



Important Message from the PMSF Medical Advisory Committee

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Vaccinations

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Dear families in the Phelan-McDermid syndrome community,

The PMSF Medical Advisory Committee provides support to families and to physicians caring for people with Phelan-McDermid syndrome. Phelan-McDermid syndrome is a rare genetic disorder which involves changes in a critical gene (*SHANK3*) on the long arm of chromosome 22. The SHANK3 protein acts as a scaffold in excitatory (glutamate) synapses and anchors specific receptors to facilitate chemical signaling across nerve cells. Glutamate is a neurochemical that is critical for learning and memory. Clinical features of Phelan-McDermid syndrome often include intellectual disability, autism, sensory-seeking behaviors, disrupted sleep, severe constipation, and related behavioral disturbances.

Recurrent upper respiratory tract infections and immune system challenges are common in individuals with Phelan-McDermid syndrome. Therefore, the PMSF Medical Advisory Committee advises that families and their medical providers follow the American Academy of Pediatrics' recommended child and adolescent immunization schedule. This includes immunizations for children under 18 years of age such as COVID-19, Tetanus, diphtheria, and acellular pertussis (Tdap), haemophilus influenzae type b, hepatitis A, hepatitis B, measles, mumps, rubella, and varicella (MMRV), respiratory syncytial virus (RSV), and rotavirus.

Vaccinations are a critical component of disease prevention and public health. In alignment with the Centers for Disease Control and Prevention (CDC), the World Health Organization (WHO), and other leading health authorities, we strongly recommend that eligible adults with Phelan-McDermid syndrome remain up to date with routine immunizations including influenza (flu), COVID-19, shingles, pneumococcal, and Tdap.

We encourage all individuals and families to consult with their healthcare providers as they make decisions around immunizations and to address any concerns they may have.