

IOWA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

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Winter 2013-14

PWSA of Iowa Seeking Volunteers

What are your talents, expertise or skills sets? PWSA of Iowa would love to tap into them for the greater good of our organization. Or do you want to be a thrill seeker and try something you have never done before?

The Chapter has so many different volunteer opportunities. Whether it be an hour a year, 50 hours, or any amount in between, we will gratefully take your assistance. If you want a more formal position, there are officer and board openings. On the other hand, if you are project-based, the world is your oyster. **Are you creative?** The editors of the newsletter routinely need fresh material. Perhaps you can write an article, share a healthy recipe or fun photo. **Do you like to host parties?** We would love help planning our Chapter socials. **Are you good with money?** How about organizing a fundraiser. **Do you like event planning?** PWSA of Iowa is needing assistance to organize a conference next May in recognition of Prader-Willi Syndrome Awareness month.

We know there are so many great things happening in your community, family, job, school, please share them with us; we love tips, trivia and ideas. Volunteering does not have to be time consuming or overwhelming. It is custom ordered to suit your needs.

If you are interested, please contact Edie Bogaczyk, PWSA of Iowa Co-President at edieiowa@gmail.com.

Thank you in advance...see you in the New Year! Season's Greetings!!

Share this newsletter!

Find it online at PWSAlowa.org/holiday2013

PWSA National Conference Happenings

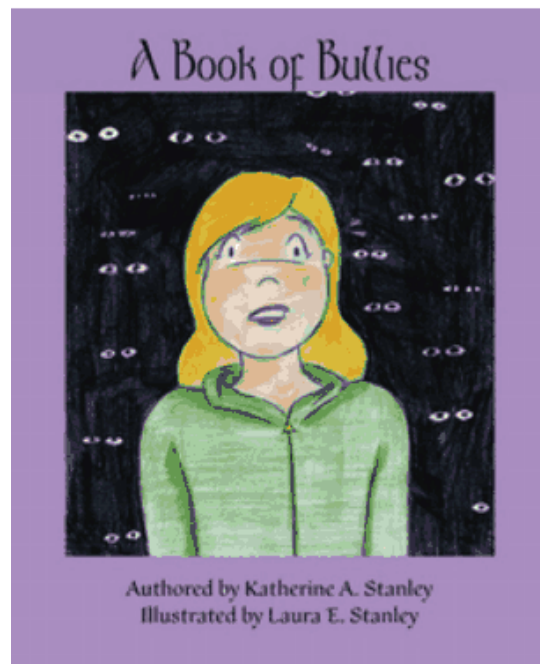
Katherine Stanley - author of "A Book of Bullies"

PWSA of Iowa Chapter Co-President Edie Bogaczyk had the privilege of meeting author extraordinaire Katherine Stanley at her book signing at the National PWS (USA) conference. Katherine recently had her first book published "A Book of Bullies" and these are her words.:

"Unfortunately, I am an expert on bullies. I was ridiculed and bullied for many years in school. It was hurtful and made me feel bad about myself. I decided to use all of those bad experiences and turn them into something good - this book. Bullies will target anyone! I was born with a rare condition called Prader-Willi syndrome, for which there is no cure. Some of the bullying that I experienced was because I am different. But we are all different in some ways. I have seen a lot of other people get bullied too. I am very passionate about the message in my book - STOP BULLYING AND BE KINDER TO EACH OTHER!"

Katherine Stanley is from Black Mountain, North Carolina. She is a senior in high school and lives with her family. She was also featured in the October/November 2013 issue of "Neurology Now."

Contact PWSA (USA) to inquire about purchasing your very own copy of "A Book of Bullies." (800) 926-4797.



PWSA National Conference Happenings

Amazing Timing

On November 6th, Zachary Bogaczyk of Clive, Iowa was present to meet Dr. Rob Nicholls as he crossed the finish line in Orlando, Florida. Dr. Nicholls had just completed his 3000-mile coast-to-coast bike ride to raise funds for and increase awareness of Prader-Willi Syndrome and obesity research.

Dr. Nicholls is a scientist who is internationally known for his genetic studies of birth defects, especially PWS. This is his 27th year of PWS research. He started in 1987 and has been a member of the PWSA (USA) Scientific Advisory Board since 1992. Dr. Nicholls is the Director of Birth Defects Laboratories in the Division of Genetics in the Department of Pediatrics at the Children's Hospital of Pittsburg of UPMC and the University of Pittsburg.

