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Twitter: www.twitter.com/PWSAofWI

Instagram: www.instagram.com/PWSAofWI

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

Website: www.pwsausa.org

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.

Letter from the President

Welcome to the latest edition of the Wisconsin Connection newsletter!

Throughout the past few months, board members and volunteers have been very busy providing education about Prader-Willi Syndrome, raising funds for PWSA-WI, Inc. and providing advocacy for members of the Prader-Willi Syndrome community. In September, the Dorn family traveled to Chicago to provide information about PWS to first year medical students. In addition, one of our board members provided IEP support to a family whose child was struggling in the school system. In October, we hosted the Knight Of Chance casino fundraising event where people had fun while raising money for the Association. Attendees also learned about PWS as they read the various fact cards displayed in the centerpieces and around the room. PWSA-WI, Inc. was also the recipient of a special benefit at the feature length documentary preview of "The Life You're Given". In addition, we hosted our Annual Ball, where participants were treated to an evening of elegance and dancing. To learn more about these activities, check out the various articles through the newsletter.

I am excited to announce we have three new faces joining the PWSA-WI, Inc Board of Directors as of January 1, 2024. To learn more about Tessie Hurd, Kristen Rathkamp and Jessica Sheldon, make sure to check out

the "Welcome to the Board" section in this edition of the newsletter. In addition to these new board members, the following board members have been re-elected for another term: Crystal Boser, Sarah Glass, Melanie Laur, Jamie Milaeger, Bobbi Pogrnt, Brandon Schmidt, Katelyn Schmidt and Melissa Sirovina. Thank you to everyone who voted in this years election. We are all very excited about this upcoming year!

To stay up to date on all of our upcoming activities and events, please visit our website at www.pwsaofwi.org or follow us on our PWSA-WI, Inc. Facebook page.

If you have any questions or need assistance from PWSA-WI, Inc., please feel free to reach out to me via email, phone, text or FaceBook messenger.

Sincerely,

Crystal L. Boser

Crystal L Boser
President

Knight of Chance for Prader-Willi Syndrome

On Saturday, October 7th, close to 85 family members and friends of the Prader-Willi community gathered at the Cornerstone Sports Pub & Eatery to raise awareness about PWS and funds for the Prader-Willi Syndrome Association of Wisconsin, Inc. When the doors opened, attendees enjoyed drinks and a buffet of hors d'oeuvres that included filet sliders, wings, corn crusted scallops, meatballs, pizza, a taco bar and fruit kabobs while reading PWS facts, engaging in conversation, and fellowship. Several attendees also participated in a wine/spirit pull.



At 7pm, the gambling began! Attendees purchased funny money that was used at the Blackjack, Roulette, Craps, and Texas Hold'Em tables. Winners at each table were given tickets that could be used to bid on raffle items, such as tickets to a Milwaukee Admirals game, Cave of the Mounds and Mt Olympus; and gift baskets from Bronzer Image Tanning, Vino Etc. and Bubble and Bourbon, to name a few. According to one guest, "this was the perfect establishment, the food was great and I'm already excited for next year's event."

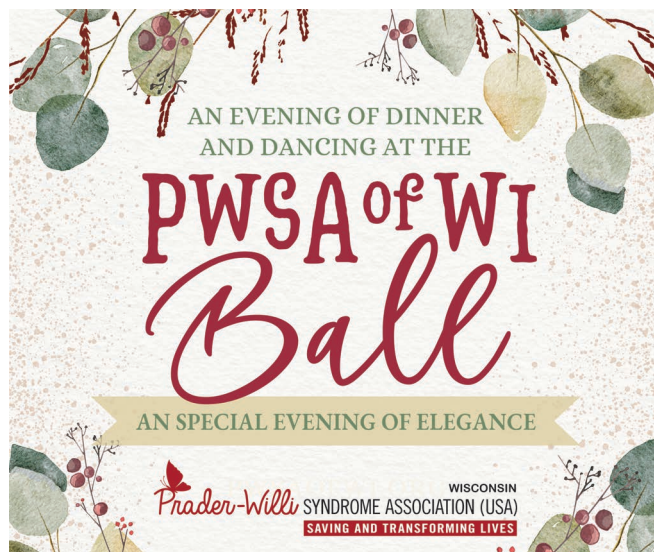
Thank you to **Cornerstone Sports Pub & Eatery** and **Vegas on Wheels** for helping us host an evening full of fun and laughs. Also, thank you to our table sponsors: **Wifinlander Guide Services, David & Sandy Nagy, Michael Munn, Larry & Patty Glass, Pantheon, Kelly Hoesly, Heather George, Jennifer Menz, and Dick & Robin Milaeger.** We'd also like to thank everyone who attended, bid on a silent auction items, participated in the wine/spirits pull or made a donation. We couldn't have raised over \$5,000 without all of you!



