



Prader-Willi Syndrome

Prader-Willi syndrome is a complex genetic condition. In infancy, symptoms include weak muscle tone (hypotonia), feeding difficulties, poor growth, and delayed development. Affected individuals develop an insatiable appetite, leading to chronic overeating (hyperphagia) and obesity.

other characteristics

- The Hypothalamic and other regions of the brain are not functioning resulting in:

Hypotonia: Low muscle tone affecting all muscles in the body.

Hyperphagia: Insatiable appetite leading to uncontrolled eating and searching for food.

Hypogonadism: Small genitalia and lack of sexual maturity.

Hypomentia: Learning disabilities and/or mental retardation.

- Emotions that are unmodulated and can lead to outbursts, temper tantrums and mood swings.
- Behavior that is inflexible and can lead to stubbornness, hoarding, self-trauma and aggression.
- An experience of pain and illness that is different from people who do not have PWS.

opening Doors of opportunity

Thanks to the foresight of our founding families, ARCA has provided nationally recognized services to thousands of children and adults with intellectual, developmental and cognitive disabilities in the greater Albuquerque area since 1957.

Today, ARCA is the largest non-profit service provider of its kind in New Mexico and is the industry gold standard in providing premier life-long supports for people with intellectual, developmental and cognitive disabilities.

ARCA operates more than 100 residences in our community and provides services to over 600 individuals every day. ARCA employees and provider families are some of the best trained and most dedicated in the industry.



Working together to open doors for people with intellectual, developmental and cognitive disabilities to be valued members of the community.

11300 Lomas Blvd. NE
Albuquerque, NM 87112
(505) 332-6700

www.ARCAOpeningDoors.org

FOLLOW US!

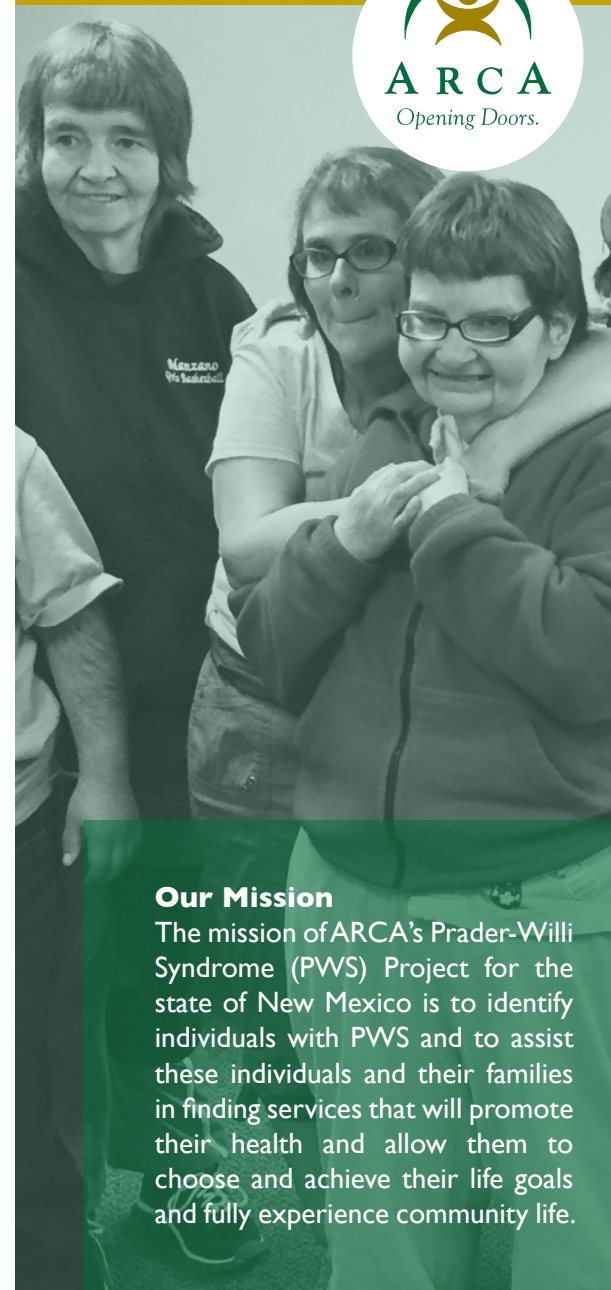


www.instagram.com/ARCAOpeningDoors



www.facebook.com/ARCAOpeningDoors

Prader-Willi Syndrome Project



Our Mission

The mission of ARCA's Prader-Willi Syndrome (PWS) Project for the state of New Mexico is to identify individuals with PWS and to assist these individuals and their families in finding services that will promote their health and allow them to choose and achieve their life goals and fully experience community life.

ARCA's Prader-Willi Syndrome Project

The only program of its kind in the nation, ARCA's Prader-Willi Syndrome (PWS) Project is a statewide program offering consultation and specialized case management for individuals with this life threatening genetic disability. Affecting 1:12,000 to 15,000 live births, PWS is a genetic disorder with no known cure. If left untreated, PWS can lead to morbid obesity and death.

Characteristics

- Short stature
- Almond-shaped eyes
- Thin, tented upper lip
- Pear-shaped body type
- Low pigmentation
- Different facial proportions
- Small hands/feet with a straight ulnar border on the side of the hand



Individuals with PWS, along with their families and key community members, are given the supports needed to feel safe in their environment so they may engage their interests and reach their goals.

Prader-Willi Syndrome Project Services

Identification and Diagnosis

If PWS is suspected, we will direct families to a geneticist who can complete diagnostic testing.

Case Consultations

Our program provides assistance in locating, developing and coordinating individualized resources and services for the management of PWS in a person's home community.

Training and Education

We offer training and education to providers who serve individuals with PWS. Our program provides behavioral training and consultation to individuals, their families and other service providers.

Nutrition Consultation

A Nutritionist develops an individualized Medical Nutrition Therapy program for each person served. We also provide consultation to other service providers and other Nutritionists/RD's as individuals require specialized nutrition supports.

Family Supports

We provide families with essential information regarding PWS and available services, including residential

opportunities, benefits and guardianships. Additionally, we collaborate with families in the development of individualized service plans.

Emergency Respite

Our program provides families with funds for respite services on an emergency basis. Prior approval from the PWS Project Director is required for this service.

We are dedicated to promoting an increased awareness and understanding of PWS. We provide written information, training, conferences and seminars to individuals and groups interested in learning more about PWS.

For more information or to refer individuals for services, please contact us.

505.550.1550

or Toll free: 1.844.302.6868

MAIN CONTACT: **Giovanna Bourguet**
New Mexico Prader-Willi Syndrome Project Case Coordinator

Office: 505.332.6828 • Cell: 505.550.1550
GBourguet@ARCASpirit.org

PWS NUTRITIONIST: **Loretta Sesbeau**
Office: 505.243.3850
LSesbeau@ARCASpirit.org

PROJECT DIRECTOR: **Michelle Harmon**
Office: 505.332.6843
MHarmon@ARCASpirit.org

www.ARCASOpeningDoors.org