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

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Find it online at PWSAIowa.org/spring2014

Spring 2014

Celebrate Prader-Willi Syndrome Awareness Month!

The month of May is PWS Awareness Month and the opportunities to celebrate, educate and donate are endless. The amount of time to invest is truly what you can give; whether it be writing an article, organizing a neighborhood walk or simply making a donation to PWSA of Iowa.

Have you considered providing PWS awareness at your church, school, local gym, civic associations you may be affiliated with, or on your Facebook page? Awareness is important to ensure our loved ones are safe and included in our communities.

The Chapter would love to hear from you...for our next newsletter edition, please share how you celebrated PWS Awareness Month!

-Edie Bogaczyk, Co-President, PWSA of Iowa

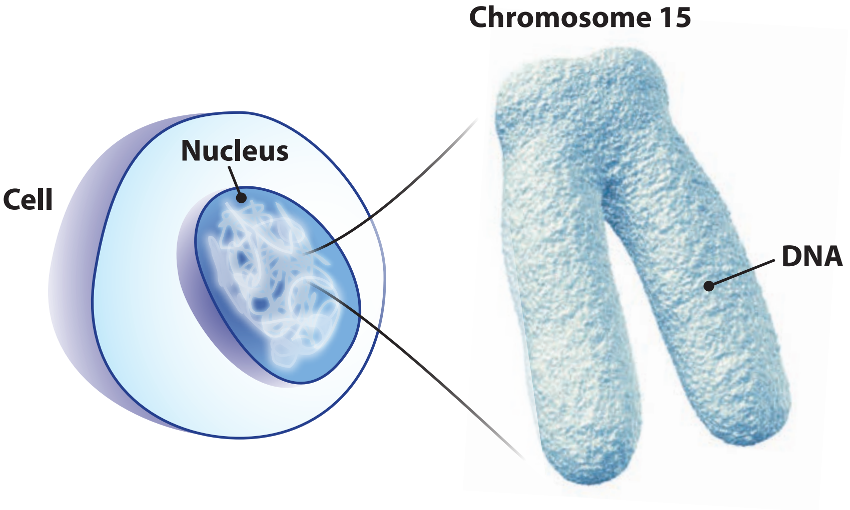
In This Issue:

Prefer to receive newsletter via email?
Send your email address to Edie Bogaczyk (edieiowa@gmail.com) and you'll be signed up!

For the latest news, events, and resources, visit us online: PWSAIowa.org

What is Prader-Willi Syndrome?

Prader-Willi syndrome (PWS) is the most common known genetic cause of life-threatening obesity in children. Although the cause is complex it results from an abnormality on the 15th chromosome. It occurs in males and females equally and in all races. Prevalence estimates have ranged from 1:8,000 to 1:25,000 with the most likely figure being 1:15,000.



Within each cell's nucleus is genetic material organized into 23 chromosomes. An abnormality in the DNA of the 15th chromosome, shown above, causes Prader-Willi Syndrome.

PWS typically causes low muscle tone, short stature if not treated with growth hormone, incomplete sexual development, and a chronic feeling of hunger that, coupled with a metabolism that utilizes drastically fewer calories than normal, can lead to excessive eating and life-threatening obesity. The food compulsion makes constant supervision necessary.

Average IQ is 70, but even those with normal IQs almost all have learning issues. Social and motor deficits also exist. At birth the infant typically has low birth weight for gestation, hypotonia (weak muscles), and difficulty sucking due to the hypotonia which can lead to a diagnosis of failure to thrive. The second stage ("thriving too well"), has a typical onset between the ages of two and five, but can be later. The hyperphagia (extreme unsatisfied drive to consume food) lasts throughout the lifetime.

Children with PWS have sweet and loving personalities, but this phase is also characterized by increased appetite, weight control issues, and motor development delays along with some behavior problems and unique medical issues.

Illustration by Michelle Davis; reproduced with permission.

Prairie View Shadows PWS Experts

Prairie View Management, Inc. is a provider not-for-profit organization located in Fayette, Iowa, that offers specialized 24-hour services to people 16 years of age and older living with Prader-Willi Syndrome. This past year, Prairie View had an opportunity to shadow "the experts" on Prader-Willi Syndrome at The Children's Institute of Pittsburgh. Laura Van Horn, Director of Social Services and Betty Davis, Site Coordinator, met with a physician, dietician, psychiatrist, and occupational therapist; premier experts in the PWS field.

