transition plans, questions, and vision for adulthood. This interactive workshop offers practical guidance, resources, and the opportunity to learn from experienced family members and professionals about navigating the transition from school-based services to adult support services and transition from pediatric to medical care. Participants will leave with a transition checklist and a personalized roadmap outlining what to do now, next steps, and what to plan for later.		

10:00 AM - 11:00 AM	Knowledge for the Climb: Genetics and Gene Therapy in Phelan-McDermid Syndrome (R)	Colorado D	Ame Shillington, DO; Guoping Feng, MD, 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, and Dr. Ame Shillington will provide clinical context and how this research translates into gene therapy approaches.		
10:00 AM - 12:00 PM	Exploring Therapies! Mini Fair	Colorado B	Carla D'Imperio; Various Presenters
	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.		
10:15 AM - 11:45 AM	Phelan-McDermid Moms Session (repeat session offered in the afternoon)	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.		
11:15 AM - 12:15 PM	Treatment Approaches for Challenging Behaviors (V)(R)	Colorado A	Latha Valluripalli 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.		
11:15 AM - 12:15 PM	SAC Spotlight: Research Updates from Our Experts (R)	Colorado D	Alex Shcheglovitov, PhD; Luigi Boccuto, MD
	This session will showcase cutting-edge research from members of the PMSF Scientific Advisory Committee (SAC). Presentations will highlight their ongoing efforts in both basic science and clinical studies to advance understanding and treatment of Phelan-McDermid syndrome.		
12:00 PM - 1:30 PM	LUNCH	On Your Own	
1:30 PM - 3:45 PM	Posters Session	Colorado Foyer B & D	Various Presenters
	Come view various scientific and family posters at your leisure - and even chat with some of the poster presenters!		
1:30 PM - 2:30 PM	Symptom Expedition: Gastrointestinal(GI) Issues (V)(R)	Colorado A	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, feeding difficulties, and motility issues. 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.		
2:30 PM - 3:00 PM	Symptom Expedition: Q&A Panel: Understanding and Managing GI Issues in Phelan-McDermid Syndrome (V)(R)	Colorado A	Billy Bennett, MD, MS; Julia Dallman, PhD; Calliope Holingue, PhD
	Join a live Q&A panel to continue the conversation on gastrointestinal issues in Phelan-McDermid syndrome. Panelists will answer audience questions and discuss practical management strategies and current research to support improved GI care for individuals with Phelan-McDermid syndrome.		
1:30 PM - 3:00 PM	Grandparents & Extended Family Support Group	Colorado B	Kiley Richards, LISW
	Join our Grandparents & Extended Family Support Group, sponsored by Jaguar Gene Therapy, to connect with others who understand the unique experience of supporting a loved one with Phelan-McDermid syndrome. Share stories, find encouragement, and build meaningful connections in a welcoming and understanding community.		
1:30 PM - 3:00 PM	Phelan-McDermid Dads Session	Colorado 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 (R)	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 in order to better capture both symptoms and meaningful changes over time, advancing clinical care and strengthening tools for future research and clinical trials.		
1:30 PM - 2:30 PM	All Abilities Yoga	Homestead 3	Mary Medellin Sims
	All Abilities Yoga creates a sensory-friendly, inclusive environment for all participants, including those with Phelan-McDermid syndrome. This class will encourage self-expression, self-advocacy, and community connection. Everyone is welcome!		
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! (V)(R)	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	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	Handling Insurance Denials (R)	Colorado C	Michael D'Imperio, Esq.
	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.		
4:00 PM - 5:00 PM	Understanding the Immune System's Role in Phelan-McDermid Syndrome (R)	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).		
3:30 PM to 5:00 PM	Community Support Group	Homestead 1	Kiley Richards, LISW
	Phelan-McDermid Syndrome Community Support Group open to all community members. Participants will be able to process, understand, and cope with the mental health topics that can come with a Phelan-McDermid syndrome diagnosis.		
