The
Gathered View
National Newsletter of the Prader-Willi Syndrome Association (USA)

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

"I want to make life easier for these kids and I believe this drug, when dosed correctly, has the potential to do that."

Oxytocin Phase 2 Trial Webinar Summary

Dr. Miller featured on Webinar offering hope and a call for your help

By Denise Servais

On July 8, 2015, PWSA (USA) hosted a webinar called, "Oxytocin Initiative: A Phase 2 study in PWS." The webinar featured Dr. Jennifer Miller, a Pediatric Endocrinologist, from the University of Florida. During the webinar, Dr. Miller discussed exciting information about a drug called oxytocin that she believes has great benefits for people, of all ages, with PWS. Her current research on a Phase 1 study of intranasal oxytocin for treatment of PWS, plus research done on mice, and anecdotal information, all suggests that oxytocin has the potential to improve the lives of people with PWS by decreasing anxiety, reducing fears, improving social interactions, and lessening the anxiety about food and food-related issues.

Oxytocin is a hormone, which is synthesized in the hypothalamus. Autopsy studies have shown a deficit in oxytocin-producing neurons in people with PWS. Mice research has shown both social deficits and behavioral rigidity were decreased when administered oxytocin. Human studies have shown an increase in prosocial behaviors and trust when healthy subjects were administered the drug. Currently the drug is off the market in the US. *Withdrawal from the US and Canadian market by the manufacturer of the IN-OT (syntocinon Novartis) in 1997 and 1992 respectively, was not related to any safety issues but was at the request of the manufacturer, for poor market profits.* Dr. Miller reported that currently the Phase 1 study is going on now in parts of the US in children with PWS and preliminary results of this pilot study look promising without any major side effects. *The funding for the Phase 1 study came from pilot grant funding from the Rare Disease Clinical Research Center grant studying the natural history of PWS, as well as from PWSA (USA) and a private donor.* Dr. Miller, along with Dr. Dan Driscoll, are asking for people to help PWSA (USA) to raise the funds necessary so that a Phase 2 study can take place as soon as possible. "I want to make life easier for these kids and I believe this drug, when dosed correctly, has the potential to do that," Dr. Miller said. The goal is to raise one million dollars by the end of 2015.

Why do we need to raise money? Can't the government or the pharmaceutical companies fund it? Dr. Miller explained that there are no pharmaceutical companies interested in this research. She believes the Phase 2 trial results will persuade

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Spotlight on

Jackie Mallow

and YIP/YAP - the infant, children, youth and adult program at 2015 Conference

Jackie with a young friend from a May 2010 conference in Taiwan.

By Lota Mitchell

Meet Jackie Mallow, one of our amazing professionals who have dedicated their lives and careers to people with PWS, and learn more about the conference's infant, children, youth and adult programs.

Co-Chair of the 2015 PWSA (USA) National Conference in November, she also recently served nine years as a member of the PWSA (USA) Board of Directors. Jackie is also on the PWSA-Wisconsin board since 1997 and currently vice-president, chairman of the Professional Providers Advisors Board, and on the board of the International Professional Providers and Caregivers. And, oh yes, she does have a job, as Director of Admissions & Consultative Services at Prader-Willi

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Jackie Mallow, *continued from page 1*

Jackie with 2013 National Conference co-chair Michelle Torbert

Homes of Oconomowoc (PWHO) in Wisconsin.

Plus…she and Marguerite Rupnow are **Program Directors of the 2015 conference Youth and Adult Program (YAP)** for those with PWS age seven and above.

In 2011 and 2013 Jackie co-chaired the National Conference. In 2011 she developed a new "formula" for YAP, to be followed again in 2015. Instead of being led by almost all volunteers, its leaders now are professionals from PWHO highly trained with PWS. Missionaries from the Church of Jesus Christ of Latter Day Saints, perform community service, by filling out the rest of the staff. Activities are structured, theme-based and fun, such as obstacle courses, art, dance and social skills.

Jackie reports that this year's theme **"Circus of Hope"** will kick off at the Welcome Reception on Thursday night, November 5. Throughout the conference, all will enjoy the added entertainment, magicians, balloons, happy clowns, face painters and much more. The participants will close the conference by performing their much anticipated choreographed dance number, as their families and friends look on with pride, laughter and maybe a few special tears.

