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Phelan-McDermid Syndrome Foundation Launches 2026 Awareness Day Campaign

"You Reading This Matters" invites the public to ask questions, learn about the rare genetic condition, and share what they discover

OSPREY, Fla., September 10, 2026 — The Phelan-McDermid Syndrome Foundation (PMSF) is inviting people around the world to recognize Phelan-McDermid Syndrome Awareness Day on October 22 and help increase understanding of this complex genetic condition that may affect far more people than previously estimated.

This year's campaign, **"You Reading This Matters,"** begins with a simple idea: Awareness grows when someone takes the time to read, ask a question, learn something new, and share it with someone else.

Phelan-McDermid syndrome is a genetic neurodevelopmental condition caused by changes on chromosome 22q13, usually involving *SHANK3*. It significantly affects communication, learning, movement, sleep, behavior, gastrointestinal health, and other important areas of development and medical care. Although the condition affects each person differently, care for individuals with Phelan-McDermid syndrome typically requires 24/7 supervision and lifelong support.

A recently published study estimates that Phelan-McDermid syndrome occurs in approximately **1 in 7,300 people**, a substantially higher prevalence than previously expected. Based on this estimate, as many as 50,000 Americans and 1.1 million people worldwide could be living with Phelan-McDermid syndrome, meaning the majority of individuals remain *without* a diagnosis.

"Awareness matters because it can change what comes next for an individual or family," said Robbie Baker, Chief Executive Officer of the Phelan-McDermid Syndrome Foundation. "It can lead someone to ask a question, pursue genetic testing, find support, or simply see the whole person beyond a diagnosis. When more people understand Phelan-McDermid syndrome, we move closer to a future where every person living with the condition is understood, supported, and treated with dignity."

Phelan-McDermid Syndrome Awareness Day began with families seeking to shine a light on the condition and has grown into a global effort. Each year on October 22, individuals, families, advocates, researchers, clinicians, industry partners, and other supporters share stories and educational resources, wear green, and illuminate landmarks around the world.

Throughout the 2026 campaign, PMSF will share personal stories from individuals and families, educational videos and resources, and opportunities for the public to participate. Our campaign will highlight both the joys and challenges experienced within the Phelan-McDermid syndrome community while ensuring that no diagnosis fully defines a person.

Members of the public can participate by:

- Learning about Phelan-McDermid syndrome from our website and social posts.
- Following and sharing PMSF's family stories, videos, and educational posts
- Asking respectful questions and listening to families' lived experiences
- Wearing green, PMSF gear, or the PMSAD campaign shirt on October 22
- Inviting schools, workplaces, care teams, and community groups to participate
- Requesting that local landmarks and buildings light up green
- Seeking proclamations from local and state governments recognizing October 22
- Visiting **PMSF.org/PMSAD** for information and participation resources

Awareness can help healthcare professionals and families recognize signs of the condition, shorten the path to diagnosis, connect families with reliable information and support, strengthen clinical care, and encourage continued investment in research.

It can also help create communities in which individuals with Phelan-McDermid syndrome are understood as whole people with distinct personalities, relationships, interests, strengths, challenges, and stories.

"Taking the time to learn about Phelan-McDermid syndrome matters. When one person asks a question, listens to a family's story, or shares what they have learned, understanding grows—and families know they are not navigating this journey alone."

To learn more about Phelan-McDermid Syndrome Awareness Day and find ways to participate, visit **PMSF.org/PMSAD**.

About Phelan-McDermid Syndrome

Phelan-McDermid syndrome is a genetic neurodevelopmental condition caused by a deletion involving the *SHANK3* gene on chromosome 22 OR a disease-causing change (variant) within the *SHANK3* gene. Common features include developmental and intellectual disability, delayed or absent speech, low muscle tone, motor delays, sleep disturbances, gastrointestinal concerns, and autism-related characteristics. The type and severity of features vary widely among individuals.

About the Phelan-McDermid Syndrome Foundation

The Phelan-McDermid Syndrome Foundation supports the largest global community of people with Phelan-McDermid syndrome and their families. PMSF is doing everything it takes to make today better and the future brighter for everyone living with this complex condition, from the moment of diagnosis to the delivery of treatments and cures. PMSF provides family support, improves clinical care, advances research, and works toward a future in which every person with Phelan-McDermid syndrome is recognized, supported, and treated with dignity.

Learn more at **PMSF.org**.