



# THE WISCONSIN CONNECTION

*The Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.  
Supporting, Educating and Advocating for Persons with Prader-Willi Syndrome and All who  
are Impacted by this Disorder*

**The mission of the Prader Willi Syndrome Association of Wisconsin, Inc. is to Support, Educate and Advocate for persons with Prader-Willi Syndrome, their families and professionals in meeting the challenges of this disability.**

A Message from the President: Mike Larson

## Stop Pushing On A Rope

We spend a lot of time in our house talking IEP's. Mary Lynn attends several every month, helping people around the state as well as friends who have kids with disabilities. It surprises me how much smoother our IEP's are than they are for so many others. I was lying awake in bed last night wondering "what are we doing different?" I don't see first hand what others do, but hear horror stories of how difficult it is to work with some schools.

We definitely have different roles that each of us play when dealing with the schools. Mary Lynn works day to day with them; answering questions and working out issues that crop up. I get called in when an issue starts escalating or during IEP time. We have two in the next month. Mary Lynn is in tune with the jargon and intimate with everything that is going on. I see my job as to come in with a fresh perspective and ask the obvious questions. I ask "why"; "how come"; "what does that mean" and "how do you measure that?" I sometimes ask, not that I don't know the answer, but so they can review why they are doing things and sometimes if it make sense.

One thing I have learned over the years is if the school doesn't want to do something, getting them to agree to it is like "pushing on a rope". You don't get too far when you are pushing on a rope compared to pulling it. It is hard to pull schools in a different direction than they want to go. But I think there are times you can get them to go where **you** want; if you make them think they want to go there too.

When you have an issue and potential solution you would like to implement, you first have to look at it from the school perspective. Any proposal is first evaluated by asking "how much does it cost?" and "how much man power will it take?". I feel the trick is to make your solution part of the path of least resistance. Money and people are the biggest barriers, even if it is best for your child. Remember—the school does not have to consider the "best" solution; they need to implement an "appropriate" solution. These sometimes are not the same. So what is best for your child may not be what is supported by laws or budgets. So you must ask, is it "appropriate"? The same way, the school must make "reasonable" accommodations. These are vague terms and need to be evaluated in your arguments.

I can go into a lot of strategies of approaches that have and have not worked. But the underlying strategies that should be considered for justification of any IEP goal and requests are best if they are looked at within the following considerations:

- Safety – Is my child safe while the school is responsible for them? If not, what is a reasonable and appropriate solution to make sure they are. This includes riding the bus, lunch times, between classes and extra-curricular activities. Be sure to include these in the IEP.
- Meeting IDEA and No Child left behind laws – Our kids have the right to a Free and Appropriate Public Education. Is what being offered appropriate and not a babysitting service? What are they getting out of their educational experience? They need to show a benefit of your child being there.
- SMART Goals (Specific, Measurable, Appropriate, Realistic, Timely) – There is no avoiding or getting around well written goals. This holds the school accountable for doing what they said they would do. Don't let the school push through poorly written goals. You are an equal part of the team to decide on these. If you allow poorly written or inappropriate goals, the teachers will give you the blame too when they fail.

When proposing goals, ideas or requests, try to remove emotions and bias. Work with facts, and documented observations. Do your homework on what is "appropriate" and what is considered "standard" for this situation. If there are professional organizations that give recommendations that back your proposal - bring them to the school. This will give backing that your request is "reasonable" and "appropriate". In a nutshell, if you can work with the schools in developing an appropriate educational plan it will be much easier than trying to "push on a rope". Good luck and if you have questions, call Mary Lynn, she has some very good experiences of what works and what doesn't.