This is one place, she notes, where the kids, young and old, don't have to worry about PWS and its associated challenges. They are making friends and having fun. It's the one time they can have a peer group who truly "gets" them. The families, too, benefit. They get a unique opportunity to breathe, to relax and make new friends with others who understand, and to see their child having "normal" fun. Seeing your child's face glow while on the dance floor with all their new friends after the YAP gala dinner is a life changer.

There is also the **Young Children & Infants Program (YIP)** for little ones 2-6. Under the directorship of highly experienced Michelle Holbrook, the children are placed in small groups according to age and ability. They enjoy structured theme-based activities where giggles and fun are a must. Babies 0-24 months are in their own nursery where caring staff give them extra TLC while their parents are being embraced by the PWS community.

Seeing your child's face glow... with all their new friends... is a life changer.

Siblings are not forgotten. A professionally-led group for siblings 7-15, who don't know what "normal" is either, gives them the opportunity to engage with other their brother or sister with PWS without worrying about the sibling with PWS. Friendships start forming with those who understand the differences in their home and what it's like to have a sibling with PWS. Siblings 16 and over can volunteer in all areas and are provided a unique leadership opportunity.

How did Jackie get involved way back with the little known birth defect Prader-Willi syndrome? While attending Oshkosh University in Wisconsin 28 years ago, she needed a summer job. She answered an ad for a "child care technician" at Oconomowoc, an organization serving children with dual diagnoses, loved the job—and stayed on.

Her first encounter with PWS was through Special Olympics and several children at the residential school. By 1996 Oconomowoc had group homes with 32 adults with PWS. In 1997 she attended her first National Conference as a presenter. She describes herself as a "big mush" and found meeting the kids and families so heartfelt. Afterwards she went home feeling the need for specialized programs for individuals diagnosed with PWS, which resulted in developing a plan for PWS having its own company under Oconomowoc Residential Programs. Now 93 residents in 11 homes are, Jackie says, "not only surviving but living and thriving."

She worked with David Wyatt to develop the PWSA (USA) professional provider board. Jackie was one of only a few USA providers who were invited by Pam Eisen to present to providers across the world. This opportunity evolved in to the creation of the international PPCB, Professional Provider and Caregiver's Board, of which Jackie is a founding member. Prader-Willi has been life-changing for her, she says, and she has a "life so fulfilled." She does have a family of her own – husband, a daughter age 18, an older son, and a three-year-old grandson. But the PWS community is also her family, a second family almost as important as the first.

For just about everyone who goes to conference, it is a mountain top, not-to-be-forgotten experience, and for most, a life-changing experience. Thank you, Jackie, for helping to make it just that!

A time to grieve… a time to heal… a time to build the future

By Ken Smith

PWSA (USA) Executive Director

In this edition of the newsletter, of the 40-year Prader-Willi Syndrome Association (USA) history, we are reflecting on the 2000-2007 era. For me, it brought back that time when I was on the Board of Directors and how 2001 was the year of trauma for our entire nation due to 9/11. This is the day that everything changed in our country. It is a time in history when so much now reverberates as "post 9/11". It may feel similar to when your child was diagnosed with Prader-Willi syndrome. Everything was changed from that point on. First the shock, then the intense grief, the fear, the anxiety about the future, and then the difficult question of -- "How do we go from here?"

What makes it easier to go on is a sense of being united with others who are fighting the same battle. We knew it then as Americans, and we know it now as parents and loved ones of a child who has PWS. We have known it as an organization that has been built on the backs of hundreds of parents and professionals who have worked and advocated and donated the funding for over 40 years to make this world a better place for those with the syndrome.

Just as they have rebuilt the World Trade Center, you have also learned to rebuild your lives – to be stronger than ever. And, with your help, we have continued to build an organization that is stronger than ever. We have built a stronger crisis and family support program; a stronger new parent support program; stronger school support programs; stronger educational support through multimedia programs; stronger resource materials; and stronger research support with a focus on research that can have a greater impact on our children's lives in the immediate future.

