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Dear parent or caregiver:

I would like to take the opportunity to introduce myself. My name is Bobbi Pogrnt and my husband, John and I are proud parents of our 8-year-old daughter, Addy, who has Prader-Willi Syndrome. We live in De Pere, WI, near Green Bay. I enjoy art and anything where I can be creative, spending time with my family and am a Girl Scout leader of my daughter's troop. I also am a board member of the Prader-Willi Syndrome Association of WI, Inc.

As a parent of a young child with Prader-Willi Syndrome, I understand how difficult it can be to receive the diagnosis of PWS. Faced with a challenge of this magnitude is overwhelming, to say the least. You may find yourself, like me, asking a million questions, searching the Internet for answers. Although, the Internet is a wonderful place to find information, I believe it is also very important to connect on a personal level with other families with children with PWS.

PWSA of WI would like to connect with families affected by Prader-Willi Syndrome, in particular, those with children ages 0-5. There are a few ways we can connect families with young children, but to do this, we are asking for your help.

One way to connect is through the closed Facebook Group named PWSA of WI Young Families 0-9 Chat. It is a great group for families to meet and exchange information with other families experiencing similar challenges. It is especially beneficial for families of younger children to meet and learn from families who have many experiences and much knowledge to share. After you join, please introduce yourself and post a pic of your child...we all love photos of adorable babies and children!!

If are not a member of Facebook, please take the opportunity to join. Then, for those who are not already members of the group, search for PWSA of WI Young Families 0-9 Chat and request to join. Please email topics you would like to see on the page and any questions regarding the Facebook group to me at youthmoderator@PWSAofWI.org.

We would also encourage you to fill out the enclosed releases and return. One is a release form granting or denying usage of any photos taken of your child. The second form is a release form for sharing contact information. By releasing this information, I would be able share your contact information with other parents of young children, in hopes of connecting families to email, chat, etc.

We would like to let you know that the Prader-Willi Syndrome Association of WI has a web site that is updated regularly with information about PWS and events. You can access the website at: www.pwsaofWI.org. While you are on the website, please take the time to apply online for a FREE membership.

Please don't hesitate to contact me with any questions you may have. I look forward to talking with you!

Thank you!

Bobbi Pogrnt
PWSA of WI, Inc.
youthmoderator@PWSAofWI.org
920-309-1880



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