Good luck, **Mike**

### Board of Directors:

**President:** Mike Larson

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**Board members:** Melissa Sirovina, Crystal Boser, Al Luening and Don Dorn

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wisconsin@pwsaofwi.org

### NEW Website:

www.pwsaofwi.org

PWSA of WI, Inc. is a chapter of PWSA (USA)

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Suite 500

Sarasota, FL 34238

**Toll free:** 800-926-4797 or  
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### Email:

info@pwsausa.org

### Website:

www.pwsausa.org

## Election Results

As you might have noted on the first page, we have new Officers and Board members after the 2008 Fall election. Our newly elected officers include:

**Vice President:** Jackie Mallow; and **Board members:** Crystal Boser and Don Dorn.

Our complete list of Officers and Board members now includes:

**President:** Mike Larson

**Vice-President:** Jackie Mallow

**Treasurer:** Tom Hughes

**Secretary:** Melissa Sirovina

**Board members:** Al Luening, Crystal Boser and Don Dorn.

These individuals are very dedicated to helping our organization progress and continuing to be a voice for persons with Prader-Willi syndrome. Please take a moment the next time you see them to say “Thank you” to them for all they do — remember, your Board of Directors are all volunteers doing this!

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### FREE Health Information Packets

As part of our ongoing efforts to educate parents, caregivers and professionals in Wisconsin about health issues that may be faced by a child or adult with PWS, PWSA of WI, Inc has free health information packets available. There are two components – a packet that provides information for the health care professional who cares for the person with PWS and a packet that provides information and resources to the health advocate – the parent, caregiver and person with PWS. To receive your free packet, contact PWSA of WI, Inc office by phone Toll free: 1-866-797-2947 or by email – [Wisconsin@pwsausa.org](mailto:Wisconsin@pwsausa.org)

## Hobby Day 2009

We are in the midst of making plans for our annual “Hobby Day”. As you will recall, we used a different format last year because of the approaching National Conference where we wanted our persons with PWS in Wisconsin to have a part in the Conference as many would not be able to attend. This year, we are again thinking of a new format. We have gotten to the point where Hobby Day has become so popular that we have really outgrown the current facilities at PWHO that we use. We are also to the point where we have used many of our proposed “hobbies” numerous times so we have been looking into some new ideas. We are going to host a spring event with a craft project that can be done by each attendee if desired, a movie, and a dance with a DJ. We are thinking of a Hawaiian theme although not all plans are in place. We plan on hosting this event on April 18, 2009 at the gym at the ODTC offices. Look for a mailing soon!



## Membership Renewal

Watch for a mailing in the next few weeks about PWSA of WI, Inc.’s membership renewal! Each year, we send a mailing to our membership and past members to remind them to renew their membership. Membership is \$25.00 per year and gets you our quarterly newsletter, discounts on trainings or conferences, the ability to apply for camp scholarships and financial assistance through our general assistance fund. We also offer associate memberships for grandparents, physicians, school personnel and others but associate memberships have no voting privileges. We want to make sure the important information is getting out to families and care providers as so often they are the ones educating medical personnel about the latest concerns and issues in dealing with clients with PWS. Remember, no one is ever denied a membership because of financial difficulty!

# PWSA of WI, Inc.'s

9<sup>th</sup> Annual

## GOLF BENEFIT

Saturday August 22, 2009



Being held at

Windwood of Watertown

Golf Course

Prizes, Food, Silent Auction &

Most of All Fun!

For more information, check out our web site  
or contact the office toll free:

1-866-797-2947

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Are you interested in joining our team who put things together for the Golf Outing? Do you have some ideas on items we could get for our Silent Auction? Or are you just interested in pitching in? We can use your help! Our chairs for the Golf Benefit have a pretty good system established for many of the different parts of the Golf outing; but we can always use assistance; whether it be getting items donated, getting the Hole Sponsor signs together and organized, or just setting up the silent auction items the day of the outing... please let us know! You can contact the office by phone or email and we will find something for you to do!

## Notes from the Office.....

By Mary Lynn Larson

Happy New Year!! I hope your holidays went well and were relaxing! We enjoyed a nice, relatively quiet holiday with our extended families.

We also welcomed a new addition to the family after the New Year — **NO**, not in the Larson household! My brother Patrick and his wife Kelly (whom some of you may have met at conference) had their first child, Aaden! And it is bringing me back to when my boys were babies!! I see Pat and Kelly getting anxious over those little details and remember how panicked I was with things with my first born, Alex!! It seems light years ago! Even with Matthew there were those panicked moments but the second one is easier, right!?! And then remembering all the time you spend just watching them, adoring them, and falling so in love!