PWSA of WI Annual Ball

On Saturday, November 4th, over 130 members of the Prader-Willi community came together at the Ingleside Hotel for fun and comradery. Similar to years past, this event provided individuals with Prader-Willi Syndrome the opportunity to participate in a prom-like experience. The night started with a special "champagne" toast then attendees were served a calorie conscious dinner of roasted pepper slaw, chicken meatloaf served over red quinoa with roasted zucchini, yellow squash, and butternut squash followed by a delicious apple crisp dessert. At the conclusion of dinner, participants showed off their dance moves to the Cupid Shuffle, Cha Cha Slide, and Wobble, to name a few. It was another evening of fun and laughter! Thank you to everyone who attended, we look forward to seeing you again next year!

We would like to extend a very special thank you to the **Stackner Foundation** for providing a \$5,000 grant towards this event!



Holiday Tips on Food Security

by Barb Dorn, RN, BSN

It's that time of year again. A time when food seems to be everywhere and it's the focus of so many social gatherings. We can never underestimate the importance of maintain vigilance during these times. It's not only important to monitor calories, it's also important to monitor the quantity of food consumed. **OVEREATING and BINGE EATING** can result in over-extension of the stomach. This can either put pressure on nearby vital organs, interfering with how they work or rupture of the stomach causing acidic contents to spill in to the abdominal cavity. This can be life-threatening. **CHOKING** is another health emergency that frequently occurs with individuals with PWS. They may steal food and eat it very fast to avoid being caught. Be sure you know how to do the Heimlich maneuver.

Prevention:

- Assign one person to supervise at gatherings. **Don't assume** someone is watching – **make sure** someone is.
- Have low calorie snack alternatives.
- Space out the timing for snacks. Make a plan. Provide the plan in writing. Set a timer.
- **Encourage the person with PWS to tell if they overeat.** They must not be punished (or why would they tell).
- Use strategies to help the person with PWS slow down eating. Have them put their eating utensil down between bites; limit quantities of food served. Make them take sips of water between bites. ("Pace & Chase")
- Make sure you know how to do the Heimlich maneuver. You may be saving a life.

Symptoms of a Possible "Gastric" Medical Emergency:

If you see any of the following **symptoms**, the person with PWS should be evaluated by health care professional immediately.

- Their stomach becomes bloated or distended. (This can be hard to detect especially if they are overweight)
- They vomit. (This is rare but if it occurs it could indicate a serious health situation)
- They may complain of "not feeling well" or have stomach pain. (Pain is not always present)

What you should do:

- **Take the child/adult with PWS to see a health care professional immediately.**
- Bring along a medical alert booklet or GI chart. If you don't have one, download a copy from the PWSA | USA website. www.pwsausa.org (Click on Resources / Resource Hub / Booklets / MEDICAL ALERTS booklet)
- If you encounter a health care professional who's not knowledgeable and you need advocacy help, contact PWSA (USA) at 1-941-312-0400. Help is available 24/7.
- Don't be afraid to educate and advocate for evaluation and monitoring to rule out a gastroparesis or a ruptured stomach.

Most important, remember to keep food locked and/or supervised. We know the holidays offer more challenges in this area. We all want everyone to have a happy, healthy holiday season.



Holiday Safety Links

Thanksgiving Safety Ideas:

https://www.pwsausa.org/celebrate-thanksgiving-safety/?bbeml=tp-psi9xB5y0KqhGk8MXKG2Q.j4a_r4z8Nj0Gt8eqW9K4MiA.rQDBP-3CR3XkOI0dLGwYvMBA.li7Rh_nH1qk-rd93EhQH8sQ

Tips and Techniques for a Safe Holiday Season:

https://www.pwsausa.org/tips-and-techniques-for-a-safe-holiday-season/?bbeml=tp-psi9xB5y0KqhGk8MXKG2Q.j4a_r4z8Nj0Gt8eqW9K4MiA.rQDBP3CR3XkOI0dLGwYvMBA.I9HzZAzaLJUmqQXYFptY-Q

The Life You're Given

A Special Preview Benefit for PWSA of WI, Inc.