4:00 PM - 5:00 PM	Caregiver Yoga	Homestead 3	Mary Medellin Sims
	This trauma-informed and highly accessible yoga session is designed to support the unique needs of caregivers. Through gentle movement, mindful breathing, and restorative practices, participants will learn practical tools to manage stress, build resilience, and prevent burnout. Suitable for all experience levels and abilities, this class offers an opportunity to pause, restore, and reconnect with oneself while continuing the important work of caring for others.		

Saturday, 7/18/26	5:15 PM - 6:15 PM	Meet-Up: Individuals with Phelan-McDermid Syndrome	Colorado D	Cynthia Schauss, Kiley Richards, LISW
		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.		
	5:00 PM - 6:30 PM	DINNER	On Your Own	
	6:30 PM - 8:30 PM	"Our Journey to the Summit" Dance Party	Colorado A	DJ Chad Hale
		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.		
	6:30 PM - 8:30 PM	Bingo Night	Colorado B	
		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>*Agenda subject to change.</i>			
	Saturday, 7/18/26			
	8:00 AM - 8:30 AM	Breakfast	On Your Own	
	8:30 AM - 9:30 AM	Symptom Expedition: Neuropsychiatric Illness Update (V)(R)	Colorado A	Teresa (Tesi) Kohlenberg, MD; Alex Kolevzon, MD
		This session will focus on understanding severe 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 advocate for improved diagnosis, care, and outcomes for their loved ones experiencing these symptoms.		
	10:00 AM - 10:45 AM	Symptom Expedition: Q&A Panel: Neuropsychiatric Illness in Phelan-McDermid Syndrome (V)(R)	Colorado A	Teresa (Tesi) Kohlenberg, MD; Alex Kolevzon, MD; Audrey Thurm, PhD; Milena Andzelm, MD, PhD; Kelli Dominick, MD, PhD
		Join a live Q&A panel with experts in neuropsychiatric illness to continue the conversation on improving care in Phelan-McDermid syndrome. Panelists will answer audience questions and share cross-disciplinary insights into the recognition and management of complex neuropsychiatric symptoms.		
	8:30 AM - 9:30 AM	Toward the Summit: New Frontiers in Treatment Research (R)	Colorado C	Boaz Barak, PhD; Haitham Amal, PhD
		This session will highlight promising new directions in the search for treatments for Phelan-McDermid syndrome. Researchers will share early-stage findings and innovative therapeutic approaches aimed at targeting the underlying biology of Phelan-McDermid syndrome.		
	8:30 AM - 9:30 AM	Feeding Challenges in Phelan-McDermid Syndrome (R)	Colorado D	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.		
	9:30 AM - 10:00 AM	BREAK	On Your Own	
	10:00 AM - 11:00 AM	Caregiver Support Group for Parents of Children Under the Age of 18	Homestead 1	Kiley Richards, LISW
		The Support Group for the Phelan-McDermid Syndrome Caregiver is an open group for all 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. This group is for caregivers of individuals with Phelan-McDermid syndrome from birth to age 18 years.		
	10:00 AM - 11:00 AM	PMSF Abstract Award Winners (R)	Colorado C	Minqing Jiang, PhD; Lidia Garcia Pradas; Amanda Fath; Sheng-Nan Qiao, PhD
		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. These presentations offer new insights into the biology of Phelan-McDermid syndrome and pathways toward future therapies.		
	10:00 AM - 11:00 AM	Neurology Update (R)	Colorado D	Jimmy Holder, MD, PhD
		This session will focus on neurology issues in individuals with Phelan-McDermid syndrome, and how they can significantly impact daily functioning and family well-being. In this session, Dr. Jimmy Holder will review and discuss current research, common challenges, and practical strategies to better support families in areas of sleep disturbances and epilepsy.		
	11:15 AM - 12:15 PM	How to Get What You Need: Lessons from a Trial Attorney (V)(R)	Colorado A	Michael D'Imperio, Esq.
