



PWSA of WI, Inc.

Prader-Willi Syndrome Association of Wisconsin, Inc

A Heartfelt Message

In many ways, it seems like just yesterday when I walked into the exam room at Riley Children's Hospital and was told my son had Prader-Willi syndrome (PWS). I remember being stunned that after 4 long years of testing we had finally received a diagnosis; however, within seconds the fear kicked in as my mother, a nurse, started to cry. Unbeknownst to me, she had been surfing the Internet throughout the years searching for a diagnosis and during her search she had read many articles about PWS. The majority of the articles had highlighted every negative aspect about PWS and had made the future for anyone who was diagnosed with the disorder seem bleak. As she started talking about the various articles I remember thinking, "What had I done to deserve this? What kind of life is my son going to have? What can I do to help my son have the most successful life possible?". In addition, I felt extreme sadness over all the things my son and I would never experience due to his disorder...no sports, school parties and no birthday bashes with cake and ice cream. Well I am ecstatic to say...boy was I wrong.

My son is now a 6'2", 183 pound 19 year old who is healthy and happy. Although he has faced some struggles throughout his life, he has also experienced many successes. He has had the pleasure of participating in Special Olympics swimming, baseball, basketball and bowling, along with horseback riding through a local organization. In addition, he has been able to participate in many of the special events at schools such as music programs, field trips, holiday parties and most importantly **GRADUATION!!** Oh, and did I mention he also has gotten to have birthday bashes with cake and ice cream? Although modifications do need to be made at times, the reality is individuals with PWS can live happy fulfilling lives!

I know right now, you may feel numb and be experiencing a wide variety of emotions. Please keep in mind that you are never alone. As president of PWSA of WI, Inc., I can honestly say that any questions or feelings you may have – have been asked or felt by fellow parents before. There is always someone a phone call or email away. Our state office is located in the home of Joshua Escher, a former teacher and uncle to a niece with special needs. He answers our toll-free phone and responds to emails promptly. If he doesn't know the answer to your question, he will do his best to get it. PWSA of WI, Inc. has become a strong voice for persons with PWS as well as those who support them.

The world today is a different place than it was 19 years ago. And the world tomorrow is filled with hope and new answers to old questions. We continue to learn so much that is helping all who are affected by this disorder. There is a lot to learn but don't worry – take things one-step at a time. We are here to help you.

Most important – enjoy your child. First and foremost, you have a beautiful, loving child that will allow you to appreciate and celebrate so many things in life that we take for granted. Do what you would do for any of your children – sing, play, laugh and ... love him/her. Treasure the childhood moments and remember always that your child is a child first.

Whenever you are ready, please contact our office. You will soon discover that you have new friends and other parents that are here to help and guide you if you ever want or need it. You are beginning the role of being a special parent. PWSA of WI, Inc is here to support and help you.

Sincerely,

Crystal L. Boser

Parent and President
PWSA of WI, Inc.



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