"The Life You're Given" is a feature length documentary about a family's experience raising a daughter born with Prader-Willi syndrome, a rare genetic disorder, from her birth thirty five years ago to the present. It presents an unusually intimate, honest look at their individual and collective joys and struggles, with hope ever present.

On Tuesday, September 12, a special preview benefit for PWSA of WI was held at the Town Cinema in Watertown, WI. The preview event raised over \$300. Thank you to the Henock-Coggeshal family for their kind support!

Those who attended were touched by the amazing story that the Henock-Coggeshal family shared with everyone through this touching documentary. Jackie Mallow, one of many who attended, summed up the experience on her Facebook page: "On September 12th I had the amazing opportunity to see the documentary film premiere of "The Life You're Given". Not only did it touch my heart but so grateful to the Henock-Coggeshal family for allowing us to view the love, laughter, pain and journey of a family over coming the challenges presented by Prader-Willi Syndrome. Also beyond blessed to call them my friends. A must see for families and friends struggling with the complexities of living with PWS and the ability to share your experiences with others."



There will be another screening of the documentary, with a date to be determined. Watch the PWSA of WI Facebook page for more info to come.

Research Updates and Resources

by Barb Dorn, RN, BSN

On October 5-6, 2023 researchers from around the world met at the Foundation for Prader-Willi Research (FPWR) Annual conference which was held in Denver, Colorado. The latest research findings and studies were reviewed, discussed, and shared with those in attendance. The following is a chart that highlights the current clinical trials that are recruiting volunteers - now and in the near future. For more information about these trials go the FPWR website at Home Page - Foundation for Prader-Willi Research (fpwr.org)

PWS CLINICAL TRIAL OVERVIEW

TNX-2900	ARD-101	NNZ-2951 (PWS-001)	RGH-706	PITOLISANT	CARBETOCIN	VAGUS NERVE STIMULATION	LIGHT THERAPY
PHASE 2	PHASE 2	PHASE 2	PHASE 2	PHASE 3	PHASE 3	PHASE 4	PHASE 4
HYPERPHAGIA	HYPERPHAGIA	PWS BEHAVIORS	HYPERPHAGIA	DAYTIME SLEEPINESS	HYPERPHAGIA	BEHAVIOR OUTBURSTS	DAYTIME SLEEPINESS
TBD	AGES 17 - 65	AGES 8-12 4, 7	AGES 17+	AGES 6+	AGES 5 - 30	AGES 10 - 40	AGES 6-18
coming soon	enrolling now	enrolling now	enrolling now	coming soon	coming soon	coming soon	coming soon

YOU make all the difference

It's that time of year for the PWSA of WI, Inc.'s annual "Caring is Sharing" fundraiser.

Your gift, your generosity helps PWSA of WI, Inc. provide support, education and social opportunities to children and adults with PWS, as well as all who support them. We need you to make the difference. No amount is too small.

MAKE A GIFT:

By Mail:
PWSA of WI, Inc.
PO Box 226, Oconomowoc, WI 53066

Online:
pwsaofwi.org/WaysToGive



YOU MAKE ALL THE DIFFERENCE
CARING IS SHARING



HAPPY BIRTHDAY TO YOU!

SEPTEMBER

- | | |
|------------|------------|
| Tommy N. | Katelyn S. |
| Ian D. | Lisa T. |
| Nathan B. | Brian H. |
| Jamil M. | Jackson D. |
| Natalie B. | Beth H. |

OCTOBER

- | | |
|------------|--------------|
| Mason H. | Chelsea C. |
| Tim S. | Teresa B. |
| Wayne B. | Eli H. |
| Richard D. | Alexander L. |
| Nick L. | Lisa G. |
| Kayla S. | Sameea S. |
| Lucy W. | David C. |
| Brandon W. | |

NOVEMBER

- | | |
|------------|------------|
| Bella A. | Mykenna P. |
| Julie H. | Sarah C. |
| Jon C. | Dallas H. |
| Kai H. | Kate K. |
| Tiffany M. | |



If you're interested in having birthday and seasonal cards sent to your loved one with PWS or

have a change of address, please contact Bobbi Pogrnt at Pogrnt1@msn.com with the name, address, and birth date of the individual with PWS.