		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	Workshop: Managing Challenging Behaviors	Colorado B	Latha Valluripalli Soorya, PhD, BCBA
		This interactive workshop will build on strategies introduced in the "Treatment Approaches for Challenging Behaviors" session. Led by clinical psychologist, Dr. Valluripalli Soorya, 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 in using these strategies at home.		
	11:15 AM - 12:15 PM	Tracking the Climb: Measuring Symptoms and Progress in Phelan-McDermid Syndrome (R)	Colorado C	Cristan Farmer, PhD; Megan Abbott, MD; Sean Halpin, 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.		
	11:15 AM - 12:15 PM	An Introduction to Palliative Care (R)	Colorado D	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.		
	12:15 PM - 1:30 PM	Get Involved with PMSF Buffet LUNCH & Giveaway (V)(R)	Colorado A	Robbie Baker

	Learn how to get involved with the Foundation with a buffet lunch provided by PMSF. Plus: free giveaways!		
1:30 PM - 2:30 PM	Special Needs Estate Planning Presentation (V)(R)	Colorado A	Rick Wood, Esq.
	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. This presentation will be interactive so please come ready to ask questions!		
1:30 PM - 2:30 PM	Lymphedema Overview and Q&A (R)	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 - 2:30 PM	Understanding ECT: Myths, Facts, and Care in Phelan-McDermid Syndrome (R)	Colorado D	Kelli Dominick, MD, PhD
	This session will focus on the management of neuropsychiatric symptoms in Phelan-McDermid syndrome, specifically highlighting electroconvulsive therapy (ECT). The presenter will address common misconceptions and outline when it may be considered as a safe and effective treatment option. The presenter also will review pharmacologic approaches and practical guidance to support clinical decision-making and individualized care.		
2:45 PM - 3:45 PM	Special Needs Estate Planning Workshop (V)(R)	Colorado A	Rick Wood, Esq.
	Continue the conversation from the "Special Needs Estate Planning Presentation" with estate planning and family law attorney—and Phelan-McDermid syndrome dad—Rick Wood in this interactive workshop. Dive deeper into topics such as special needs trusts, ABLE accounts, Medicaid eligibility, guardianship, and estate planning, with plenty of time for questions and discussion.		
2:45 PM - 3:45 PM	Caregiver Support Group for Parents of Adults Over the Age of 18	Homestead 1	Kiley Richards, LISW
	The Support Group for the Phelan-McDermid Syndrome Caregiver is an open group for all 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. This group is for caregivers of adults with Phelan-McDermid syndrome ages 18 and up.		
2:45 PM - 3:45 PM	Autism Diagnosis in Phelan-McDermid Syndrome (R)	Colorado C	Somer Bishop, PhD
	This session will focus on autism in Phelan-McDermid syndrome. Somer Bishop, one of the co-creators of a gold-standard autism diagnostic measure, will review what a diagnosis means in Phelan-McDermid syndrome and why sometimes the diagnosis "fits" and why sometimes it does not.		
2:45 PM - 3:45 PM	PMS GO International Organization Meeting	Colorado D	Susan Lomas, Katy Phelan, PhD
	Join Susan Lomas and Katy Phelan, PhD, for the first official meeting of PMS GO (Phelan-McDermid Syndrome Global Organization), now a registered charity in Spain. Learn how PMS GO is helping establish and connect Phelan-McDermid syndrome associations around the world. All international families are welcome, whether you're part of an existing association or interested in starting one in your country.		
4:00 PM - 5:00 PM	Back Together at Basecamp: Closing out the Conference (V)(R)	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	Plus One Meetings
	Treat yourself to a caregivers' night out with our special evening care! Pre-registration required.		
*Agenda subject to change.			
PMSF 8 Sorrento Dr, Osprey, FL 34229 pmsf.org Agenda as of 7/04/26			