



THE WISCONSIN CONNECTION

The Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.

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.

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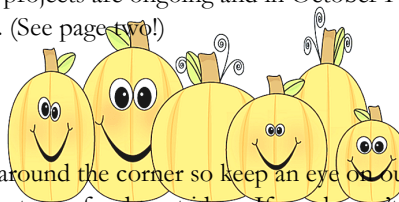
Program Director's Report

By: Joshua Escher



It certainly has been a little bit different summer here in the office! We moved our golf benefit to the end of September this year (fingers crossed for beautiful weather) and set it up at a new location as well. I am looking forward to checking out The Oaks in Cottage Grove. Instead of an August golf benefit we held our first ever Sparkle and Shine Gala. We descended on Red Circle Inn in Nashotah, the same venue we held the Snowflake Ball in this year, and rocked the night away after an incredible meal and some tasty drinks.

The next month will be quite busy around here. The aforementioned golf benefit is fast approaching. I will be attending a conference in Milwaukee to learn more about the IEP process. Many support and advocacy projects are ongoing and in October I will be attending the PWSA (USA) National Convention. (See page two!)



Halloween is right around the corner so keep an eye on our social media for info on the Teal Pumpkin project for great non-food treat ideas. If you haven't already, follow us on Facebook/Twitter/Instagram for the most up to date information.

As always, if you need any kind of support, be it questions, support, education, or advocacy, do not be afraid to reach out! It is what I am here for. PWSA of WI is happy to have me travel to you if needed.



In Loving Memory

Jean Van Tuyle



Many generous donations were made to PWSA of WI in her memory. She will be dearly missed.

Labor Dept rules IEP meetings a valid reason for family and medical leave

By Linda Jacobson

Article appeared on educationdive.com

Dive Brief:

- The U.S. Department of Labor (DOL) has issued an opinion letter stating parents and guardians are allowed to use the Family and Medical Leave Act (FMLA) intermittently to attend Individual Education Program (IEP) meetings with teachers, school administrators and others involved in planning education services for children with special needs.
- The letter was in response to a family's complaint that the mother's employer allowed her to use FLMA time for her two children's medical appointments, but not for meetings at school. Cheryl M. Stanton, a DOL administrator, wrote that a child's doctor does not have to be present at an IEP meeting for the parent to qualify for FMLA leave.
- IEP meetings, Stanton wrote, "help participants make medical decisions concerning your children's medically prescribed speech, physical and occupational therapy; to discuss your children's well-being and progress with the providers of such services, and to ensure that your children's school environment is suitable to their medical, social and academic needs."

Dive Insight:

The opinion gives educators a tool for helping families participate in the IEP process, which can be daunting and is often a source of frustration for parents.

A 2017 study suggested that parents "often feel like outsiders" during the process. And worrying about being penalized for missing work is only likely to make the meetings less productive. The authors recommended sending questionnaires to parents, teachers, other service providers and the student's peers to gain a more complete picture of the child's strengths and needs prior to the meeting.

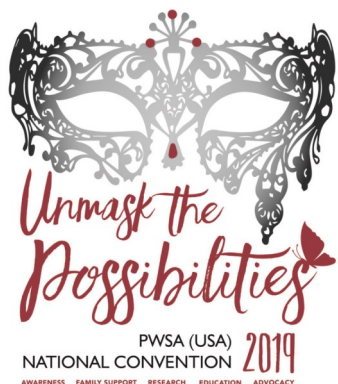
Principals are responsible for ensuring that IEPs are implemented, but with many schools facing shortages of special education teachers, ensuring each step is followed according to law can take up more of a principal's already-busy schedule.

In a Q&A for the Council for Exceptional Children, David Bateman, a professor of educational leadership and special education at Shippensburg University in Pennsylvania, summarizes the principal's role in the IEP process. He recommends ensuring special and general education teachers have time to collaborate and that principals fully participate in IEP meetings.

In an article last year, Jennifer Butterfoss, an administrator with the San Francisco Unified School District, suggested other ways principals can improve the IEP process, such as meeting with the student in class a few days before the meeting, setting a clear agenda for the meeting, and debriefing afterward with other educators on the IEP team.