The current research in Dr. Nicholl's laboratory focuses primarily on PWS, with a major goal of understanding the biomedical basis of PWS and developing therapeutic approaches for hyperphagia (extreme unsatisfied drive to consume food) and other major clinical traits related to this syndrome. PWSA of Iowa is so grateful Dr. Rob, it was a pleasure supporting your ride and having the opportunity to thank you in person!!

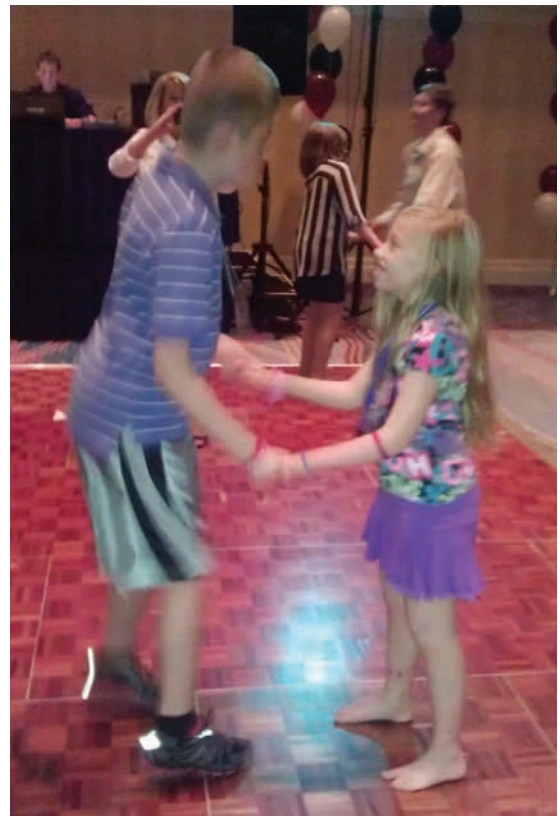


PWSA National Conference Happenings

Zachary at the Conference

To the right is Edie and Zachary Bogaczyk from Clive, Iowa arriving at the PWSA (USA) national conference gala. Zachary may have arrived stag with mom but after showing off his dance moves, he swept a special little lady off her feet!

To encourage participation and fellowship at the national convention, PWSA (USA) organizes age-related tracks for individuals living with PWS. Zachary Bogaczyk was a first-time attendee and had an amazing experience throughout. The schedules and agendas were pre-set so there was no concern regarding what activity was going to take place next. Best of all, he knew exactly what time meals and snacks were served, a priority no doubt for the majority of the participants. Zachary especially enjoyed the gala, a separate event from other conference registrants. He danced until the lights were switched on and the music was turned off. He also met a special friend on the dance floor, Lauren Pfeiffer, from the Indiana Chapter. Since returning home, they have become pen-pals. True friendships can sometimes be more challenging as our children grow older, so happy to see this new one blossoming.



PWSA National Conference Happenings

Reunion Time!

Edie Bogaczyk, Co-President of PWSA of Iowa, was so excited to run into and catch-up with long-time friends and supporters of our State Chapter, Bob & Waunita Lehman of Merritt Island, Florida.



Meeting New Friends

The PWSA (USA) national conference hosted a gala and silent auction fundraiser. Edie Bogaczyk met her new friend/peer/colleague Amy Pfeiffer, President of the PWS Indiana State Chapter. Looking forward to possibly collaborating with Indiana and others in the region on a mid-west event.

Chapter Leaders Day

PWSA (USA) coordinated a day-long Chapter Leaders Day at its recent National Conference. This meeting allowed the chapter delegates to come together to rejuvenate, learn, gather resources and share information. PWSA of Iowa Co-President Edie Bogaczyk was in attendance and is looking forward to networking with her peers around the country to keep our common message and advocacy efforts thriving.



7th Annual Anneke Kramer Softball Tournament

June 22, 2013, we woke to thunder, lightning, and over an inch of rain. The forecast had been for a partially sunny, 80-degree day but they were wrong. As a farmer's daughter, I am rarely sad to see it rain (especially after last summer in NW Iowa), but I was sad that morning. Four sisters, three brothers-in-law, and a few friends stood out on rain-drenched softball fields with their shoes all but covered in mud brainstorming what to do for the 7th Annual Anneke Kramer Softball Tournament and Silent Auction. Some friends had hosted a great golf event, Drive for a Cure, and an "Epic" Bean Bag Tournament on Friday with beautiful June weather, but our event was currently up in the air.

