

INDIANA PRADER-WILLI SYNDROME ASSOCIATION

Still hungry for a cure.

August 1, 2010
Issue 1

In this issue

- 1 Welcome
- 2 Meet the Board of Directors
- 4 Bragging Corner
- 5 About PWSA of Indiana
- 7 Healthy eating tips
- 8 PWSA of Indiana 2010 Conference

PWSA of Indiana
7536 Moonbeam Drive
Indianapolis, IN 46259
(317) 527-9173
amypfeiffer@comcast.net

PWSA OF INDIANA NEWSLETTER

I want to welcome you to the new PWSA of Indiana newsletter. My name is Amy Pfeiffer and I am the Executive Director of PWSA of Indiana. My husband, Mike, and I have four beautiful little girls. Our oldest daughter Lauren is 6 and has Prader-Willi syndrome (PWS). Her sisters are Mary (4), Madeleine (2 ½), and Rachael (9 months). I am a registered nurse and work part-time at St. Francis Heart Center and also work at Southside Family Practice occasionally. I am privileged to be serving as the Executive Director of this organization and am very excited about the progress we have made over the last three years. Please check out our new website @ www.pwsain.org.

In this newsletter I will introduce the PWSA of

Indiana Board of Directors. We have an exceptional group of individuals on the board and I am really looking forward to continue working with them.

Hopefully this newsletter will be a great source of information and a great place to share ideas and suggestions to help support Indiana families impacted by PWS. I am looking for creative suggestions for a name for our newsletter. Please email them to me and we can vote on them at our October 2, 2010 Indiana conference.

Please feel free to send suggestions, articles, recipes, items for our bragging corner, etc. Thanks for all you do to improve the life of someone with PWS.

Meet the 2010 Board of Directors and Officers

Janice M. Agarwal, P.T.

Janice has 21 years of Pediatric Physical Therapy experience, with emphasis on children and adults with Prader-Willi syndrome and the birth to three year old children. She uses Neurodevelopmental Training (NDT certified in 1995 by the Bobath Centre in London, England) and Sensory Integration (SI) techniques. She was part of the Neurodevelopmental Evaluation team at Boston City Hospital and the Early Intervention team at St. Mary's Hospital for Children in New York. She has lectured extensively on infant development and therapeutic intervention for children with PWS and the Sensory Integration and the behavioral challenges it addresses for therapists and parents at National PWSA (USA) and International (IPSWO) Conferences. She currently sits on the National PWSA (USA) Board of Directors, finishing her third term. She is the mother of a 10 year old son with PWS and 9 year old Sam.

Bret Johnson

Bret and his wife, Michelle, have three children: Lacey (24), Brady (20), and Brandt (20). Bret is a graduate of Indiana State University where he received a BS degree in Math and Computer Science. He is currently employed with 30 years of service at the Naval Weapons Support Center

Crane, where he manages an Inventory group but has served as a Computer Programmer for the majority of his career. Bret and Michelle reside in Bedford, IN. Their son, Brady, was diagnosed with Prader-Willi Syndrome (PWS) when he was 5 years of age. Brady lived at home until age 20 when he moved into a Group Home located in Southern Indiana. Bret enjoys all sports but is active in golf, softball, tennis, walking, and bike riding. He is an avid Indiana University basketball, St Louis Cardinals baseball, and Indianapolis Colts football fan. Bret also enjoys eating out with his family. After exhaustive searches for a suitable group home, Bret desires to serve on the Board of PWSA of Indiana to aid in the establishment of group homes capable of caring for those impacted with PWS.

James L. Koerber, President and Board Chair

Jim and his wife Rita have four adult children and three grand children living in California. Their youngest daughter Alison has Prader-Willi syndrome. She is 32 years old and lives in a group home in Citrus Heights, CA. Jim got involved with the Prader-Willi Syndrome Association (PWSA) shortly after Alison was diagnosed at age nine. He served on the Board of Directors and as President

of the Prader-Willi California Foundation. He also was elected to the National Board in 1997, but had to resign when he and Rita moved to Indonesia in early 1998. He was re-elected in 2009 and is currently serving a three year term on the National Board.