> "You cannot live a perfect day without doing something for someone without a thought of repayment."
>
> *John Wooden*
>
> *Contributed by Clint Hurdle*

Because we know that our services are not only important, but essential, we continue to work on securing the strength and survival of PWSA (USA) so that we can continue to save and transform lives not only for this generation of children with PWS, but all generations. May we continue to be that beacon of hope and the lifeline of support – until we are no longer needed. If that time ever comes, we will be happy to turn off the lights and close the doors. Until then, remember that we cannot do this alone, that we need to be united with our support of PWSA (USA) – just as we felt that unity as a nation in 2001. ■

Oxytocin Webinar, *continued from page 1*

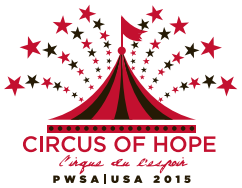
them to fund a Phase 3 trial, which is needed before a drug can seek approval from the FDA. Dr. Miller explained that funding through the NIH (National Institutes of Health) may be possible, but NIH funding for research has been reduced significantly and is very difficult to obtain. There is tremendous competition for the funding, and even if you are awarded grant funding, it can take up to a year or more to receive the funds.

So how can you help? PWSA (USA) and TREND have partnered to help raise funds specifically for this study on oxytocin. The site for donations is https://www.firstgiving.com/pwsausa/oxytocin-study. This is the ONLY site where all of our donations will go directly to the study, or you may donate directly to PWSA (USA) by contacting ...

We are an awesome and powerful PWS community! With your donations and fundraisers we CAN do this! We can make this happen for our loved ones with PWS. More details are available on page 4 under Fundraising.

The author Denise, also mother to Maya with PWS, shares her thoughts: *There is something that bothers me even more than when my child has meltdowns when she wants to eat. And that's when she looks into my eyes and pleads softly for more food because she is hungry. Maybe it's because deep down inside I am experiencing a mother's innate sense to feed her child or maybe it's because it's just a sad circumstance, I'm not sure. I feel fortunate to have received good advice from very caring professionals. However, I am excited to hear about the positive research that is going on with oxytocin. This could not only be another tool in our toolbox, but a game-changer. To imagine a world where my child is more social and engaging; less hungry and rigid? Yes, this is the world I would love to imagine for my daughter. To think that it could be a reality makes me hopeful for what's in store for my child with PWS.* ■

Hear Dr. Miller with other presenters, plus meet, learn, and share with other PWS families at the **PWSA (USA) National Conference, November 4-7**
Early Bird discount ends soon!
Visit: www.pwsausa.org/conference



Oxytocin Phase 2 Study Campaign Update

By Jack Hannings, Development Director

"What if I could tell you that your child can be changed, even though he has PWS? What if he was more present? More engaging? Participated in class? No longer wanted to play alone? And actually cared if you don't feel well or asked how you are? That is what oxytocin has done for my child."

Anecdotal reports such as this touting the benefits of oxytocin for children with Prader-Willi syndrome (PWS) are circulating on social media. Drs. Miller and Driscoll are thrilled to announce that they have almost completed Phase 1 of their oxytocin trial in individuals with PWS and the preliminary results are very promising. They are working swiftly to develop a Phase 2 multi-center study that will include a dose-finding component and a wider age range of participants. PWSA (USA) is leading the campaign to make the phase 2 study a reality.

In the first two months, the special campaign led by PWSA (USA) has raised over $250,000. What an incredible response from our supporters.

The PWSA (USA) Board of Directors and seven of our Chapters have contributed $117,000 directly to this initiative. A big thank you goes to the following chapters; Utah ($25,000), Minnesota, Michigan, and Indiana who contributed $10,000 each, Connecticut and Ohio contributed $5,000 each, and the New England Chapter contributed $2,000.

PWS families have created 100 fundraising pages to support PWSA (USA) in our effort to make this promising research study a reality. You can support the initiative through a donation or by creating your family's own fundraising page at: https://www.firstgiving.com/pwsausa/oxytocin-study or you may donate directly to PWSA (USA) at 8588 Potter Park Drive, Suite 500, Sarasota, FL 34238. Or contact Jack Hannings at jhannings@pwsausa.org ■

Utah Chapter is "On the Move"

Photos from the May 2015 fundraiser.