"Rarely will you get the chances to sit down with busy teachers," she wrote. "An IEP meeting is an opportunity to engage staff members in conversation around instruction."

You can follow Linda Jacobson on Twitter [@lrj417](https://twitter.com/lrj417)



Are you unable to attend the PWSA (USA) Convention this year in Florida? Wish you could get some of the information? Let us know what types of information you would like our program director to bring back with him! Josh will be attending the convention and often has to decide between different speakers based on what info he thinks will be most useful to the folks here in Wisconsin. Your input can help with that. Contact us via email progdir@pwsaofwi.org or phone 920-733-3077 and let us know what you want to know! Future newsletters will feature new information learned.

10 Questions Every Parent Should Ask at an IEP Meeting

By Carly Anderson

TheMighty.com (a great resource for special needs parents!)

In my career as an elementary school teacher and intervention coordinator, I've sat in hundreds of individualized education program (IEP) meetings. They're a regular part of my weekly schedule.

This is probably a weird thing to say, but I actually really like them. Why? They're an opportunity. It's a chance for families and support staff to sit down and communicate, a chance to hash out plans for children who need support and a chance to create a positive learning environment for every child.

An IEP meeting is a chance for school personnel and parents to communicate. The one thing I say to every parent before an IEP meeting? Be prepared. Do your homework. An IEP meeting can be an amazingly positive experience if everyone is able to communicate clearly.

Here are several things to do before an IEP meeting:

- Observe in your child's current classroom setting.
- Reread their expiring IEP if they already have one. Do you feel their academic and behavioral goals have been met? Be prepared to share your thoughts.
- Make a list of concerns and a list of accomplishments. What is going well? What is still a challenge?
- Research the academic standards for your child's grade level. Consider where they currently fall in terms of those standards. They may need support still, and that's totally fine. But the more you've thought about these long-term goals, the more prepared you'll be to speak to them and to listen to the team.
- Be prepared to ask questions (a lot of them).

Once you're at the IEP meeting, here are 10 questions you should ask:

1. How can I contact you?

Ask each member of the IEP team (classroom teacher, resource teacher, speech therapist, occupational therapist, etc.) the best way to contact them. Let them know you'll be checking in regularly. Set progress reporting meetings.

2. When is a good time to have an informal conversation about my child's progress?

A couple years back, I had a parent ask if they could come in the mornings before they started their work day. This mother wanted to be able to get weekly feedback about her child's progress. So she came in one morning a week and helped me pass out papers before the children started their day. She sharpened pencils with me, and we got a protected time to chat. It was an amazing experience. I was more than happy to talk to her, and her assistance while we chatted was a wonderful way for her to give back to our classroom.

3. What do you see as my child's strengths? How can I support and encourage them?

An IEP meeting shouldn't be all about weaknesses or discrepancies. Ask how you can support your child's strengths and passions. Those things are what will make your kiddo successful as an adult.

4. What type of progress can I expect to see? What will this look like?

The great thing about an IEP meeting is that you get the input of specialists. But it can also be tough at times. There are acronyms, teacher speak, developmental milestones — it can be very overwhelming. After each IEP section, ask the team: What should this look like? How long will it be before I see progress? What are the signs that we are moving in the right directions? What should I watch out for?

5. What can I do at home to support our goals?

For students to make the most progress (emotionally or academically), goals need to be fluid between school and home. Ask the team: What can I do at home? Ask for specific suggestions. If it doesn't make sense, ask for more information.

6. Which of these goals are the top priority?

By the end of an IEP meeting — between behavioral goals and academic goals — you might feel like your head is spinning. Important things to ask: Which goal is top priority? Is it behavioral (transitioning to school, for instance)? Is it academic (phonemic awareness, etc.)? Ask the team. That way, you'll know what to focus on in discussions about school.

Continued on page 4

Continued from page 3

7. How will we measure progress? How will we communicate about this with my child?

Progress towards goals (both academic and behavioral) can be measured in many ways. Will the team be using test scores? A running record with observations of the child? A tally system of behaviors being exhibited (or not exhibited)?