Upon returning to Iowa, Prairie View has since incorporated valuable recommendations garnered from this visit into its own program. It also further confirmed what they already knew, the importance of completing exercise routines; and even more important, to incorporate strength training in its PWS homes since many individuals they serve experience low muscle tone.

Prairie View appreciates the professional relationships it fostered with the Pittsburgh Institute; recognizing it has a valuable resource to assist when necessary with the ongoing support of its own clients and staff members. This collaboration of PWS services helped to support and focus on crucial matters such as food security and supervision. On a final note, equally gratifying to Prairie View was gaining reassurance that many components of its current programming are very effective and a great benefit to individuals with PWS.

To learn more about Prairie View's PWS services, please call their agency at (563) 425-3291.

Public Service Announcement with Clint Hurdle, Former Manager of the Colorado Rockies Baseball Team, Hitting Coach for Texas Rangers

Clint Hurdle and the Colorado Rockies are teaming up with PWSA (USA) for PWS Awareness. Clint Hurdle, who serves as National Celebrity Spokesperson for PWSA (USA), has a young daughter, Madison, with PWS. Clint, his family, and the Rockies organization continue to advance progress for PWS by working with PWSA (USA). Many thanks are extended to them from all who have and are affected by PWS.

Watch online at pwsausa.org/rockies !


12.14.13
PWS
Social

The Bruce Springsteen of Parenting

Lisa Peters
(Lisa writes about family life at
www.onalifelessperfect.blogspot.com)

I believe that parents who raise children diagnosed with special needs are a lot like the rock stars of the parenting world.

In fact, if I had to choose a rock star we most closely resemble, I would say...

We are a lot like Bruce Springsteen.

Let me explain.

In the early years, Bruce Springsteen was a skinny, scruffy teenager living in New Jersey.

He was defiant, rebelling against his religious upbringing and the social dogma associated with high school.

He was different.

Former teachers have said he was a "loner, who wanted nothing more than to play his guitar." He completed high school, but felt so uncomfortable that he skipped his own graduation ceremony.

I am sure at some point in his life his parents had nightmares of retrieving their son's body from the city jail or perhaps even the local morgue.

How is it then, that this young man was able to achieve greatness?

His words resonating with folks from all over the world?

Now, I am no Einstein, but I believe that his success....not his "fame" or the "I am the most popular man on the planet" success but his "ability to relate to others" success...originates from an energy that comes from somewhere deep within him.

If you are a Springsteen fan, you know his song lyrics are more like poetry, an honest reflection of his pain. He uses "more words in some individual songs than other artists use in whole albums"

In the recording of his album "Born to Run," Springsteen battled with anger and frustration, saying he heard "sounds in his head" that he could not explain to the others in the studio.

Concert-goers have likened the "Boss" experience to a spiritual awakening.

He does not question the origin of the voice in his head but instead expresses it, exposing the true essence of his soul. This heartfelt expression creates a type of energy that has a powerful attraction to those who are also willing to bare their souls, celebrate their suffering and in the process begin to heal themselves.

I believe "soul" energy is a very powerful thing.

It is what connects us as human beings. We are drawn to its purity.

I believe there are many other folks in this world who also possess this unique ability to become in sync with their soul. They are poets, writers, athletes, physicians, scientists. mathematicians and yes even

"Springsteen" con'd on next page

"Springsteen" con'd from previous page

special needs parents.

To me, what is unique about Bruce is his ability to be present.

He is alive.

He is in the moment.

His spirit is not confined within walls.

He is free.

Laws and rules have no meaning.

There is no boundary.

There just is.

And for Bruce Springsteen, the "IS" is always changing.

In my quest to embrace special needs parenting, to me, it is all about becoming Bruce Springsteen.

When you are the parent of a child diagnosed with disease, your ability to assist your child is directly related to your ability to be present, to truly "see" your child. It is about having the courage to create a new normal. It is about listening to that voice. It is about embracing and implementing change.

Can you see the spirit that lies beneath your child's disability?

Can you discover the shining life energy that is difficult to see in a child who cannot walk, talk, write or behave?