If it rained any more, we would be lucky to start the 8-team round-robin tournament by noon. If the wind came up as well as rain, what would we do with all of the items donated for the silent auction? And, even if it didn't rain anymore or the wind didn't come up, would people come out and support the lunch deals and silent auction? What if they just assumed it was cancelled or postponed due to weather? What do we do? We KEPT CALM and PLAYED ON – that's what we did!

After some prayers, 300 pounds of quick dry (aka kitty litter) and blisterous raking, the fields were not really playable, but thanks to supportive teams and friends, the cause was worth the mud and dreadful playing conditions. The first games were played at 11:45 am and the championship finished by 7:45 pm. The silent auction started by noon and concluded by 5 pm. Family from Denver started a paracord bracelet-making campaign around 1:00 pm and didn't stop until fingers were literally fried. Pork burgers were grilled and ready to be chowed

down by noon. By 8 pm that night, over \$11,000 was raised for PWSA (USA) and Iowa. It was an AWESOME day – a little damp to start, but cloudy, cool, and no wind – filled with fun, family, and awareness of our little girl and PWS.



Foundation for Prader-Willi Research Conference November 2012

Stacy Kramer

I believe it's safe to say that there isn't a day that goes by without a thought, or better yet hate, of PWS. I can't believe it's been 7 years already, and while I love my daughter with all of my heart, I hate PWS. If I didn't hate it, I would feel that I accept it, and I don't; I will never "accept" PWS. I hate that it literally eats away at the quality of life my daughter deserves. I hate that it eats away at the time I feel I don't spend with my sons because of my daughter's needs. I hate that I teach my boys to "lie" about food or "hide" food when they eat something that my daughter can't have or at a time when it's not okay for her to eat. I hate that it eats away at our family gatherings because "alterations" are needed for my daughter. I hate that we are "that family" who has that daughter who looks "normal" but "supposedly" needs so many "exceptions." I hate that I hate PWS even though PWS has made me become a better organized, patient, and tolerant person.

"Still hungry for a cure" are words we are all too familiar with. We are still hungry because there is no cure; not yet anyway. That "not yet" is what keeps me going some days. That "not yet" is what helps me continue to realize that "hating" PWS isn't a solution. While I will always hate PWS and what it does to my children and my family, I do always have hope. I hope for a better future for all three of my kids. I hope for a day when PWS is just

a "complication" that can be managed and have a prognosis of "normal quality of life." I hope that all families who battle PWS can someday have fair treatments regardless of income or location. But what I mostly hope for is peace and fulfillment for my daughter. Regardless of PWS, she is an AMAZING little girl full of smiles and dreams – my hope is that she will live out all of those dreams.

Martin Luther King, Jr. said, "We must accept finite disappointment, but never lose hope." In order to "survive" PWS, I believe these are words to live by. Ryan and I were able to attend the Foundation for Prader-Willi Research conference in Philadelphia last year, and it was FULL of hope. The line-up included:

Melanie Silverman, a registered dietitian and lactation consultant with a business called Feeding Philosophies (www.feedingphilosophies.com), presented information on feeding and nutrition. Her presentation was easy to understand and practical.

Her presentation was easy to understand and practical.

- Janet Agarwal (PT, cNDT, and mother of a child with PWS) presented information on sensory integration. She is a fantastic presenter who "gets" PWS and therefore gives information that's easy to incorporate and is usually "fun."
- Dr. Jennifer Miller, MD (pediatric endocrinology at the University of Florida), presented on Growth

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hormone treatment, Provigil, N-acetylcysteine, and new research into hyperphagia treatments. For those of you who may not know or have not met Dr. Miller, she is an amazing person with a heart of gold for our kiddos with PWS.

- Rob Nicholls (Division of Medical Genetics, Pediatrics Children’s Hospital of Pittsburgh of UPMC & Department of Human Genetics, University of Pittsburgh, Pittsburgh, PA) presented on the vital role cell and animal models in studying PWS. An accurate animal model is necessary in order to understand complex human syndromes and to develop therapeutic approaches that can translate to humans. Currently, many disorders are researched with a pig because the pig fulfills key criteria such as similarities in: physiology, anatomy, body size, genome, and genetic technologies making neurobehavioral studies feasible in the pig.
- Teresa Strong, Grants Program Director for FPWR, spoke about the challenges of PWS and the goals

of FPWR along with reasons to be hopeful.