8. What do these supports look like on a daily basis? How will my child's day look?

Academic and behavior supports can be provided in many ways. Will the supports be a pull-out model (student removed from the class for small-group support) or a push-in model (the support staff blends into the classroom for a period of time)? I've often sat in meetings where parents were unaware their child was being taken to a separate classroom for academic support and seemed surprised. You should know exactly what your child's day looks like!

9. Who will provide these supports? How will my child's classroom teacher be provided with resources and assistance to implement these supports?

The best thing about having a support team in place? Everyone helps each other (that includes you, mom and dad!) Ask questions. How can you support the teacher? How can the speech therapist support you?

10. What would you do if this were your child?

An IEP meeting can often be all business. In the end, what would I want to know? If this were your own family member, what would you suggest? Trust me, you'll get some pretty honest answers.

A version of this post originally appeared on Lipglossandcrayons.com

We had an amazing time at our first annual Sparkle and Shine Gala! 53 people dined and danced with us to help raise money for our organization. We hope you will join us next year!



A huge thanks to our Ruby Sponsor!



www.zephyrclinicaltrial.com

S.2158: A bill to improve certain programs of the Department of Health and Human Services with respect to heritable disorders

What is S.2158?

This is the Senate companion bill to H.R. 2507: Newborn Screening Saves Lives Reauthorization Act of 2019; it was introduced to the Senate on July 18, 2019. It will continue critical federal programs that provide assistance to states to improve and expand their newborn screening programs, support parent and provider education, and ensure laboratory quality and surveillance for newborn screening. The bill includes reforms to ensure that the activities of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) are transparent, including requiring the creation of a publicly accessible website that details the uniform screening panel nomination process. The bill also requires the CDC to standardize data collection and reporting to track and monitor newborn screening in real time. Additionally, the bill orders a study on the modernization of newborn screening.

Why is this issue important to the PWS community?

While introduction in the Senate is a crucial milestone, the language in the Senate bill is more of a clear reauthorization, not inclusive of increased funding level in the House bill. PWS advocates should encourage their Senators to support the House bill's funding levels. The FY 2019 Budget for HHS included \$110 million to support birth defects and developmental disabilities, which was \$27 million below the FY 2018 Continuing Resolution. In order to ensure the HHS continues to enhance and protect the health and wellbeing of the PWS community in 2020, we need to advocate for sound, sustained advances in the sciences underlying medicine, public health, and social services.

dollars in millions	2018	2019	2020	difference from 2019 to 2020
Maternal and Child Health				
Maternal and Child Health Block Grant	650	678	661	-17
Autism and Other Developmental Disorders	49	51	0	-51
Heritable Disorders	16	16	0	-16
Universal Newborn Hearing Screening	18	18	0	-18
Disability Programs, Research and Services				
State Councils on Developmental Disabilities	76	76	56	-20
Developmental Disabilities Protection and Advocacy	41	41	39	-2
University Centers for Excellence in Developmental Disabilities	41	41	33	-8
Independent Living	113	116	109	-8

Source: HHS FY 2020 Budget in Brief

Contact your senator and ask them to support this bill. Tell them your story!

PRADER-WILLI SYNDROME ASSOCIATION OF WI, INC.



COME JOIN US!

- 4-PERSON SCRAMBLE
- GOODY BAGS
- PRIZES AND CONTESTS
- 18 HOLES
- LUNCH AND REFRESHMENTS
- FUN!!!

**PWSA OF WI, INC.
19TH ANNUAL GOLF BENEFIT**

SUNDAY, SEPTEMBER 29TH, 2019
THE OAKS GOLF COURSE • COTTAGE GROVE, WI

To register, head over to our website PWSAofWI.org.