Without speaking, can you connect with this energy?

Will you love this energy, unconditionally? Can you enable and free it?

Teaching others to see it too?

Are you brave enough to feel the brutal pain of raising a special child. Can you describe this pain honestly to others feeling free to expose the nakedness of your soul?

Can you surrender to it

Is it in you to defy laws, rules and the expected way of doing things to create a new normal?

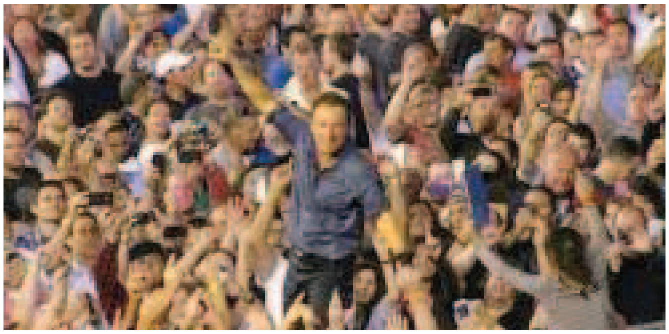
Will you change?

Do you have the power to be yourself and understand what makes you special?

Can you create your own unharnessable energy that has a powerful attraction to those who are also willing to bare their souls, celebrate their suffering and in the process begin to heal?

Can you see that which connects us all?

Knowing that we are all born to run.



Special Needs Parents, You Are Not Invisible, I See You

By Ellen Stumbo | EllenStumbo.com
Ellen writes on her blog about 'finding beauty in brokenness'

Having a child with a disability can be difficult. There are moments you wonder if anyone will ever understand or get what it is like to walk in your shoes. You parent a child with special needs and sometimes you feel alone and invisible.

But you are not. Today, I want to tell you that I see you.

I see you in the middle of the day, tired. Your hair pulled back in a ponytail and a stain on your shirt. You sacrifice so much for your child.
You are beautiful.

I see you at the ballpark, cheering and encouraging the kids playing in the Little League. Yet, I know while you cheer your heart aches, wishing that your son could play ball too, not in a special league, but here, running and moving his body like those kids rather than spending his days in a wheelchair.
You are courageous.

I see you at the therapy office programming your child's speech device, entering phrases and words to help her communicate with others. You lean over to your spouse with a grin and push a button, I hear the computer's voice say, "I farted." ***You are funny.***

I see you at the support group. New parents are visiting with their baby, they seem scared, nervous, and they are trying to deal with the diagnosis. You approach them, ask questions, affirm their feelings, and assure them it won't always be easy, but it will be good. ***You are compassionate.***

I see you walking into the school for the third time this school year. A binder full of notes, lists, and goals. Your don't feel your child's team is following the IEP, and you won't give up inclusion for your child. You will do whatever it takes to provide the services that your child needs. ***You are resilient.***

I see you at the hospital, a place you are too familiar with. Tubes, machines, tests, and specialists. Your child's feeding tube is the least of your concerns.
You are brave.

I see you at the restaurant, with a menu in your hand. But the noise is too much for your child, the smells and unfamiliarity overwhelm him. Soon, he is yelling and screaming. While people stare, you exit the place and get into your car as quickly as you can. ***You are flexible.***

I see you at church asking one of the new moms if you can bring her a meal on Tuesday afternoon. You have so much on your plate, but you also remember how hard the first few weeks are after a baby comes home. ***You are generous.***

I see you at social gatherings where well meaning people ask ignorant questions about your child or her disability, they make hurtful comments, or fail to recognize that your child is a child first. You don't get angry, you don't yell. Instead, you smile, answer their questions politely, and you educate them in a gentle manner and thank them for their concerns.
You are gracious.

I see you out there in the world, living a selfless life. You give so much, you feel so deeply, and you love so abundantly. ***You are admirable.***

These qualities you display are precious gifts you give to your child and to those around you, they don't go unnoticed…***I see you.***

Help Us Strike Out PWS!

SIGN UP and/or DONATE NOW for the 8th Annual Anneke Kramer Co-ed Slowpitch Softball Tournament & Silent Auction

benefiting the Prader-Willi Syndrome Association of Iowa!