Spotlight on Success

Sienna S.



When Siena was diagnosed with Prader-Willi Syndrome, we were told there were many tasks that she would probably not be able to do during her lifetime. One of those things was being able to ride a two-wheeled bike. That was disappointing because our active family loves family bike rides. We were able to accommodate her through the years using a bike trailer, and later, a tag-along bike, but she eventually outgrew both. Then I heard about the "iCan Bike" program.

Siena was nervous to enroll in the program knowing that her balance was hard to control, but she was determined to try it. Each day during the five-day program, she challenged herself to do all of the activities asked of her—and she did it—she learned to ride a bike without training wheels! After camp was completed, she insisted we continue with a 20-minute practice each day at home (recommended by camp instructors). Even on the hottest August summer days, she enthusiastically made it a daily priority. One month later, our family is once again going on family bike rides! Siena's goal is to take a family bike ride to Culvers and back (about 8 miles round trip). The program, instructors, and volunteers were amazing—so patient and encouraging—and their methods of teaching bike riding really work.

Do you want to share a success story of an individual with PWS to be featured in future Wisconsin Connection newsletters? Please email your story and photo to Barb Dorn at bdorn84@gmail.com.

SUBMIT
YOUR SUCCESSES!

Advocacy and Training

On Friday September 22, 2023, Don, Barb and Tony Dorn traveled to Rosalind Franklin University of Medicine and Science in North Chicago, Illinois. They shared information about PWS with first year medical students. Tony shared a little bit about himself and Barb and Don focused on teaching them about some of the unique health issues often seen in PWS as well as their parenting journey. Their hope is that this personal experience will leave a memorable imprint in their minds as they begin their medical training journey.



Barb, Don and Tony Dorn along with Dr. David Mueller from Rosalind Franklin University Medical School.



Welcome to the Board!!

Congratulations to the following who have been elected to continue another term on the PWSA of WI Board of Directors:

Crystal Boser, Sarah Glass, Melanie Laur, Jamie Milaeger, Bobbi Pogrnt, Brandon Schmidt, Katelyn Schmidt, and Melissa Sirovina.

We are so happy to welcome the following new members to the PWSA of WI Board of Directors - Tessie, Kristen, and Jessica:



Tessie Hurd

Tessie is the mom of five beautiful children, three who have special needs (18 year old and almost 9 year old have PWS). Tessie learned about PWSA-WI, Inc. when her almost 9 year old was diagnosed with Prader-Willi Syndrome as an infant. Through the Association, she found a community of people she could relate to and she soon started attending PWSA-WI, Inc. sponsored events and the PWSA|USA National Conference. Tessie also learned about a child with PWS who was looking for a forever home through her connections in the PWS community and ended up adopting her second son with PWS

as a result. After almost 9 years of belonging to the Association, Tessie feels it's time to give back to the organization that was/is her saving grace. She also wants to share her knowledge on raising kids with special needs and PWS along with her knowledge on adopting a child with PWS. benefited by supporters.



Kristen Rathkamp

Kristen has worked with individuals with disabilities in a variety of environments and at different levels for the last 20 years. These environments and roles include group homes, day programs, in home therapist, para in a high school level classroom, respite, job supports and development along with prevocational programs. For the past 4.5 years, Kristen has worked with individuals with PWS. She currently oversees a prevocational program. She has placed and worked with developers who have placed individuals with PWS in the community. Kristen would love to continue to learn, network and advocate for those with PWS as a board member of PWSA-WI, Inc.



Jessica Sheldon

Jessica Sheldon's son, Audric, has Prader-Willi Syndrome. Once learning about his diagnosis, participating and supporting the community is something she feels passionate about.

She would like to continue to support the PWS community. She has participated in fundraising efforts for the PWSA-WI, Inc. walk and bowl-a-thon. It is her hope that she is able to disseminate components of Applied Behavior Analysis to individuals with PWS and their families. She hopes to learn more about PWS to better support other families including her own. She had the honor of presenting on PWS at a national conference in July of 2023. She anticipates continuing to present on PWS at other conferences throughout the state of Wisconsin in the upcoming year(s). She currently works with children with autism spectrum disorder; ages ranging 2 years to 6 years; she provides and supports ABA services for these children and their family(s).