Jim earned a BS in Mechanical Engineering from Purdue University and an MBA in management from Golden Gate University.

On July 1, 2007, he retired from Chevron Corporation after almost 41 years and move from London, England to their 80 acre farm near Corydon, IN. He splits his time between the farm and their second home in Santa Fe, NM. During his career at Chevron, he held a number of technical and management positions in the US as well as international. Even with his work and travel, he maintained a strong connection with the Prader-Willi Syndrome Association. Since his retirement, he now has time to restore his 1926 Model T Ford, lower his golf handicap, contribute more time to community activities, and still be a gentleman farmer. One of his first community activities was to provide leadership for the re-establishing of the PWSA Chapter in Indiana. He is currently serving as

President. His broad leadership experience and his desire to make PWSA of IN the best organization it can be to serve those affected by Prader-Willi syndrome, are the reasons Jim wants to serve on the Board of PWSA of IN and serve as your President.

Rita B. Koerber, Treasurer

Rita and her husband Jim have four adult children and three grandchildren living in California. Their youngest daughter Alison has Prader-Willi Syndrome. She is 32 years old and lives in a group home in Citrus Heights, CA. Rita has been involved with the Prader-Willi Syndrome Association (PWSA) for over 22 years. On July 1, 2007, her husband retired and they move from London, England to their 80 acre farm near Corydon, IN. One of her first community activities was to assist in re-establishing the PWSA Chapter in Indiana. She is currently serving as Treasurer. Rita has been involved in finance activities for many years. During the late 1970's, she owned and operated her own business as well as served as church treasurer in Kirksville, MO. During the 1980's, she was an account executive for several television broadcasting companies in various locations in the US. In the 1990's, she operated her own interior design business in California. Also during the 1990's, she secured several grants to

upgrade PWS group homes in Northern California to make them safer and more adaptive for the clients, as well as create a pleasant home environment. Her finance experience and her desire to help PWSA of IN be an organization to best serve those affected by Prader-Willi syndrome, are the reasons Rita wants to serve on the Board of PWSA of IN and serve as your Treasurer.

Darla Legan, Vice President

Darla is a graduate of Ball State University where she received a BS degree in Accounting. She is currently employed with Rolls-Royce Corporation in Indianapolis as a Business Manager in the Helicopter Engines Business Unit and recently celebrated her 15-year anniversary with the company. Darla and her husband, Shawn, married for 14 years are the proud parents of Drew (10) and Riley (3) with PWS. Riley was diagnosed at four months of age and has made tremendous progress with the help of therapists, doctors, family and friends. Riley recently started attending preschool and loves it. Darla enjoys reading, taking walks, bike riding, traveling, Drew's sporting events, spending time with family and friends.

Jacque McGuire

Jacque is a Christian. She is a joyful, most of the time, mother of four; Mallory 20,

Hunter Valant 16, with PWS, Liam 11 and Quinn, 9. Jacque is a salon owner and cosmetologist and loves it! Fitness instructor: yoga, pilates, kickboxing and weight training. She states "Exercise is a need in all of our lives." 1998 Graduate of "Partner's in Policy Making" through the Indiana Governor's Planning Council for people with Disabilities. She has experience in raising a child with PWS in several areas. Many beautiful successes, many, many funny stories! Hunter is successfully being educated in public schools. She might be of service in helping families with school issues and IEP's. Jacque has a strong interest in residential development and practical and functional management for individuals with PWS. Hunter's father works for Habitat for Humanity. He is also a general contractor in the building arena with several years of practical experience. He also has a desire to offer what his services in this journey that we are all on together. "I think we all have God given gifts and strengths to offer this community. We will work together to gain strength and progress toward our goals. Stay on track to fulfill our mission on this, difficult at times, journey. What a ride it will be! A beautiful friend of mine shared this word in Zulu, "Ubuntu", which is translated "I am because we are". This is true, we

need each other. Pray hard, live and love!"