This article is late in coming, but if you have the opportunity to attend a FPWR conference, I highly recommend it as we not only came home with a lot of great information from great presenters, we came home with more hope as well as with new friends who live in the same PWS-world we didn’t choose but a world we all can navigate better together.

Our PWS voices are being heard and recognized, but that doesn’t mean PWS will get easier anytime soon. Nevertheless, we have a great community of parents, providers, researchers, and support with PWSA (USA) and state chapters as well as FPWR. In the words of Albert Einstein, we need to “learn from yesterday, live for today, and hope for tomorrow, but never stop questioning.” As a PWS community, we are hopeful, we are “hungry,” and we will NEVER stop seeking – for funding, for support, for research, for hope, and for a cure.

Dry Mouth

“Dry Mouth” is a common trait amongst individuals living with Prader-Willi syndrome. They can experience less, thick or sticky saliva. Dentists will be quick to say that saliva does more than just moisten your mouth. Saliva helps wash away food particles and neutralizes acids. Losing saliva’s natural protection can significantly increase risk of cavities, bad breath, and mouth infections.

Merely sipping water is not enough, it only wets a dry mouth but the relief does not last. Unlike

natural saliva, water does not contain moisturizers and lubricants a healthy mouth needs. There are products on the market which provide this type of relief and protection. You can discuss with your medical/dental professional what may be most helpful. A brand often used is Biotene which is sold over-the-counter in most pharmacies. This company carries gels, mouth sprays, tooth paste and an oral rinse. There is also a Biotene Dry Mouth Gum to assist in the stimulation of saliva’s natural protection.

Holiday Survival Tips

By Beverly Ekaitis, DTR

The Children's Institute Prader-Willi Syndrome Program, Pittsburgh, Pa.

Slide into a new year with control of your weight. Don't let the "party like it's 1999" syndrome get you off track. Celebrate with friends and family, by keep the emphasis off food. Here are some ideas to help keep the New Year healthy and happy.

- Plan activities such as caroling, tree trimming, skating and ornament making. Serve sugar-free hot chocolate and low-calorie veggie snacks.
- Exercise before and after dinner or holiday party.
- Have a gift-wrapping party, and then play cards for fun.
- Volunteer to help prepare and send holiday cards.
- Do a holiday jigsaw puzzle with family.
- Learn to knit or crochet presents for your family.
- When attending a party, take a tray of vegetables and fat-free dip for the buffet.
- Bring fresh out-of-season fruit (a ripe pineapple, perhaps) to gatherings – a welcome contribution and something to eat besides heavy holiday fare.
- At parties, converse with friends away from the food table or coffee table.
- Have a family member fill your plate with low-calorie hor d'oeuvres. Skip the buttered, breaded, fried or sauce-covered offerings. Choose lean meat or cheese, fruit, shrimp, crudités (raw veggies), or pretzels. Avoid bacon-wrapped items, cocktail hot dogs, eggrolls, nuts, potato chips, corn chips, chocolate candy, and paté.
- Discuss food choices before attending the party. One option is to use your meal pattern for the

dinner meal at party time.

- On party day eat lightly at other meals.
- Allow second servings of vegetables and no-calorie drinks only.
- Try calorie-free soda, sugar-free punch, or ice cold water with lemon or lime before or after meals as a "cocktail."
- Avoid alcohol, as it is an appetite stimulant. Ask for a "Virgin Mary" (spiced-up tomato juice minus the vodka).
- Develop an "allergy" to help say no and prevent overeating. ("No thanks; I'm allergic to chocolate.")
- When finished eating, hold your cup in both hands to keep from picking up your fork.
- For Christmas dinner allow 1-2 tablespoons of all the foods on the table to prevent the feeling of being deprived of a favorite food.
- Choose one favorite food and have a regular serving of this food to count as the special treat for the holiday.
- Chew a piece of sugar-free gum after the meal is over.

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Use the following substitutions as a guideline to reduce calories in holiday baking.