Exercise Tips for Those With Limited Mobility

by Brandon Schmidt; PWSA-WI Board Member & Abilities Midwest Athletic Director

In this article, you will find exercise tips for people with PWS who have limited mobility.

- **Tip #1** is swimming. If you are able, utilize your local YMCA, or local community centers to participate in aerobic classes, or free swimming.
- **Tip #2** is seated chair exercises. While sitting in a chair, you can use small weighted dumbbells to do exercises such as bicep curls, tricep extensions, calf raises, and arm presses. You can also do modified versions of other exercises such as arm raises, seated marching, knee lifts, and shoulder circles.
- **Tip #3** is just walking indoors or outside. If you can find a local high school with a track, the local YMCA or a local community center, you can use their track. By utilizing a track, you can set a goal of how far or how many laps you'd want someone to accomplish. For example, I have had residents with limited mobility who thought they couldn't complete laps on the track. By setting goals and using positive motivation, they have a better chance at completing their walks. Start with a small number of laps, and once they can complete this number within a good time limit, then go up by 1 lap.

People with PWS love encouragement, and praise when they accomplish things, such as workouts, so incorporating that into workouts is important.

If you have any questions, feel free to reach out to me via email at Brandon@abilitiesmidwest.com, or my cell phone number at 715-222-8899. Have a great and safe winter everyone!

SAVE THE DATES:



05/11/24

PWSA of WI – A Walk in the Park

Come help us spread awareness and raise funds for Prader-Willi Syndrome, spend some time with family and friends, enjoy lunch and dancing!

Location To Be Determined



07/20/24

PWSA of WI Family Fun Day – Henry Vilas Zoo

A fun casual meetup for families. A stroll through the zoo is followed by a picnic lunch in the park.

Henry Vilas Zoo • Madison, WI



PWSA of WI Golf Benefit

Golfers of all abilities gather together for a round of golf followed by a luncheon, door prizes and a silent auction.

Date and Location To Be Determined



Tentative Date: 11/9/24

PWSA of WI Annual Ball

An evening of elegance for individuals with Prader-Willi syndrome and their families and friends. It is a fun and safe evening with dinner and dancing that many look forward to all year.

Venue to Be Determined

WATCH OUR FACEBOOK PAGE FOR MORE INFO TO COME!

“Don’t Fall For Me” – Preventing Falls

by Barb Dorn, RN, BSN

Preventing falls for people of all ages who have PWS is an ongoing challenge. Many children and adults may have issues with balance, poor muscle tone, depth perception as well as other mobility risk factors. The following is a handout that was developed to help address this issue. It was originally designed for care providers but the information is applicable to all.

People fall. When a person with PWS falls, a serious injury could happen.

WHY?

- Most people with PWS have low muscle tone, fragile bones/low bone density, poor judgment in moving their body, as well as a lower pain response.
- They do not always feel pain accurately.
- Low bone density (fragile bones) also makes bones break very easily.
- Many are at higher risk for falling and experience problems with walking.
- Some require use of a walker or cane.
- Many don't pick up their feet when they walk which makes it easier for them to trip and fall.

WHAT TO DO:

If/when a person with PWS falls:

- Closely evaluate him/her at time of injury and every 4 hours for (at least) 24 hours. Watch for swelling, pain (of any kind), and an inability to use the affected area.
- Contact your supervisor or seek medical care **IMMEDIATELY** if:
 - Person complains of moderate to severe pain or if the area looks deformed (“it just doesn't look right”).
 - Person is not using or moving their hand/arm/foot/knee or legin a normal way.
- Contact your supervisor or seek medical care **LATER** if:
 - Complaints of pain or discomfort **persist**.
- Because persons may not be able to accurately share how severe their pain is – strongly advocate for an x-ray. (No one can see a crack in bone without one!).
- Report all falls (**no matter how minor**) to your supervisor.

