



Prader-Willi

SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

CONTACT US



info@pwsausa.org



(941) 312-0400



"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



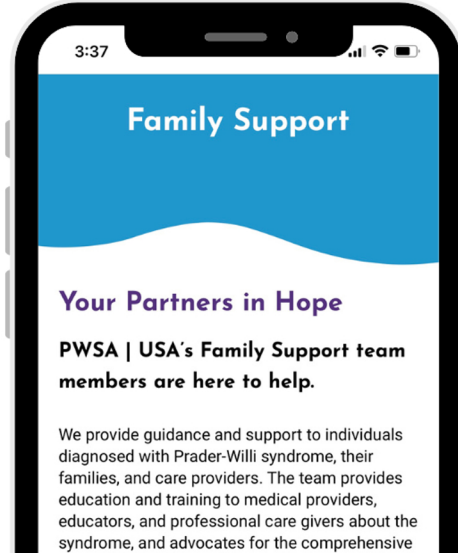
"PWSA | USA is a soft place to land, a light shining in the darkness, and a community that cheers us on this grand adventure."

- Christina, Mom to Oaklyn

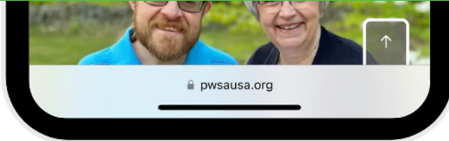


"Family Support from PWSA | USA is such a critical part of our lives and for so many others who have a loved one with Prader-Willi syndrome."

- John, Dad to Hunter



LEARN MORE AT WWW.PWSAUSA.ORG



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FAMILY SUPPORT RESOURCES

**PWSA | USA is here for you
and your family 24 hours a
day, 7 days a week,
365 days a year**

HOW PWSA | USA PROVIDES SUPPORT

NEW DIAGNOSIS SUPPORT AND PARENT MENTORING

PWSA | USA offers comprehensive support and education to families at time of diagnosis and provides factual 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 to and meeting (with) other families. Each of our mentors has shared similar experiences. PWSA | USA is committed to ensuring that newly diagnosed families have the most up-to-date research material, 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 families throughout their child’s lifetime.

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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