



*“PWSA | USA has provided our family with ongoing support, and brings us so much hope for Michael to live an independent and full life.”*

- Rachel, Adoptive Mom to Michael



*“PWSA | USA was our rainbow after the storm of diagnosis. Providing us with all the latest information available so we can better understand PWS. Knowledge of what is possible is the beginning of a journey filled with hope.”*

- Sue, Mom to Shealynn



*“PWS is challenging and everyone should have access to the expertise, comfort, and connections provided by PWSA | USA.”*

- Rob, Dad to Isabel



Our mission is to enhance the quality of life and empower those affected by Prader-Willi syndrome.

## CONTACT US

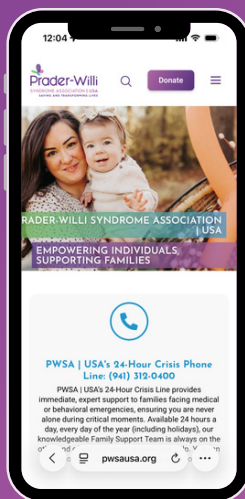


Phone: (941) 312-0400

*This number also serves as PWSA | USA's 24-Hour Crisis Phone Line*



Email: [info@pwsausa.org](mailto:info@pwsausa.org)



*Find more helpful resources on PWSA | USA's website. Scan the QR code below with your mobile device.*



## FAMILY SUPPORT SERVICES

*PWSA | USA is here for families affected by Prader-Willi syndrome 24 hours a day, 7 days a week, and 365 days a year.*

PWSA | USA Provides  
**HELP**  **HOPE**

# HOW PWSA | USA PROVIDES SUPPORT

## NEW DIAGNOSIS SUPPORT AND PARENT MENTORS

PWSA | USA offers comprehensive support and education to families at the time of diagnosis, providing factual and up-to-date information about PWS. Our Family Mentoring Program connects families with experienced "veteran" members who understand the journey

firsthand. We carefully select mentors based on each family's specific needs, offering guidance and support throughout their child's lifetime. One of the most comforting parts of this journey is connecting with other families who truly understand. Through our Package of Hope, newly diagnosed families receive the latest research, educational materials, and medical, nutritional, and counseling resources, all designed to help them feel informed, supported, and welcomed into the community. We also deliver a New Diagnosis Care Package directly to new parents, a warm welcome into the PWSA | USA community designed to help families feel connected and supported from the very start.

## MEDICAL PEER-TO-PEER CONSULTATION

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

## SPECIAL EDUCATION ADVOCACY

PWSA | USA provides special education advocacy to assist parents in making sure their child's special education needs are met. We help parents understand available services, interpret test results, and work with schools and parents to plan and evaluate Individualized Educational Plans (IEPs).

## BEHAVIOR SUPPORT

PWSA | USA provides 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.

## 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.

## 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).

## ONE-ON-ONE TRAINING OPPORTUNITIES

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.

## RESIDENTIAL PLACEMENT SUPPORT

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

## GRIEF AND BEREAVEMENT SUPPORT

Most people associate grieving with the loss of life, but grief comes in many forms. Parents of children who have a rare genetic condition often experience two types of grief: anticipatory grief and disenfranchised grief. Anticipatory grief is just that, grief experienced in anticipation of death. Parents who worry that their child's Prader-Willi syndrome 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.

## MEET THE FAMILY SUPPORT TEAM



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Learn more about PWSA | USA's Family Support programs and services by scanning the QR code with your mobile device