The silent auction will be during the tournament, but we need your help! items needed: gift baskets, gift certificates, sports memorabilia, hotel night stays, etc…

Prader-Willi syndrome is the most common known genetic cause of life-threatening obesity in children. It is a life-long condition and there is currently NO cure!

Tournament Information:

When: Saturday, June 28, from 8-6 p.m. (Silent Auction from 10-5 p.m.)
Where: Hawarden South Softball Complex, Hawarden, Iowa
Why: To raise money for PWSA Iowa
Cost: $200/co-ed softball team (need at least 4 girls)
**Tournament champions will win back their entry fee!!
Teams: SIGN UP Now! The Deadline is Friday, June 20!

How can I sign up a team or donate to the silent auction?

- Call or email Stephanie Mundy @ 720.326.7601 or stephdaale@yahoo.com OR call Stacy Kramer @ 712.552.3052.
- A team contact person will need to be designated and a team roster will need to be sent with payment at least one week before the tournament. More details and schedules will be sent prior to the event!
- Scan the qr code below to make a safe, secure online donation!

**Prader-Willi Syndrome Association of Iowa is a non-profit organization. Tax ID number is 42-1449477. Donations are tax deductible to the extent permitted by law.

How Important is Physical Activity?

Edie Bogaczyk, Co-President, PWSA of Iowa

In one word it is EXTREMELY important for individuals living with PWS. Low tone is one of the typcial characteristics and therefore, activities that involve cardio require much more physical effort.

We try to make exercising fun at our house. Whether it be taking a family bike ride or even mall walking. The key is to ensure physical activity is part of the regular daily routine.

Having a *variety* of options is equally important to keep our son Zachary interested. He participates in activites at our local YMCA, Special Olymics League, Challenger League as well as with the integrated program Courage Leaugue Sports. Zachary has access to pools, tracks, and many team sporting events ranging from soccer, basketball, softball, floor hockey, fencing and volleyball. Zachary loves interacting with his peers and wearing a uniform! Partnering up with a buddy is an incentive, it simultaneously encourages him to work on his social skills and develop meaningful friendships.

If you check with some of these local sporting leagues, many provide financial assistance with membership fees and if your loved one is eligible, Consumer Choice Option (CCO) funds some of these activites as well.

The key is to encourage and set up a healthy fitness routine, have input from your loved one with PWS as to the types of exercise activites interested in and where to best participate. If necessary, please work with the primary physician and physical therapist to come up with an approved routine or list of activities.

Lastly, I am not a medical professional, just a mom sharing some tips and ideas. If a healthy snack is ever involved, Zachary has full disclosure in advance that he must participate in the exercise activity beforehand and then an agreement is made as to when he will be able ot enjoy his treat! He often participates without any food incentive, but when we mall walk, he loves having a latte at Starbucks, so we put in our mile first!

He shoots...He Scores!!!! Zachary (13 years old) participated at the recent Basketball Skills Special Olympics Event.

Selections from

Exercise and Physical Activity for Children with Prader Willi Syndrome | A Guide for Parents and Carers

By Kristy Reid and Peter SW Davies, Children's Nutrition Research Centre, The University of Queensland

Reprinted with Permission

The Benefits of Exercise

It was established earlier that excess energy consumed will be stored as fat if a child's energy intake is not increased through exercise and physical activity. But what are the other benefits of getting your child active?

Exercise and physical activity have many benefits – they help to:

- keep bones strong
- keep the heart healthy
- strengthen muscles
- increase endurance
- increase flexibility
- improve mood through the release of endorphins
- decrease feelings of depression and anxiety

Daily exercise enhances aerobic fitness and energy expenditure while minimising the loss of lean body mass and muscle tone. Aerobic exercise helps to burn body fat, while a lack of physical activity can decrease the tone and strength of muscles.

How do I introduce exercise to my child?

When your child is first starting out, sporting activities may be limited. Children with PWS usually have poor muscle strength, poor coordination and decreased muscle mass. It is not uncommon for high impact sports such as running and jumping to cause joint injuries in these children.

Low impact activities are recommended when introducing exercise to your child. Swimming, walking and stationary exercise equipment such as exercise bikes and rowing machines are all possible alternatives. They can help to build your child's strength until they are able to participate in other activities.