Lisa Thornton, President of the Utah Chapter, reports that this year has been very active for fundraising. Each May during the PWS Awareness month they have a fundraiser. These funds are used for two social outings per year for the families and charitable giving. This year a $25,000 gift was given to PWSA (USA) for the Oxytocin Phase 2 campaign. Additionally, for the Phase 2 Campaign Utah has been very successful with their FirstGiving Page. To date, they have raised $56,000!

Established in 1984 with Janalee Heinemann's help, this chapter has received significant support from the national organization at every turn. They share ideas, get support and guidance from other state chapters, too. The medical community notifies them of a new diagnosis and puts families in touch with the chapter. Utah has done significant outreach so the medical community knows us and refers new families to us. Approximately 80 families are part of our organization; about 100 children with PWS are in Utah, ranging in age from newborn to 60.

Now that their medical clinic is strong, taking care of the children and adults, they are working on developing a life-long college program for adults with intellectual disabilities in Utah. Visit the website at thecurtiscenter.org.

This medical clinic (8 clinicians) see most in the state. This strong network provides the best medical care, and rallies and supports their kids, including testifying in court to helping through tough hospital stays.

The Utah Chapter holds two socials per year - a fun swim party with games, races, prizes, socializing, and a lunch; a Christmas party with lunch, Santa, musical entertainment, games, includes a service project. An annual parent conference features a guest expert.

Utah has been active in lobbying the legislature and received funding for a medical care manager and other expenses related to our medical clinic: $60,000 a year. Last year, lobbying resulted in the filings fees for Guardianship process being reduced from $360 to $35.

An education advocate on contract with the state, helps with children's IEPs and other school issues. Their medical care manager serves on various committees dealing with the children. We have several PWS-only group homes in Utah. The Chrysalis organization runs the group homes currently. The providers are strong supporters of our Chapter. Utah is indeed a chapter that supports its families, creating awareness and supporting national efforts. ■

Fundraising with Smiles

THANK YOU for making a difference! Our passionate PWS community members make events successful! Space was limited last issue, so we're delighted to share photos of your events. Your hard work will support many different programs for those affected by PWS on both local and national levels. If you're interested in hosting a fundraiser in your area to help us reach our goal of 40 events in our 40th year, please contact Leanne Gilliland at lgilliland@pwsausa.org or 941-487-6743.

The **Michigan Chapter** hosted an **"On The Move"** *May 9 at Cascade Falls Park*

The Graves family in front of their sign at the Michigan May 9 ***"On The Move"*** *event.*

Hunter Lens Golf Tournament: *Hosted June 6th by the Lens Family at The Back Nine Golf Club L-R: Nicholas Frongillo and Hunter Lens*

The **Wisconsin Chapter** hosted their **"On The Move" Walk** *May 9 at Roosevelt Park*

Greysen Gaulke, Eden Duquesnoy, and Mason Hurd are "friends for life".

Flashback 2000–2007

By Lota Mitchell
PWSA (USA) president 2000-2007, Gathered View Editor 2008-2014

The world, the PWS family, and PWSA (USA) made it safely from 1999 to 2000 in spite of the worries of many people. And we lived through the tragedy of 9/11. Here are some verbal "snapshots" reflecting on the years 2000 to 2007.

Snapshot #1 Conferences

National Conference 2000 in my hometown of Pittsburgh was special because it celebrated the 25th anniversary of PWSA (USA). I wrote some forgettable doggerel that started with

"In the beginning was darkness and drear. No one had heard of Prader-Willi.

If you had described a syndrome like this, People would say you're just silly!"

In 2001 Minneapolis welcomed the International Prader-Willi Syndrome World Conference which **Joan and Jim Gardner** dedicated three years of their lives to planning… the conference I went to, but didn't attend; the conference where I became PWSA (USA) president--in absentia; the conference I left to go to NC when new grandson didn't wait for his due date. 1380 people registered, plus 125 international scientists, 365 volunteers, and 280 in YAP (200 with PWS). Our international focus increased. A beautiful new song was introduced, written by two parents, **Giorgio Fornasier** (music) from Italy and **Linda Thornton** (lyrics) from New Zealand. Refrain: *"Across the world's oceans, across the world's skies*

We join hands together and love makes us fly—high!"