It seems I had forgotten some of those precious moments over the years, - what with having to coordinate the numerous MD appointments, school IEP meetings, running to and from therapies and trying to keep up with the never ending load of laundry!! Seeing Aaden has reminded me to take joy in the current moment! I no longer have the never ending feedings of an infant with PWS, the diapers, or the constant checking on them because of the apnea monitor and other medical equipment.... Now I have two relatively independent, non-stop talking boys who always checking on **me** about..." - *what will we do next?* - *Mom, what time is dinner?* - *Mom, where is my Nintendo DS?* - *how come my brother gets to do that and I don't?*" And while I love my new nephew to death and adore being able to rekindle my "baby" skills—I am pretty comfortable in where my life is now ...the daily calorie count, the foreshadowing of an upcoming event, the diversion to prevent a meltdown and then offering them a Nintendo DS just to have a few moments of peace and quiet without arguing... And then the day starts over again with some new little obsession that Matthew must complete before he can go to brush his teeth or maybe today I can talk Alex into a compromise on eating a different sandwich when we go out to lunch rather than a bacon double cheese burger with a side of barbeque sauce!! (Yeah, we know it was an awful choice to allow—but we forgot that "once is a habit" speech that Mike offers to many new parents!!) And with them being older and more independent, I can now answer the toll free number without having to interrupt a phone call for "potty time". So feel free to call me when you have questions!! I can talk generally uninterrupted! Take care! **Mary Lynn**

# Communicating with school personnel

By Mary Lynn Larson

Recently I was introduced to a parent who had moved into the Appleton area by a mutual friend. This family has a young child with Down's syndrome who was going to be starting 1st grade and his parents were concerned about the transition. It is now January and there have been NUMEROUS meetings regarding the IEP and numerous communications. This mother had put together a version of the following letter addressing many of the concerns and asked for my input. I thought the letter was well written and factual. Mom had written a letter without fault-finding and without dragging her emotions into it! She even included documentation from the American Speech Language Hearing Association (the National group that certifies speech therapists as certified to practice in their field) on their recommendations on what children with the specific diagnosis of apraxia recommend! I asked her if I could share it with the families I support and she agreed. (Remember: This letter is addressing the specific issues with her son and their school district policies. Things may work differently in the school district you are working with.) I think this is a great starting place for many of us as we work with our child's school system to get things just right for targeting specific goals that we are concerned with. We are all aware of the importance of starting a paper trail! This is a great example of a well written letter to do it. Feel free to contact me if you have any questions.

Special Ed Coordinator  
Ourtown School District  
P.O. Box ,1234  
Happy Place, WI 12345

21<sup>st</sup> December 2008

**RE:- Draft IEP Document – MY CHILD**

Dear Sir or Madam

With reference to draft IEP document received 01 December 2008, we enclose the following concerns and queries. Please include this letter in MY CHILD's school record.

## **PLAAP (Present Level of Academic Achievement and Functional Performance:**

### **Student's strengths -**

As reported in IEP meeting 9<sup>th</sup> October and 15<sup>th</sup> October 2008, MY CHILD is able to use signs in a smaller setting (which is also documented in MY CHILD's IEP May 16th 2008) and is signing over 240 signs. This is a strength of MY CHILD's, please include in student strengths.

### **Concerns:**

Parents define MY CHILD as very *Apraxic* not non verbal. Due to his apraxia, MY CHILD requires extensive daily work for expressive language – as documented by IEP team Spring 2008.

### **Goals:**

“MY CHILD will increase his functional language skills using signs.....”

PLAAP has identified the area of need that “signing for MY CHILD can also be complicated due to his fine motor delays” and MY CHILD's signs are often imprecise”; yet working on improving dexterity for signing is not being addressed.

### **Special Education: Speech & Language**

360 –480 contacts/month 9-16 contacts/month special education/regular education

What does this mean? Please clarify. Kindly identify the amount of time per week MY CHILD receives individual speech therapy, together with location. Kindly identify the amount of time per week MY CHILD receives group speech therapy and the number of children in the group, together with location.