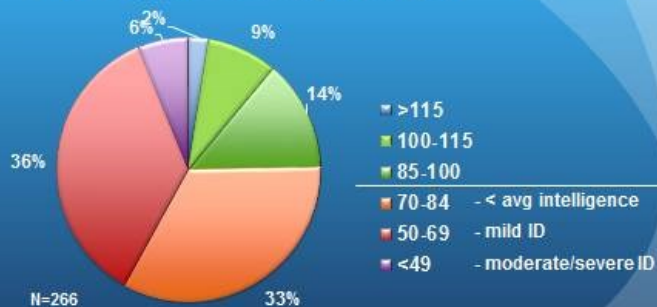


PWSA of WI
Annual Golf Benefit
SUPPORT • EDUCATE • ADVOCATE

QUESTIONS? CALL JOSHUA ESCHER (920) 733-3077

IQ of Participants

- 75% of participants who have had IQ testing score below 85
- Did not differentiate among IQ test types



Did you know?

Prader-Willi syndrome is a spectrum disorder. As such, the range of IQ's documented is very wide! (infographic taken from the PWS Global Registry) This can be important to understand when looking at qualifying for special education services. Often students must have a score that falls two standard deviations below the mean (IQ 70 or less) as part of the qualification criteria. Here in Wisconsin though, PWS is a recognized disorder that allows us to circumvent that requirement.



Southwestern Vegetable Chowder

Makes 6 servings

Ingredients:

- | | |
|---------------------------------------|--|
| 3 tablespoons extra-virgin olive oil | 1 cup diced onion |
| 1 cup diced celery | 1/2 cup all-purpose flour |
| 1 tablespoon chili powder | 1 1/2 teaspoons ground cumin |
| 1 teaspoon dried oregano | 1/4 teaspoon salt |
| 4 cups reduced-sodium vegetable broth | 1 cup whole milk |
| 2 cups diced sweet potato | 2 medium poblanos or red/green bell peppers, diced |
| 2 (15 ounce) cans black beans, rinsed | |
- Cilantro for garnish toasted pepitas for garnish lime wedges for garnish

Preparation:

1. Heat oil in a large pot over medium heat. Add onion and celery; cook, stirring frequently, until softened and beginning to brown, 3 to 6 minutes. Sprinkle flour, chili powder, cumin, oregano and salt over the vegetables and cook, stirring, for 1 minute more. Add vegetable broth and milk; bring to a gentle boil, stirring constantly.
2. Stir in sweet potatoes and peppers and bring just to a simmer. Simmer, uncovered, stirring occasionally, until the vegetables are tender, 12 to 15 minutes.
3. Add black beans and cook, stirring frequently, until heated through, 2 to 4 minutes. Serve topped with cilantro and pepitas, and garnished with lime wedges, if desired.

To make ahead: Cover and refrigerate for up to 3 days, slowly reheat over medium-low or microwave on Medium power.

Serving size: 1 1/2 cups

Per serving: 307 calories; 10 g fat(2 g sat); 10 g fiber; 43 g carbohydrates; 11 g protein; 60 mcg folate; 4 mg cholesterol; 7 g sugars; 7,609 IU vitamin A; 35 mg vitamin C; 154 mg calcium; 3 mg iron; 310 mg sodium; 704 mg potassium

Nutrition Bonus: Vitamin A (152% daily value), Vitamin C (58% dv)

Carbohydrate Servings: 3

Exchanges: 2 starch, 1 1/2 fat, 1 lean protein, 1 vegetable

This recipe taken from eatingwell.com this website is a great resource for healthy recipes!

STRIKE OUT PWS

A FUNDRAISER TO BENEFIT THE PRADER-WILLI SYNDROME ASSOCIATION OF WI, INC.

LET'S BOWL!

OCTOBER 12, 2019

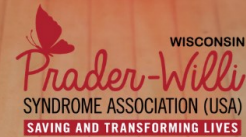
Bowlero Lanes

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CHECK-IN 1:00-1:30 PM

BOWLING 1:30-3:30 PM

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PWSA of WI, Inc.'s Event Calendar		
The Oaks Golf Course, Cottage Grove, WI	19th Annual PWSA of WI Golf Benefit	September 29th, 2019
Bowlero, Wauwatosa, WI	Strike Out PWS Bowling event	October 12th, 2018
Red Circle Inn and Bistro, Nashotah, WI	PWSA of WI, Inc. Snowflake Ball	February 1st, 2020