A FEW TIPS TO PREVENT FALLING:

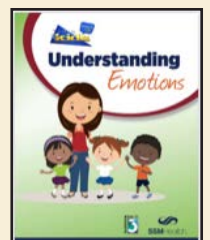
- Help and encourage person to remove “things” from floors to prevent tripping.
- Turn on lights or use a nightlight when it is dark.
- Make sure shoes fit properly.
- Keep eyeglasses clean.
- If he/she wears bi-focal eyeglasses, it may be safer to remove them when going down stairs.
- Keep sidewalks clear of leaves, ice and/or snow. Encourage slow, careful walking on these surfaces.
- Report complaints of dizziness to the nurse.
- Encourage to use a handrail. Install guardrails in shower or tub area if needed.
- Assist residents with carrying laundry baskets to a lower level. They can easily lose their balance.

People with PWS can be injured and have painful conditions that don't hurt them very much (and sometimes not at all.)

Understanding Emotions

It can be challenging to help little ones with PWS to express and understand their feelings of anxiety and stress. This resource is one way to help teach and/or reinforce these important strategies and the good news is – it is FREE. Click on the link to download.

time-for-kids-activity-book.pdf (ssmhealth.com)



Menu Planning Made Easier

As we learn how to plan for a healthy, low-calorie menu for the persons with PWS figuring out to create a menu plan can be challenging. This is can be challenging for everyone who provides support to these individuals but it can be extra challenging for those who have limited experience in this area. A parent of a young women who is being served by a care provider who faced this challenge located this resource. It is an "artificial intelligence" tool that can help you plan out a menu. It's free. I tried it out. I put in the following "create a 7-day 1200 calorie menu plan with 3 meals and 3- 100-calorie snacks". Within a few seconds, it created exactly what I had requested. What it didn't do was to suggest specific products however, but it was a great start for those who don't know where to begin. We may not all be comfortable with this sort of technology but it is a great tool.

The website is: [ChatGPT \(openai.com\)](https://chatgpt.com)

Also available form the app store: ChatGPT app



Scholarships and General Assistance Programs

Did you know PWSA of WI offers different types of assistance in order for families of a person with Prader-Willi syndrome to help meet the unique needs of these individuals and their families? It is easy to apply for these programs at pwsaofwi.org/Scholarships

Membership Scholarships

We offer our services to all. We request a membership registration so that we send information only to those who wish to receive our mailings. We ask that you update your contact information with our office once a year so we can get ensure our information gets to you.

Holiday/Birthday Special Assistance Program

PWSA of WI, Inc has created a program to reach out to adults with PWS who are 18 years or older who no longer have family to help them celebrate holiday or birthday events. The "Holiday-Birthday Special Assistance Program" is a program that attempts to make all adults with PWS feel special and be able to continue to have special memories and gifts - no matter what their age.

Workshop or Conference Scholarships

Please see registration form for workshop or conference you would like to attend for more information on how to apply for a scholarship. Every year, PWSA of WI, Inc. sponsors a social and/or workshop for persons with Prader-Willi syndrome as well as families and others who support them. Scholarships are always available for those in need.

Camp Scholarships

Every year, the Board of PWSA of WI, Inc. sets aside funds to assist children and adults with Prader-Willi syndrome so that they can attend summer camp. These camping experiences provide a time of fun and adventure for the camper as well as a time of respite for parents and caregivers.

General Assistance

The Board of Directors allocates funds to assist persons with Prader-Willi syndrome as well as those who support them in areas that help them manage some of the extra costs they may incur because of their disability. In addition, the Board provides funds for families to attend conferences or other workshops, for respite, home modifications or other requests. Unfortunately, because our funding is limited, we are not able to approve all requests our organization receives.

NEW!! "Fact Sheet" Resources

Looking for a quick reference to share with aides, bus drivers, librarians, and/or relatives? Here are some new PWSA - USA "Fact Sheets" that have been recently created to assist with this. These resources target age groups - infants, toddlers, school age and young adults and adults. They are 1 page (front and back) that highlight some of the main features often seen in children and adults with PWS. These resources can also be a great resource when doing any presentations where you are looking for a quick reference so participants can concisely begin to understand the complexities of PWS.

INFANTS:

Fact Sheet INFANTS Final.pdf

TODDLER:

Fact Sheet TODDLER Final.pdf

SCHOOL AGE / YOUNG ADULT:

Fact Sheet SCHOOLAGE & YOUNG ADULT final.pdf

ADULT:

Fact Sheet ADULT final.pdf

"I wish I knew more about...."?

Send an email to **Barb Dorn** at **bdorn84@gmail.com** and let us know what you want us to help you learn about.