Michael L. Pfeiffer

The father of four beautiful little girls [Lauren (6), Mary (4), Madeleine (2) and Rachael (6 mos.)] and husband to Amy who have taught him more about himself and life in six years than he seemed to be able to learn on his own in the previous 33. Mike is a graduate of Purdue University and St. Joseph's College, holds degrees in both Chemistry and Chemical Engineering, and is an employee of Eli Lilly and Company where he is involved in the development and manufacturing of life saving medicines. Mike played four years of varsity baseball in college, and continued to play and coach at different levels after graduation. Most recently, Mike coached Lauren's U5 soccer team, and both had a blast! Greatest hope for PWSA of Indiana is that the organization become strong enough to help drive funding for research, raise awareness in the

general community, and realize goals such as Group Homes for individuals with PWS in Indiana.

Patrick Phernetton

Patrick lives in Evansville, IN. He has been a police officer for over 20 years. Patrick and his wife, Lisa, have three children including Mickey (PWS) who is 13 years old. He is also the founder of a Non-profit organization called "911 Gives Hope" which raises money to better the lives of children and people with disabilities, which includes Prader-Willi syndrome. They are currently planning to build several group homes for individuals with PWS in the Evansville area.

Danielle Warmuth, Secretary

Danielle is a graduate of Michigan State University. She received a BA in International Studies as well as Japanese and French languages. She met her husband, Richard while living in Miami, FL. Danielle is a mother and home

school mom of three children: Ryan (18), Katie (15) and Andrew (3). Her new motto in life is, "Some people retire; some of us start over!" Andrew was a blessed surprise and was diagnosed with PWS at six weeks. He's doing well and definitely keeps the cat on-it's-paws and the family entertained! Danielle will be the first to tell you that God has a purpose for our children and that He will equip them with everything they need to carry out His plan. Whether it's through the public school system or home education, our special calling as parents is to discover our children's gifts and to nurture these talents. She's excited to be a part of PWSA of Indiana and feels that it's important that our families within Indiana find support and encouragement from their state's chapter, as well as from each other. We all share similar goals and desires for our children. We are a 'family' bonded by one common characteristic – PWS.



Bragging Corner

Brady Johnson (21) of Bedford, IN completed the Indiana University 5K for Cancer Survivors on April 3, 2010! Great job Brady...keep up the good work!!

ABOUT PRADER-WILLI SYNDROME ASSOCIATION OF INDIANA

Jim Koerber, President

PRADER-WILLI SYNDROME ASSOCIATION OF INDIANA

(PWSA of IN) is a non-profit, charitable corporation originally established in 1997. PWSA of IN is a chapter of Prader-Willi Syndrome Association (USA), and is comprised of parents, friends, and relatives of persons with Prader-Willi syndrome, as well as dedicated professionals and care providers.

OUR ORGANIZATION

- PWSA of IN serves all of Indiana with a network of support persons located throughout the state.
- PWSA of IN has over 70 members. Membership is comprised of parents, relatives, and friends as well as interested professionals.
- All members of the Board of Directors are parents or relatives or other dedicated supporters. All are volunteers committed to helping.
- PWSA of IN works in close cooperation with the national Prader-Willi Syndrome Association (USA) to achieve our mutual objectives.

OUR VISION

The vision of Prader-Willi Syndrome Association of Indiana is that every individual with Prader-Willi syndrome will achieve their maximum potential through our research, education, awareness, lobbying, advocacy, and support of families and caregivers.

OUR MISSION

The mission of the Prader-Willi Syndrome Association of Indiana is to promote and fund research, provide education, advocate and offer support to enhance the quality of life of those affected by Prader-Willi syndrome.