(Continued on page 5)

*(Continued from page 4)*

As we already advised, we are most concerned that MY CHILD receives intensive individual speech therapy as recommended by Speech Evaluation done this spring by MY CHILD's former school speech therapist: **“overall, MY CHILD responds well to therapy and intensive drill and repetition on sound patterns is needed to facilitate growth”**.

Kindly explain the basis for the suggested 40-50 minutes of individual speech therapy weekly and how this will meet MY CHILD's needs, given the severity of MY CHILD's apraxia, and given that MY CHILD was deemed to require 30 minutes daily of intensive one on one individual speech therapy - IEP May 16<sup>th</sup> 2008. Please note that the recommendation of ASHA with regard to treatment of apraxia (copy of ASHA recommendations given school speech therapist 17<sup>th</sup> November, 2008) is intensive short drills of one on one speech therapy. Please explain how reducing Intensive Individual Speech therapy from 150 minutes weekly to 40-50 minutes weekly is meeting MY CHILD's individual needs. Perhaps you would kindly forward us a copy of supporting research/scientific data.

We are also concerned as to how MY CHILD's speech/sign progress is monitored. It was reported at IEP meeting on December 4<sup>th</sup> 2008 by speech therapist that there is no way to get a base line with regard to MY CHILD's speech/sign production. If this is a misinterpretation on our part, please clarify and advise of base line and how MY CHILD's communication progress is monitored.

We fail to understand how including MY CHILD in group speech therapy will address MY CHILD's needs and note the other children in this group are very verbally challenged. Kindly explain the basis of how this is appropriate and will meet MY CHILD's needs and perhaps you would kindly share the supporting research/scientific data.

We note that the deaf and hard of hearing teacher monitored MY CHILD and was scheduled to monitor MY CHILD monthly (per IEP May 16<sup>th</sup> 2008). We are wondering why this is not continuing given MY CHILD communicates via sign. Perhaps you might kindly clarify. Also, who has responsibility for teaching MY CHILD sign? Who has responsibility for monitoring MY CHILD's signs i.e. identifying areas of need with regard to production of his signs, topography, dialect, etc?

#### **Toileting/skin care assistance—disability related**

##### **Amount/frequency: 2-5 times per day**

We note this frequency was not discussed at any meeting and we feel taking MY CHILD to the bathroom 2 times or changing MY CHILD 2 times over the course of a school day (7 hours almost) is inappropriate. MY CHILD is still in diapers and is at the initial stage of potty training. MY CHILD needs to be taken to bathroom a minimum of at least 4 times over the course of school day and changed whenever he has wet/soiled diaper. Given the number of times MY CHILD has wet through his clothes, 2 times a day for taking to the bathroom is inappropriate and would suggest this wording be changed to: **4-5 times a day and whenever diaper wet/soiled** instead of 2-5 times per day as is written in draft IEP.

We note that when we suggested a monthly meeting between parents and staff, we were advised this would not support the goals. We do not agree and do not understand the reason for this. Given MY CHILD's cognitive and communication challenges, he cannot at this time communicate pertinent information from school to home and home to school i.e. new signs learned and topography of same, dialect, academic content, etc. How are new signs to be communicated home so we may carryover, and reinforce same?

We look forward to your written reply.

Kind regards,

Mom and Dad of MY CHILD

*(Continued on page 6)*

## Tips for IEP meetings:

By Mary Lynn Larson

Over the last several months, I have attended numerous Individual Educational Plan (IEP) meetings; - for other families with children with PWS, for friends who have children needing IEPs and for our own boys. Some of these IEP meetings have been successful and some less than successful... As I have thought about the results, I have come up with some ideas that parents might consider and maybe implement to help to make things flow easier.

First, if the meeting is for your child, review the previous year's IEP document and evaluate (as best you can) your child's progress towards the targeted goals. It is important to walk into the meeting having an idea on where your child is, as well as, how they are working towards goals. Remember, just because a child may not have met the goals does not mean the child—or their staff have failed, a number of factors may have influenced their progress that you, or they may have no control over. Ask yourself, can we eliminate some of these factors?; are we expecting too much? have health issues come into play that slowed their expected progress? Once you can isolate and potentially eliminate some of these factors, decide if these same areas should be targeted again or if the focus has changed. Depending on the age of your child, it might be appropriate to get input from them on areas that they want to work on. This information would be very appropriate to place in the area under **Parent concerns** or **student's strengths**.