All the conferences have been memorable. 2002: Utah; 2003: Orlando, PWSA (USA)'s 25th national conference; 2004: Ohio; 2005: Orlando; 2006: New York; 2007: Dallas

Snapshot #2 We lost some special people

*__Dr. Andrea Prader__, the Swiss doctor, who along with Dr. Willi and Dr. Labhart, wrote the first publication about PWS.

*__Dr. Rob Wharton,__ pediatrician and co-chair of our Clinical Advisory Board, who for his dedication and love for our children with PWS was given an "Angel of Hope" award at the 2001 conference.

*__Dr. Richard Wett__, anesthesiologist, father of a daughter with PWS, was the first president, then chairman of the board, of PWSA (USA).

*__Frank Moss__, past board member, father of a daughter with PWS, national conference chair, used his talents as a brilliant businessman in his deep commitment to PWS.

Snapshot #3 A National Spokesperson

Clint Hurdle, now manager of the Pittsburgh Pirates baseball team, joined the PWS family with the birth of his daughter, Madison "Maddy" on Aug. 7, 2002. He became national spokesperson for PWSA (USA), he and his wife **Karla** established an Endowment Fund for PWSA (USA), and he has been a keynote speaker at conference. Each year the families of the Pennsylvania PWS Chapter have a ***Meet and Greet*** with Clint and then attend the game together.

Snapshot #4 Sponsored Services and Activities

PWSA (USA) continued to increase its services to its members, such as the **New Parent Mentoring Program** initiated by **Carolyn Loker**, the **PWS Advisory Board** for our young adults with PWS, and the **Bereavement Program**, and to develop and add to its large library of materials from medical information to management tools, from one-page handouts to sponsoring the 3rd edition of *Management of Prader-Willi Syndrome*, a textbook edited by **M. Butler, P. Lee and B. Whitman**. The television program *60 Minutes* did a feature story on PWS. On the lighter side, a CD of the rap song was created by Tad Tomaseski, brother of Matt Heinemann, and his church leaders and teen group, entitled "My Name's Not Willy!" Yes, the CD is available for purchase through the website or the National office.

First verse:
The day I was born, my parents got the news
My fifteenth chromosome had blown a fuse
I was born with Prader-Willi, so weight's tough to lose
But you ain't gonna hear me singin' the blues.
Tenth and last verse:
There's a lot more to me, than meets the eye
I have dreams for my life, my only limit's the sky
So if you really want to know me, come close and take a peek
One promise I can make you, I am truly unique.

Snapshot #6 Medical Information

This era saw no huge breakthroughs, but ongoing research continued to investigate and provide our ever-increasing knowledge of genetics, management, growth hormone, dental issues, appetite, obesity, psychosis, gastrointestinal problems and other areas relating to PWS.

Dr. Merlin Butler, a medical geneticist, prolific researcher and writer of scientific articles, became the third chairman of the Scientific Advisory Board in 2001 and continues to serve faithfully to this day.

Chromosome 15q11-q13 Type I and II were characterized.

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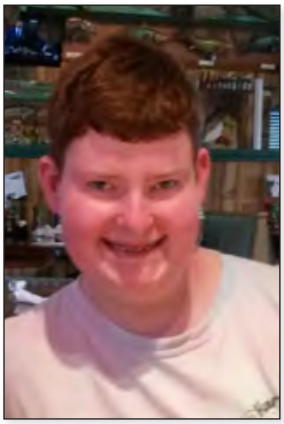
From the Home Front



Carter is 13 years old

I don't know about yours, but my child is not "PWS." He is a person with PWS. He is a person FIRST - a human being with feelings, emotions, likes, dislikes, wants, desires, and needs. He is a child first - who does things and acts in ways much like "typical" children. Not everything he does or that happens to him physically is because of PWS. We don't define our son as PWS, or refer to him as "A PWS," because we refuse to let him be defined by his diagnosis. I implore everyone with a child with PWS to consider this - if you define your child by the symptoms and characteristics of Prader-Willi syndrome, you are setting him up for a lifetime of doubting his ability, and restricting her from realizing her full potential in life. It doesn't take much more time to say or write, "My child with PWS," or, "My child who has PWS." Sometimes, all you need to say is, "My child," "My son," or, "My daughter," and leave out the PWS altogether. I'm not saying to ignore the fact that a child has PWS, or not to tell a child he or she has PWS, just don't make everything about your child relate back to PWS, and don't define your child solely based on what PWS brings to the table. My son is so much more than his diagnosis, and so is a child who has PWS. Respect. ■

~ Michele Shingleton
Burlington, CT

Editor's Note: the last electronic issue of Gathered View showed this copy along with a different photo, and attributed it to another writer. Our sincerest regrets and apology for this error.