To preserve muscle tone, resistance activities can be effective. Try training with very light weights or use your child's own body weight as the resistance in activities such as push ups, pull ups, crunches, dips, lunges, squats and calf raises.

When starting any new exercise routine, it is always beneficial to enlist the help of a specialised trainer or physiotherapist to outline and supervise an appropriate training program for your child.

Selections from

Exercise and Physical Activity for Children with Prader Willi Syndrome | A Guide for Parents and Carers

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What age should I involve my child in exercise and physical activity?

It is important to teach your child sport specific skills and to get them involved in activity at a young age.

Improvement in basic skills at an early age will help to build your child's self confidence and will enable greater participation in recreational activities as they get older. Participation also fosters social skills, promotes peer acceptance and improves co-ordination, strength and endurance.

What activities will help my child lose weight?

Activities targeting both fitness (Aerobic) and strength (Anaerobic) will help your child to lose or maintain their weight through an increase in energy expenditure.

Humans use their aerobic energy system when completing exercise or physical activity at low or moderate intensity for an extended period of time. It results in an increased breathing rate and an elevated heart rate. Some examples of aerobic activity include:

- Walking briskly
- Cycling
- Jogging

Aerobic exercise uses oxygen to generate energy for the working muscles and uses glycogen and fat as the primary fuel sources. It is very important for burning fat stores. Aerobic exercise assists in weight control in the following ways:

- by burning excess energy (primarily fat stores)
- improving heart function and the body's ability to circulate oxygen
- preventing osteoporosis
- strengthening muscles, tendons, joints and ligaments
- improving temperature regulation at rest and during exercise in different environments
- Improving blood pressure control

Exercise Equipment Tips!!

- Try to vary the types of machines your child uses to target different muscle groups. e.g. Stationary cycling can provide a steady workout for hips, thighs, legs and gluteals as well as a cardiovascular workout, while rowing machines target legs and gluteals, upper and lower back and the abdominal muscles.
- Stationary exercise bikes can be useful if your child is having difficulty learning the correct cycling technique. Pedalling on a stationary bike will help them to learn until they are ready to progress to a real bike. Training wheels may also help when they are first starting out!
- Don't forget the trampoline – it's fun and a great way to burn energy!

Selections from

Exercise and Physical Activity for Children with Prader Willi Syndrome | A Guide for Parents and Carers

By Kristy Reid and Peter SW Davies, Children's Nutrition Research Centre, The University of Queensland

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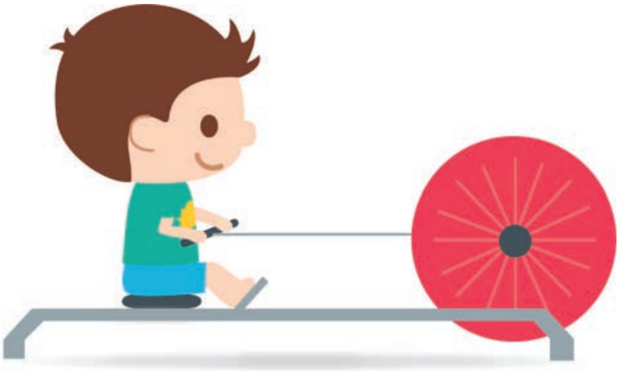
Stationary Exercise Equipment

The benefits of using stationary exercise equipment include:

- Stationary exercise equipment such as cycling and rowing machines allow your child to burn energy without moving around a great deal.
- Resistance levels can be altered with equipment such as stationary cycles.
- Many types of equipment, such as stationary cycles and rowing machines help to increase cardiovascular and muscular endurance.



- Depending on the type of machine used, your child can achieve an effective workout targeting many muscle groups.
- Many exercise machines may also decrease the risk of injury to your child helping to spread the load over a number of joints. Rowing machines are a great example.

Why is incidental exercise so important?

Incidental exercise is the incorporation of exercise into daily tasks and is considered to be any movement performed during the day as a part of everyday life (e.g. hanging out the washing, vacuuming the house, washing the car, etc). Planned and structured exercise is very important but keeping active throughout the day will help your child to reduce body fat and expend extra energy.