- Reduce the amount of fat in muffin or quick-bread recipes by one-third to one-half.
- Use fat-free sugar-free ice cream or frozen yogurt instead of ice cream.
- Substitute cocoa powder for chocolate in cookies or cake to reduce fat (3 tablespoons unsweetened cocoa powder = 1 ounce unsweetened chocolate.)
- Replace heavy cream with evaporated skim milk.
- Use non-fat yogurt or low-fat cottage cheese with 1 tsp. lemon juice per ½ cup cheese to substitute for sour cream, or use fat-free sour cream.
- Substitute two egg whites for each whole egg.
- Top cake with fresh fruit, fruit sauce, or a sprinkle of powdered sugar instead of frosting.
- Eliminate nuts.
- Get through the holidays "one day and one party" at a time. If you binge, treat it as an error and go right back to your regular meal plan the next day. A little extra exercise won't hurt either.

Holiday Tips for the Hostess

- Keep calories down, flavor up, by experimenting with herbs and spices as seasonings for vegetables. Try cinnamon with carrots or oregano with green beans.
- Use all low-cal products. Fat-free margarine, cream cheese, sour cream, and cooking spray in place of traditional ingredients can decrease calories in some recipes. Use sugar substitute in place of sugar or honey.
- Wrap and freeze baked goods in individual portions so you can defrost just what you need when guests arrive, eliminating leftovers and temptations.
- Give any leftovers to friends at the end of the party.

Positive Behavior Strategies: Tips For Educators of Students with Prader-Willi Syndrome

We can become frustrated when the student with Prader-Willi syndrome (PWS) does not seem to hear what we are saying and does not stop when we ask them to do so. So often, educators, therapists and others who work with these individuals get caught using phrases and instructions which emphasize the negative - "don't statements". When a person with Prader-Willi syndrome is starting to become anxious and frustrated, in most cases he/she is incapable of taking a "don't request" and turning it around to a "do action." With their frustration and anger escalating, we come to a point where we have lost our opportunity to teach and for them to hear what we are saying.

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The most effective way to address negative behavior and to change these into more socially appropriate responses is to teach, and ask for the behavior you want to see. Sounds simple right? Well, it can be a challenging change for many of us.

Communication-The Key

Below are some examples of positive ways to communicate behavior requests and/or expectations.

IF the child or adult with PWS is:

- Yelling, whining ... You can say "I need to hear a quiet voice".
- Hitting, pushing, kicking ... You can say, "I need you to keep your hands to yourself. I need quiet hands/feet".
- Misbehaving on the bus ... You can say, "You must sit in your seat with a soft voice while you ride on the bus." (Instead of yelling at him because he is getting up and jumping and yelling on the bus.)
- Be specific in your requests:
- "I need you to put your book into your backpack" (Instead of "Get ready for the bell!")
- "I need you to put your math book away." (Instead of "Get ready for your next class.")
- "I need you to get your jacket and put it on". (Instead of saying, "Get dressed for recess")
- Give choices. it often empowers the person with PWS. It gives them a sense of control and it allows us the ability direct those choices.
- "When you want to ask a question, you can either raise your hand or hold up your question card."
- "You can have a snack- your choices are string cheese or a small container of yogurt".

- "You need to wear a jacket- do you want to have the zipper open or the zipper closed."

Make the student your "special helper". If you want him/her to get ready for the next topic or activity and you need him/her to cooperate you can say, "TJ, will you be my special helper? I need you to help me find the special paper we will need for this activity- I can't seem to find it." No matter the age; most like to please and help.

Teach the child or adult with PWS what they CAN do when they are frustrated or angry. So often, we tell them what "not to do" but we must teach, practice and re-teach strategies that they CAN do to deal with these feelings. The best time to teach these is when the person is calm and can hear what you are saying. Oftentimes, when the person with PWS starts practicing strategies, the strategies themselves become a diversion when it comes time to use them.

Some students may be able to control some emotions using a diversion strategy utilizing an activity that is known to be calming. For some, they can de-escalate by being removed from an area and listening to music, doing a puzzle, or going for a walk. Other students with PWS may feel a need to utilize behaviors that allow them to release some of their pent up emotions. These students may want to go to a "safe area" to tear paper or hit a pillow when they are upset. This strategy can be easily used at school as well as in the home and other environments. Once again, the important part is talking about the plan ahead of time and having the person with PWS "buy" into it and practice it before it is needed.