40th Flashback, *continued from page 6*

Our first Medical Alert for the Emergency Room was published and is now in 17 languages.

In 2003 PWSA (USA) was accepted as part of a major NIH research grant. Rare Diseases Clinical Research Center will include Prader-Willi, Angelman, and Rett syndromes, each with its own research committee. Our Chair of the Clinical Advisory Board, **Dr. Dan Driscoll**, will chair the PWS rare disease consortium.

Snapshot #7 Some quotes from the era

Janalee Heinemann, then Executive Director, PWSA (USA):

"How do you measure a person's worth?

"Not so much by what the person has done, but by what he or she has overcome. Not by what the person has, but by what he or she gives. Not by how thin the body is, but by how big the heart is. Not by the love someone gives when it is easy, but by the love given when it is difficult."

From my final President's Message, as true today as it was then:

*"…support PWSA (USA). It's a wonderful organization with wonderful people and wonderful goals for our wonderful (yes, they are) children. It's more than an organization—it's a **family**. Support it with your time, your talents and your treasure. Together, we can reach those goals."* ■

Cole Lombardi, age 8

Just wanted to send you this pic! He is so proud of his abs! I NEVER thought after receiving a diagnosis of PWS I would ever see him have a six pack! Thank you for all you do and for all the research that helps make this picture possible!

Love,
The Lombardi Family
Tracey, Bart, Cole, Grace and Bryce
Sent from my iPhone

GI Flow Chart provides time saving ER success

PWSA (USA) recently received a letter as a "thank you" for helping a family through a medical crisis:

Dear PWSA-USA; I am a parent of a 25-year-old with Prader-Willi syndrome. A few months ago I received your handy flow chart "Evaluation of Individuals with PWS with GI Complaints". I made copies for the "emergency packets" I have at my daughter's house for her supported living staff. Last Friday evening she was having stomach pain, and her staff person took her into the ER with the emergency packet. The ER doctor diagnosed intestinal blockage and used the flow chart to provide treatment, which was successful in clearing out the problem. The doctor specifically thanked us for providing the flow chart, which she found invaluable in providing fast and appropriate treatment. I thank you, Dr. Loker, Dr. Scheimann, and your wonderful Clinical Advisory Board for preparing and disseminating this important and possibly life-saving document. Keep up the good work, I am proud to be a member of this wonderful organization and extremely thankful for the many ways PWSA (USA) makes parenting and caregiving for people with PWS a little less stressful.

From,

A grateful parent

Editor's Note: The GI flow chart appeared as part of an article in the Volume 40 Issue 3 (May/June 2015) of **The Gathered View** *on page three. It can also be seen on the PWSA (USA) website http://www.pwsausa.org/medical/medical-issues/gastric-and-intestinal listed as "Life Saving GI Evaluation Algorithm Chart".* ■

Noninvasive Prenatal Screening – testing now available for PWS

By Janalee Heinemann, M.S.W., PWSA (USA) Coordinator of Research and International Affairs

Noninvasive prenatal screening (NIPS) – also called noninvasive prenatal testing (NIPT) or cell–free DNA testing – is now available for Prader-Willi syndrome (PWS). Testing can be done any time after 9-10 weeks gestation because DNA from the fetus circulates in maternal blood. The testing is non-invasive, involving a maternal blood draw, so the pregnancy is not put at risk for miscarriage or other adverse outcomes associated with invasive testing procedures. The results are typically available within a week to 10 days. This testing has been available for trisomy 21 (Down syndrome) for 4 years, but recently they have added the option of testing for Prader-Willi syndrome and several other microdeletion syndromes plus sex chromosome abnormalities. Note: This is a screening test, not a diagnostic test. Currently it is mainly available to high risk women, but is most likely going to become available to all pregnant women.