PWSA of IN works hard to:

- Protect and promote the welfare of persons with PWS
- Provide education and support services to the families of persons with PWS, as well as other care providers, extended family members, and family friends
- Communicate and publicize information about the syndrome to the general public
- Improve professional awareness of the syndrome and the use of state-of-the-art

treatment and management strategies

- Support professionals' commitment to continued research of the syndrome
- Promote the establishment and improvement of residential facilities
- Establish and maintain a state-wide network that supports:
 - Early identification
 - Early intervention services
 - Referrals to appropriate resources
 - Coordination with specialists for diagnosis, medical intervention and treatment, therapeutic interventions and treatment, nutritional management, and behavioral and psychiatric management strategies
 - Educational programs, workshops, in-service programs for parents, care-providers, regional center caseworkers, educators, and

- health care professionals
- Advocacy services and community awareness
- Respite services

OUR APPROACH

- Raise funds to support research, this will ultimately lead to a cure.
- Attend conferences, bringing specialists to our chapter meetings, thus providing education and resources in order to improve the quality of life for everyone with the syndrome, as well as the people who support them.
- Instill a sense of compassion and understanding through our dedication to

providing awareness and enlightened knowledge about Prader-Willi syndrome.

- Lobby and work with State officials and agencies to develop legislation that supports individuals with Prader-Willi syndrome.
- Advocate for individuals with Prader-Willi syndrome and helping provide more residential living options for those individuals.
- Provide emotional support to families and caregivers, and nurturing a sense of hope, strength and connection as we strive together to improve

the quality of life of individuals with Prader-Willi syndrome.

FUNDRAISING

- PWSA of IN depends wholly on private contributions and dues for its support. PWSA of IN is a non-profit 501(c)(3) organization, and donations to PWSA of IN are tax-deductible as a charitable contribution.
- PWSA of IN invites your support of and participation in our awareness, fundraising, and other special events and activities.

Healthy Eating Tips



These are a few tips from Jill Boughton, mother of April Boughton (21) from South Bend, IN.

A few things we've discovered to cut calories:

- Walden Farms makes peanut butter, salad dressings, chocolate sauce and other products that are zero-calorie. If your local grocery store doesn't carry them, they can be ordered from the company. By using these
- and spray butter, we've cut out a lot of unnecessary calories.
- We usually just serve fresh fruit for dessert, but on occasions where something else would be nice, we've tried sugar-free pudding mixes, and

low-calorie yogurt, either plain, mixed with fruit, or mixed into sugar-free jello with or without fruit. It's also easy to make pies with just fruit, no added sugar, though of course the crust has a lot of flour and fat. I don't much like using artificial sweetener, so I sometimes grind up dried dates or raisins to sweeten cakes, muffins, etc. Or use fruit juice instead of water or milk.

- Baking chicken, pork chops and other meats on top of the broiler pan (at 325 or 350 rather than "broil") allows extra fat to drip down and be discarded. Of course I also trim visible fat before cooking.
- April plans our weekly menus. She has some low-calorie cookbooks she likes to use (there's a nice one from PWSA). This makes up for her not being safe in the kitchen

helping with actual food preparation.

- For meatloaf, instead of using oatmeal or another starch and/or ketchup, we grind up raw veggies (onion, carrots, celery, broccoli, peppers, whatever you have around) to mix with the meat so she can have a bigger piece.

PWSA of Indiana **2010 Conference**

Please mark your calendars for our next annual Conference and General meeting. It will be held October 2, 2010 at the Ruth Lilly Learning Center at Riley Hospital for Children's outpatient center, 702 Barnhill Dr. Indianapolis, IN 46202. Check-in will begin at 10:30am with the general meeting beginning promptly at 11:00am. The conference will conclude at 3:00pm.

At this year's event we will hear from Dr. David Agarwal, Gordon Homes, and a representative from PWSA (USA). Dr. Agarwal practices interventional radiology and vascular radiology and diagnostic radiology in Indianapolis and will be speaking about scoliosis and general issues with PWS and surgery. Gordon is MetLife's senior financial planner for the Division of Estate Planning for Special Kids. He is also the father of a son with special needs. Also, we will get an update on what's happening at National from John Heybach. John is co-chair of PWSA(USA) Board of Directors We are very fortunate to have

these speakers at this year's conference. This event is free, we just ask that you bring a sack lunch for your family.

Babysitting will be available on-site.

Hope to see you there!