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If the student with PWS is found with food he should not have, do NOT attempt to physically take it away from him/her. Try to negotiate or trade. “Let’s make a deal. If you give me that cupcake, I will make sure to call your mom and tell her what a great job you did. I will let you have a piece of candy (sugar-free) from my special drawer. (Locked drawer).”

Don’t threaten the student; you will only make him/her angry and make the situation worse. It is NOT a good idea to say things like: “If you don’t give me that cupcake, you won’t be able to have any supper tonight. I am going to call your mother.” Do let the parent know about the incident so appropriate diet and calorie changes can be made. However, do it in a non-threatening way.

An important part of any behavior management plan is to evaluate and correct the cause of frustration and/or anger. If we can problem-solve around the causative issue, we may be able to prevent future escalations from reoccurring. How did they get the food? What can we do to prevent this from happening again?

The student with PWS can make educators use skills they may not have had to use in a long time.

These students can make you more organized; more creative and more positive in order to get cooperation. They can challenge your imagination in mastering behavior management and motivation. Asking the person with PWS to demonstrate the behavior you want to see, as well as providing choices and teaching ways to exhibit anger and frustration are just a few strategies or ideas of how to assist the child or adult with PWS to use behaviors that are more socially appropriate and less dangerous for themselves and those who support them.

Example:

Sara was having trouble in school. When she started to become frustrated, the volume of her voice would increase and she would start to yell.

Her teacher sat down with her and they both decided that when Sarah became frustrated and felt she needed to yell, she and an adult would take a walk outside to an area where she could yell and scream. Sarah and her teacher practiced this several times. Sarah and the teacher would often times start to laugh while practicing this strategy since it seemed “silly” to yell when you really did not need to.

However, one day when the teacher noticed Sarah’s face becoming red and she was clearly demonstrating an escalating moment, the classroom paraprofessional approached her in a positive way. “Come on Sarah, it looks like you need a break. You get to go yell the way you have been practicing.” Sarah became so enthralled with finally getting to use this strategy - she quickly wen with the paraprofessional and had her screaming time. By the time the two had reached an area where it was “ok” to yell, Sarah had clearly become less angry so the yelling session was very short.

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Behavior Plans

Tips On Using Behavior Plans

DO Discuss the plan with the sagest members of the household FIRST. Ask them to offer suggestions or if they foresee problems with implementing the plan. Adjust the plan according to everyone's input.

DO Introduce the plan to your child in upbeat tone and during time when he or she seems most receptive. Older children can contribute ideas to what incentives and what rewards they would like to work for. The PRICE/Cost (in tokens) of the incentive is not up to the child.

DO emphasize the behavior you are seeking, not the one you are trying to avoid. E.g. "You did a very good job playing nicely with your sister. You earned your star!" Not: "You get a star for not hitting your sister"

DO communicate frequently. Give the child frequent verbal and visual reminders of 1) what behavior you are looking for 2) the reward [or goal] 3) what incentives or credits (tokens/points) toward the goal he has already earned

DO give frequent encouragement and praise. If the child is not earning his points, do not scold* but do tell him what he has done wrong and what you prefer for him to do. Remind him of the incentive and encourage him that he can earn it during the next time period.

DO NOT use the loss of incentives as a threat. Use the possibility of earning the incentive as encouragement. Avoid all negative statements. Do

not announce the loss of a star or other incentive at the time of the behavior, never announce it in anger. ONLY mention the loss of an incentive when the child asks or at the end of the period when the incentive could be earned. State matter of factly. "You did not earn a star this morning but let's see if you can get one this afternoon."

DO expect the angry or volatile child to become frustrated when he first loses an incentive. Expect him/her to say, "I don't care about" Ignore this statement. Do not abandon the program. Wait until he or she is calm and speak encouragingly of the next opportunity to earn tokens. You can comfort him/her for the loss but do not give in or change your mind.

DO expect to use this plan or a variation of it for months or years. Do not expect to "fix" a behavior problem and then abandon the program.

DO NOT Abandon the plan if it does not seem to be working well. Adjust the plan based on your recent experience with it or seek help (from other family members or therapist who helped you to design the plan) ASAP to modify the plan.

Remember, however you build the plan, it MUST BE RIGGED to enable the child to succeed!