But New Technologies Bring New Ethical Dilemmas…

I was on a panel in July at an international conference in D.C. on this issue representing Prader-Willi syndrome from a patient advocacy perspective. The title of the conference was "Stakeholder Perspectives on Noninvasive Prenatal Genetic Testing: What we have learnt and where we are going." We discussed the legal, ethical and social implications of NIPS plus clinical implementation issues and disability rights. The following notes are from some of the presentations and discussions that day.

Advantages – NIPS streamlines information. You can get the blood test while at a regular appointment and it can be more private. There is no risk of miscarriage. If it is negative for a high risk mother, it may reduce the stress on her and her spouse/partner. NIPS is more accurate than other first and second trimester serum screening tests, and as a result fewer women need to have diagnostic tests (like amniocentesis) for confirmation of serum screening results. If the parents and the medical staff know what to expect and are prepared to address the potential medical issues at the time of birth, for some, this diagnosis can make a life and death difference.

Disadvantages – Although the testing companies claim that NIPS is 90%-99% accurate, there is a chance of false positives or false negatives, especially with rare conditions such as PWS. Often, all of the information on all of the tests needs to be relayed in a 20 minute visit. This can cause anxiety and stress and raise ethical concerns about informed decision-making. It is a screening test, not a diagnostic test – yet 6% of women who receive a positive NIPS result terminate without confirmation. Noninvasive testing for PWS can detect whether a fetus has a good chance of having PWS or Angelman syndrome but cannot separate out which one – and there is a big difference in the phenotype between the two. At this time it will only pick up on deletion, not UPD.

What does informed consent look like? – Ideally, a genetic counselor would meet with the person/couple before screening, and afterwards if there is a positive result. The meeting before the screening is to make sure that the person /couple understands the benefits and risks associated with

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Pre-Natal Screening, *continued from page 8*

screening and that they know the emotional and ethical issues that will arise if the test comes back positive. In reality though, there is limited access to genetic counselors and it will become even more of a problem as use of NIPS increases potentially among average risk women. There are not enough genetic counselor training programs or enough people going to medical school receiving training on medical genetics. In fact, the number of geneticists is predicted to be decreasing just as there is a greater need due to the explosion in genetics. The role of informed consent and counseling will increasingly become the responsibility of the GP or OB/GYN – who typically has little experience in genetics. In a survey, a lot of GPs thought they should refer to a geneticist, but in reality fewer actually make that referral. Also, the counseling is needed in a very timely manner, not an appointment months away after the woman and her partner already have had to make a decision. Better education of GPs and OB/GYNs and more objective educational materials are needed. This is far from ideal but more realistic than trying to refer all women considering NIPS to geneticists and genetic counselors. There should be standards of what women are told about NIPS, including that they have the right to decline screening. In one state, NIPS may be ordered and the testing done without actually going to an appointment with a physician – just going to a blood lab. Will this be the wave of the future?

No matter what that decision would be, I think we all agree that our children are precious and deserve to be on this earth as much as we do.

Reimbursement issues – NIPS coverage, like other coverage, depends on whether insurers consider it "medically necessary" and it has "analytic and clinical validity" vs "experimental" or "investigational". Insurance policies differ and lead to inconsistent access. And in some states, decisions about NIPS usually depend less on assessments of the validity of NIPS, and more on the local political and economic situation – as such. Medicaid coverage varies state-to-state. In the US, women who are White and/or have a higher socioeconomic status are more likely to have NIPS. In some European countries it is likely to be covered by public health care.

When it becomes available to the mass population:

- Ethical issues may increase because of "routinization" of testing
- Informed consent may be eroded raising ethical concerns about patient autonomy
- Due to increasing peer pressure to test there is concern about discrimination regarding the worth of a child with disabilities
- Women may not be asked for a detailed family history or be advised of potential additional genetic risks
- There will need to be education of non-specialist providers, which is not industry driven alone. What tools and methods would be best to educate the physicians? Should there be online courses for physicians? How do we evaluate the effectiveness of education? Should there be CME's?
- There will need to be patient education that is not industry driven
- There is aggressive marketing by companies. Is it being implemented too fast?

