



Dear Parent,

Thank you for contacting PWSA | USA, and congratulations on the birth of your baby! We are grateful to have the opportunity to support your important role as the parent of a child with Prader-Willi syndrome (PWS). One of the main missions of PWSA | USA over the past 48 years is to bring families like yours the latest medical treatments, research information, and support.

We are pleased to provide this Package of Hope, which includes a variety of materials we believe will answer some of your questions and offer guidance on critical issues such as nutrition, medical concerns, and the use of Growth Hormone as a treatment for PWS. In addition, you will receive future materials and publications that will aid you on your journey.

First and foremost, remember that Prader-Willi syndrome is a condition your child has, not who your child is. We understand that you are probably trying to process the diagnosis and certainly worried about your child with PWS. In the beginning, the focus may have been on what's "different" about your baby but pause and take moments to enjoy and embrace the perfect beauty of YOUR child.

In the days, weeks, and years ahead, you will likely have new questions and face new challenges. Please call us at any time. We have counselors and parent mentors available to talk and to help. Our office is open Monday through Friday from 9-5, EST and our 24-Hour Support Phone Line is available 365 days a year at 941-312-0400. We are also available by email at info@pwsausa.org. Remember to visit our website frequently for new information, sign up for our newsletter – The Pulse and receive updated information at <http://www.pwsausa.org/>. If you are on Facebook, we invite you to "like" our page at <http://www.facebook.com/PWSAUSA>. We also offer several Facebook groups by age.

The services and resources offered by PWSA | USA are available because of the generosity of the families and friends of a loved one with PWS across the country who contribute regularly to support our organization. In many cases, our families actively raise money to support our work by conducting a fundraising event virtually, or in their local community. Our [PWS Hope United](#) peer-to-peer fundraising platform allows individuals to easily host events, such as walks, trivia nights, birthday fundraisers, golf tournaments and other fun events that provide vital funding for our work. As you are able, we hope you will join others who provide support for our research, programs, and services so that even more parents of children with PWS will benefit from our help in the future.

As we walk this journey together, we believe you will find hope in this package and in your beautiful child who is full of potential, personality, and love. Please share pictures and stories from your child's life with us. We love to hear what every child with PWS is doing and what they are accomplishing.

Sincerely,

A handwritten signature in black ink that reads "Paige Rivard". The signature is written in a cursive, flowing style.

Paige Rivard, MBA | CEO
Mom to Jake, 12, living with PWS