

Family Support Services

PWSA | USA's Family Support team provides support to individuals diagnosed with Prader-Willi syndrome, their families, and providers. They also educate medical providers, education professionals, and professional care givers about PWS and advocate for the comprehensive needs of the entire PWS community.

What We Do

New Diagnosis Support and Parent Mentoring

PWSA | USA offers comprehensive support and education to families at the time of diagnosis and provide information about PWS. Our Parent Mentoring Program is all about making connections with other “veteran” parents.

One of the most comforting parts of this journey is talking and meeting other families. Each of our mentors has shared similar experiences. We too have been comforted and nourished by our Parent Mentor. We have wept together, and we have laughed together. We are committed to ensuring that newly diagnosed families have the most up-to-date research materials, educational literature, counseling, nutrition, and medical information all within our Package of Hope, which we have been providing to families for well over a decade. We hand select our parent mentors with each family's specific needs in mind, to guide and support you throughout your child's lifetime. The compassion and caring from these very special connections can be a lifeline of HOPE.

Diet and Weight Management

Effective weight management is a crucial part of the care of a person with Prader-Willi syndrome. PWSA | USA supports families to manage weight effectively through appropriate meal planning, environmental supports, and other effective strategies.

Behavior Support

We provide behavior support to families, school districts, and residential providers by assisting with the development of positive behavior intervention plans, review of plans, and training implementation of best practices.

Consultations and Trainings

PWSA | USA offers consultations and trainings to residential providers, school personnel, and other support staff who need guidance or increased knowledge to support their client. Consultations may be provided in person, via telephone, or teleconference.

Peer Consultations

We facilitate consultations between PWSA | USA's volunteer medical consultants and an individual's medical team, emergency room physicians, or specialty clinicians.

Insurance/Medicaid/SSI Appeal Assistance

PWSA | USA provides support letters and guidance when appealing denials for Medicaid, Insurance coverage, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).

Residential Placement Support

PWSA | USA has created a Residential Care Database of agencies that provide residential services to individuals diagnosed with PWS. We support families through their search for the most appropriate provider for their loved one.

Grief and Bereavement Support

Grief is the response to loss, particularly the loss of someone or something that has died to which a bond or affection was formed. Most people associate grieving with the loss of life, but grief comes in many forms. Two types of grief sometimes experienced by parents of children who have a rare genetic condition are anticipatory grief and disenfranchised grief. Anticipatory grief is just that, grief experienced in anticipation of death. Parents who worry that their child's PWS diagnosis might shorten his or her life might be experiencing anticipatory grief. Disenfranchised grief might occur when a parent mourns the loss of the child they thought they were having. PWSA | USA has a certified grief counselor on staff to help you through your journey.

If you need support, you can contact our Family Support Team by calling (941) 312-0400 or emailing info@pwsausa.org.