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Behavior Plans

Behavior Plan for FREQUENT Behavior (more than 1 per day)

DAY Monday Jeffrey gets 15 minutes on the computer or DS!	
Following Rules Day Total 15	morning great job 5 min.
	afternoon 5 min. 😊
	evening 5 more min! ☆
Listening and following directions Day Total 15	morning 5 min. Yaaaay!
	afternoon 5 min. Whoopee!
	evening 5 min TOPS!
(choose a desired behavior) BEING ON TIME Day Total 15	morning 5 min. Good job!
	afternoon 5 min Nice!
	evening 5 min..
TODAY'S GRAND TOTAL 45 BONUS!	

Behavior Plan for FREQUENT Behavior (more than 1 per day)

DAY	
Following rules Day Total _____	morning
	afternoon
	evening
Listening and following directions Day Total _____	morning
	afternoon
	evening
(choose a desired behavior) _____ Day Total _____	morning
	afternoon
	evening
TODAY'S GRAND TOTAL _____ BONUS!	

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Behavior Plans

Guaranteed Time _____ Minutes

Favorite Activity = _____

DAY	SUN	MON	TUES	WED	THUR	FRI	SAT
Following rules 15 minutes Bonus Time!							
Listening and following directions (2) prompts 15 minutes Bonus Time!							
Staying calm/being respectful 15 minutes Bonus Time!							
Daily TOTAL BONUS TIME							

Someone With
 ♥Prader-Willi♥
 makes me proud
 everyday!

Interested in Joining the Prader-Willi Syndrom Association of Iowa?

We'd love to have you!

Fill out this page and 1) mail it to:

Prader-Willi Syndrome Association of Iowa
15130 Holcomb Avenue
Clive, Iowa 50325

OR 2) email it to: edieiowa@gmail.com

OR 3) sign up online at: PWSAlowa.org/contact

Questions? Email us or call us at 515-770-5297

Name: _____
(required)

Mailing Address: (required)

Street

City

State

Zip

Email: _____
(required)

Phone Number: _____
(required)

Tell us about yourself!

(Does some one in your family have Prader-Willi Syndrome? How old are they? Would you like additional information? Etc.)

The Krumm Family Fund for the Advancement of Persons with Prader-Willi Syndrome in Iowa

PURPOSE:

This fund will make grants available to individuals, families and service providers to promote the well-being of persons with Prader-Willi Syndrome who reside in the State of Iowa. The interest generated from this Fund can be used for grants with the principal staying in an interest-generating investment.

ADMINISTRATION:

The current Board of Directors of the Prader-Willi Syndrome Association of Iowa and a Krumm family member will have control over the dissemination of this Fund. The grants and their eligibility requirements can be changed with a majority vote of this Administering Board.

GRANTS:

Application can be made on an annual basis for each of these grants. A limit of \$100 applies per individual, family or service provider to each grant. An individual, family or service provider can receive up to two grants per year.

HOME MODIFICATIONS:

Grants are available for home modifications that are not covered by other services, including but not limited to locks and installation of locks for the purpose of protecting a person with Prader-Willi Syndrome from access to food. Receipts as proof of purchase of supplies and charges for installation will be considered. This grant is available to individuals, but will be limited to two grants (\$200) per house per year.

TRANSPORTATION:

To assist persons with Prader-Willi Syndrome in traveling in the community to and from work, taxi fees (punch cards) can be reimbursed with proof of purchase.

HEALTH CLUB MEMBERSHIP:

To promote the good health of persons with Prader-Willi Syndrome, reimbursement of membership to a health club can be reimbursed with proof of purchase.

CONFERENCE REGISTRATIONS:

Registration for conferences sponsored by the PWSA-USA and PWSA-Iowa can be reimbursed with proof of registration and attendance.

TRAINING FOR SERVICES SPECIFIC TO PRADER-WILLI SYNDROME:

Opportunities for individual or group trainings specific to Prader-Willi Syndrome are eligible for funds. Submission of full information to the Administering Board prior to the event is recommended.

GRANT FOR RESEARCH:

At the discretion of the Administering Board, an amount of up to \$500 per year can be given to the PWSA-USA Research Fund.

Krumm family members serving on this Fund:
Wanda Askelson, Carlene Krumm, and Valerie Hammond.

PARTING WORDS

from the Prader-Willi Syndrome Association of Iowa:



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