People who keep active through the day by engaging in a high level of incidental exercise experience the following benefits:

- increased muscle mass
- improved heart and lung strength
- improved joint mobility
- improved blood flow
- injury prevention
- improved brain function
- better self esteem

Opportunities to undertake incidental exercise are becoming reduced as modern technologies remove our need to expend energy. The convenience of elevators, remote controls, drive through automatic car washers and cordless phones, causes us to become more sedentary. Many people are now not expending an adequate amount of energy in daily activity.

Incidental exercise is a great way to increase your child's energy expenditure.

Selections from

Exercise and Physical Activity for Children with Prader Willi Syndrome | A Guide for Parents and Carers

By Kristy Reid and Peter SW Davies, Children's Nutrition Research Centre, The University of Queensland

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Incidental Exercise Tips!!

- Try walking the dog with your child for a few minutes extra each day.
- Encourage your child to take the stairs instead of the elevator as this will increase their heart rate and strengthen leg muscles.
- Park the car further away from the supermarket/school entrance to increase the distance you need to walk.
- Encourage your child to help you wash the car by hand.
- Involve your child in the garden – get them to weed the garden, mow the lawn and rake up leaves.
- Don't use the clothes dryer. Encourage your child to help you hang out the clothes on the washing line.
- Walk while you talk on the telephone instead of sitting down – encourage your family to do the same!
- Put limits on activities such as watching TV, playing on the computer, playing video games and encourage physical activities instead.
- Encourage your child to get up to change the television channel instead of using the remote control – why not try hiding it for a bit of fun!
- Try walking or cycling with your family instead of driving wherever possible.

MEXICAN BLACK BEAN CHILI

1 cup diced onion
1 cup diced green bell pepper
1 pound ground chuck
1 ½ cups no-salt-added beef broth
1 tablespoon chili powder
1 ½ teaspoons ground cumin
¾ teaspoon dried oregano
½ teaspoon salt
1/8 teaspoon pepper
3 garlic cloves, crushed
2 (14.5-ounce) cans no-salt-added diced tomatoes, undrained
2 (15-ounce) cans black beans, drained
6 tablespoons fat-free sour cream
6 tablespoons chopped fresh cilantro

Preparation

Place a large nonstick skillet over medium-high heat until hot. Add first 3 ingredients; cook until browned, stirring to crumble. Drain well; return meat mixture to pan. Add broth and next 8 ingredients (broth through beans); bring to a boil. Reduce heat; simmer 15 minutes or until slightly thick, stirring occasionally.

Ladle chili into soup bowls; top with sour cream and cilantro.

Makes six 1½ cup servings, 346 calories, 30 from fat, 25 grams protein, 35.5 grams carbs.

(Recipe from Cooking Light Magazine)

News from the

FOUNDATION FOR PRADER-WILLI RESEARCH

2013 was a record-breaking year for the Foundation for Prader-Willi Reserach (FPWR)! We were excited to be able to support more than $1,000,000 in cutting edge research projects and initiatives.