As parents, then you should **JOINTLY** determine three or four areas that you would like to see targeted for improvement. (Again, dependent upon your child's age, he or she might be part of this discussion.) There may actually be more than this, but select the most important areas to be addressed for your child. It is in this area that you must then collaborate with school personnel on developing targeted goals as they know your child's current level of functioning and if your child is developmentally ready to target this area. These would generally include

academic goals, but may also include functional and behavioral goals.

Think about areas within the school environment that may also need assistance, i.e., in standardized testing, school assemblies, school cafeteria, extra-curricular activities, going from one area of the school to another (—will they need someone to walk with them to keep them from eloping or searching for food?) There is an area on the IEP where this would be addressed.

Once you have an idea on areas you want targeted, think about how you, as a parent, might be able to assist the school in getting your child to achieve the targeted goals. In many cases, the school staff do not know the triggers that may make an activity a success or failure for your child. Maybe you can help them by sharing what you have tried. For example, maybe your child **HATES** sticker charts, but loves it when they get time with you to read a special book. Can you suggest that if they achieve a specific task, they get time to read a short story with an aide? Maybe, they need activity right after they return to class after lunch—could that be the time when they are scheduled with PT staff? Or the Special Phy. Ed. teacher? These specifics would not necessarily go into the IEP form, but could be beneficial for the staff working with your child to be aware of.

It takes a lot of effort to establish a good relationship with school staff—but remember they truly do have your child's best interests at heart. I was able to truly see this last week, after a friend came to observe Matthew's IEP re-evaluation. She had been having some difficulty with her son's IEP team and was amazed at how smoothly things were run. She was astounded that we did not even review and revise the targeted goals the team suggested. I reminded her that we have been working with many of the same staff on Matthew's IEP as when Alex was in the same elementary school over the last 13 years! We had a relationship with them and recognized we were all equal member of a team working for what was **BEST** for Matthew. Best of luck.

## Donations and Contributions

**Thank you for the recent generous donations received at PWSA of WI, Inc. from 09/01/2008 through 12/31/2008.**

We try to be accurate in recognizing contributors and apologize for any errors or omissions. If you note an error, please do not hesitate to contact us so we might correct it.

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Prader-Willi Homes of Oconomowoc

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**Honoring Andy Mankowski:** Lillian Peronto

**Honoring Addison Pograd:** John & Betty Pograd



## IT'S TIME TO BE THINKING ABOUT... SUMMER CAMP!!

It is the end of January as I write this—and we are thinking about summer camp! Are you? Summer camp is a great time for both youth and adults with PWS. It allows for your child to develop some great skills, new friends -and allows time for everyone to have a bit of respite! Living with this disability is challenging, as we all know! And having time away so you can refresh yourself and your skills helps everyone!

Knowing what camp to send your child to and what age is best for your child to go to summer camp is a decision that each parent/care provider needs to make. Each year, we have a list of camps that we share with our membership of a variety of camps that families of persons with PWS have attended. Look for it in our next newsletter.... But start thinking if this would be an option for you and your child. Camps fill up quick, so don't delay!!

## PWSA of WI, Inc.'s Event Calendar

|                         |   |                                  |
|-------------------------|---|----------------------------------|
| <b>February 7, 2009</b> | <b>PWSA of WI, Inc.'s Board/<br/>Conference Meeting</b> | <b>Verona, WI</b>                |
| <b>April 18, 2009</b>   | <b>Hobby Day</b>  | <b>Oconomowoc, WI</b>            |
| <b>August 22, 2009</b>  | <b>PWSA of WI, Inc.'s<br/>9th Annual Golf Benefit</b>   | <b>Windwood of<br/>Watertown</b> |

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NEW Web site: [www.pwsaofwi.org](http://www.pwsaofwi.org)