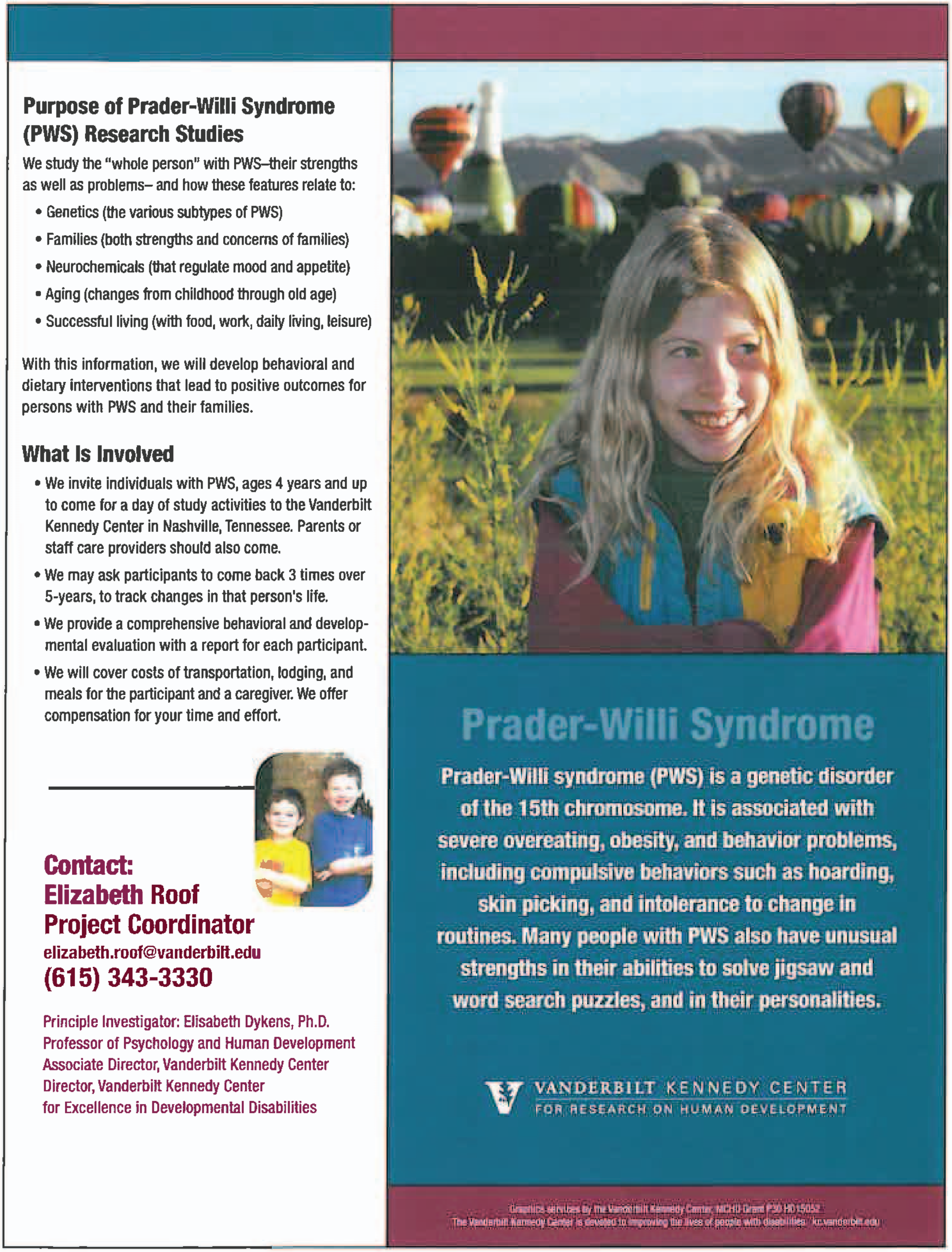
Our scientific and advocate reviewers worked together to review grant applications from some of the brightest minds around the world. With more promising proposals than funds available, this was a challenging task, but, we were thrilled with the outcome; a strong portfolio of grants that addresses many pressing needs in PWS research.

2014 looks to be another great year for Prader-Willi research and may be our best yet! Our most recent cycle of grant applications have been reviewed and the proposals are fascinating!

Forty-four projects from outstanding scientists from around the globe have been submitted for review, the most in FPWR history! An amazing array of scientific disciplines, know-how, and cutting edge techniques are represented, all being applied to better understand and treat PWS.

We look forward to announcing our latest round of funded grants on next research webinar on May 15th - please join us!

Several new PWS clinical trials around the country are evaluating potential therapies for children and adults with PWS. The active involvement of our community will be critical to seeing these studies through and FPWR is dedicated to providing the most up to date information on clinical trial opportunities. Information on PWS clinical trials may be found on our website at **www.fpwr.org/pws-clinical-trials**.



Purpose of Prader-Willi Syndrome (PWS) Research Studies

We study the "whole person" with PWS–their strengths as well as problems– and how these features relate to:

- Genetics (the various subtypes of PWS)
- Families (both strengths and concerns of families)
- Neurochemicals (that regulate mood and appetite)
- Aging (changes from childhood through old age)
- Successful living (with food, work, daily living, leisure)

With this information, we will develop behavioral and dietary interventions that lead to positive outcomes for persons with PWS and their families.

What Is Involved

- We invite individuals with PWS, ages 4 years and up to come for a day of study activities to the Vanderbilt Kennedy Center in Nashville, Tennessee. Parents or staff care providers should also come.
- We may ask participants to come back 3 times over 5-years, to track changes in that person's life.
- We provide a comprehensive behavioral and developmental evaluation with a report for each participant.
- We will cover costs of transportation, lodging, and meals for the participant and a caregiver. We offer compensation for your time and effort.

Contact:
Elizabeth Roof
Project Coordinator
elizabeth.roof@vanderbilt.edu
(615) 343-3330

Principle Investigator: Elisabeth Dykens, Ph.D.
Professor of Psychology and Human Development
Associate Director, Vanderbilt Kennedy Center
Director, Vanderbilt Kennedy Center
for Excellence in Developmental Disabilities

Prader-Willi Syndrome

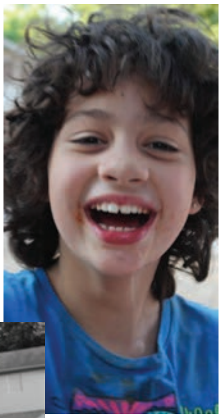
Prader-Willi syndrome (PWS) is a genetic disorder of the 15th chromosome. It is associated with severe overeating, obesity, and behavior problems, including compulsive behaviors such as hoarding, skin picking, and intolerance to change in routines. Many people with PWS also have unusual strengths in their abilities to solve jigsaw and word search puzzles, and in their personalities.

VANDERBILT KENNEDY CENTER
FOR RESEARCH ON HUMAN DEVELOPMENT

Graphics services by the Vanderbilt Kennedy Center, NICHD Grant P30 HD15052
The Vanderbilt Kennedy Center is devoted to improving the lives of people with disabilities. kc.vanderbilt.edu

Wonderland Camp

Providing a fun, educational camp experience for
individuals with disabilities.



Come to Wonderland Camp!

- Specific Weeks for Individuals with Prader-Willi Syndrome (PWS):
  - ⇒ June 15th - 20th
  - ⇒ July 13th - 18th
- Individualized experience based on the campers' needs.
- We understand individuals with PWS. Camp leadership has over 20 years combined working with individuals with PWS.
- Wonderland Camp was started because our Founder's son had PWS.
- More information contact our Office @ 573-392-1000 or info@wonderlandcamp.org; Website: www.WonderlandCamp.org

"It wouldn't be summer without Camp."

www.wonderlandcamp.org www.facebook.com/wonderlandcamp

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: PWSAIowa.org/contact

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

Suggested membership annual dues: $20
**Membership can still be accepted if this is not financially affordable.

Checks can be made payable to "PWSA of Iowa".
Send payment to: PWSA of Iowa, 15130 Holcomb Avenue, Clive, IA 50325

Name: ____
(required)

Mailing Address: *(required)*

____
Street City State Zip

Email: ____
(required)

Phone Number: ____
(required)

Tell us about yourself!
(Does someone 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.

Save the Date!

Don't Miss the PWS Awareness Event

When: Saturday, May 3, 2014, 2:00pm-7:00pm
Where: Fayette IA
What: "On the Move" Trail Walk, PWS Resource Fair, Crafts, Entertainment, Complimentary Dinner, Dancing and Fellowship!

This awareness outreach event is open to the public; membership is not required to attend!

Line-up of Events

Fayette Sports Complex 100 Old Highway 150
2:00pm "On the Move" Buddy Walk

Fayette Community Church 205 W. State St Fayette
3:00-4:00pm Resource Fair and Activities
4:00pm Hot Meal
5:00-7:00pm DJ/Karaoke/Dancing
5:00-6:00pm Mr. Nick Balloons

Please call the Chapter for any questions: (515) 770-5297
We hope to see you all there!!!

Co-hosted by
IOWA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.
and
PRAIRIE VIEW

Prairie View Management, Inc.

PARTING WORDS

from the Prader-Willi Syndrome Association of Iowa:

> **SOMETIMES IT'S BETTER TO REACT WITH NO REACTION.**
>
> *KUSHANDWIZDOM*

Has Your Home or E-mail Address Changed?

If you change your home or e-mail address, please notify the PWSA of Iowa chapter office at **edieiowa@gmail.com or 515-770-5297.** We want to stay connected, keep you on our newsletter mailing list and also inform you of all upcoming PWSA of Iowa events; including socials, fundraisers and mini-conferences.

Share this newsletter! Find it online at PWSAIowa.org/spring2014