Kaiser Permanente Health Care in Southern CA – They serve 10% of California. They have 8 clinical geneticists and 40 genetic counselors. Every one of their female patients considering NIPS sees a genetic counselor, but this will not be sustainable as testing expands. Amniocentesis testing has dropped significantly due to improved ultrasounds and NIPS. Approximately 80% of women who are offered NIPS decide to have it. Kaiser Permanente Health Care in Southern California does 140-150 tests a week. Of 6,931 women tested so far, 227 had an abnormal (positive) NIPS result. Currently if you factor in the cost for all that get tested, the cost per abnormal diagnosis for NIPS = $56,000, but if offered to all, it will be $250,000 per abnormal diagnosis. Testing for Down syndrome has been available for a long time. At Kaiser, in the past, 65% terminated the pregnancy for Down syndrome– now with NIPS, it has increased to 75%, not as much of an increase as expected.

Report on Buenos Aires, Argentina – One-half of all patients are in the public health care system and one-half are in the private system. Abortion is not legal. The only exception is if the mother's life is at risk. Although abortion is not legal, it is the leading cause of maternal mortality with 85% of the deaths occurring in public hospitals. Those that can afford it go elsewhere for the abortion, thus illegal abortion is unsafe for the poor – but not unsafe for the rich. Only one in 500 have had NIPS so far.

Report on China – It is illegal to remove Chinese citizens DNA from China, so only Chinese companies can offer genetic testing within China. It is also illegal to test for fetal

continued on page 10

PWSA (USA) is sponsoring a grant that will bring therapy to the home!

The PWSA (USA) Joseph McErlane Research Grant

Principal Investigator: Anastasia Dimitropoulos, Associate Professor of Psychology, Ph.D.
Case Western Reserve University, Cleveland, OH

Project Title:

Evaluating the Feasibility of a Telehealth Intervention of Early Social Cognitive Processes in Children with Prader-Willi syndrome

Relevance of this study:

Current research in typically developing children has shown that pretend play, the ability to play with toys in an imaginative way, is related to important areas of development, such as social-emotional understanding. Research has also shown that individuals with PWS have difficulty in social situations, in emotionally understanding others, and have difficulties with regulating their behavior and emotions in difficult situations. Since many children with PWS have trouble with social-emotional skills, intervention targeting these skills through pretend play could increase quality of life while also decreasing problem behaviors, as has been shown in children with other developmental disabilities.

Through this grant, they will administer intervention in the participant's home (using telehealth videoconferencing) to increase its accessibility to the PWS population. If feasibility and improvements are found, these results will lead to establishing a practical treatment alternative for families dealing with Prader-Willi syndrome.

Eligible participants will be children with PWS between 5 and 11 years of age. Individuals without Internet capable computers will be excluded from participation; however, equipment will be available for participating families who do not have necessary components (i.e., webcam). ***Details of participant eligibility will be available in the near future on PWSA (USA)'s website and Facebook pages.***

(Note: Wouldn't it be wonderful if we could provide help for families that live far from major treatment centers and spare all families dealing with PWS from some of the multiple trips needed to get the proper intervention? We see this pilot project as the first step in bringing this type of intervention to your home. It's the wave of the future! ~ Janalee) ■

Pre-Natal Screening, *continued from page 9*

sex in China due to a history of sex-selective abortions and giving girls up for adoption. On the other hand, if the screening shows an abnormality, it is culturally expected that the pregnancy will be terminated. Berry Genomics in China reports that they have done more than a million NIPS. It costs an average of one month's income for the testing. Testing is paid for out of pocket and there are NO trained genetic counselors to perform pre-test counseling. There are attempts by the government to improve genetics education of physicians.

Patient advocate panel – We were there to bring the face to the statistics, and the human and ethical issues to the clinicians and technicians. To some of you, I am sure that terminating a pregnancy would have never been an option under any circumstances. But, to others, you may wonder what your decision would have been if NIPS had been an option to you at the time. What would it be if one of your other children was at risk once they are grown and have children of their own? No matter what that decision would be, I think we all agree that our children are precious and deserve to be on this earth as much as we do. I was told one country had a goal to be "Down syndrome free" by a certain year. Would we really be a better world without children who have Down syndrome – or PWS? ■

CHUCKLE CORNER

Wanted!

Do you have a funny story? I mean a really funny story you would like to share with our families? We would love to make people smile with your submission:
Please email your story with your name, town and state (for the credit) to:
pwsaeditor@pwsausa.org

Thank you!

We hope you find this publication and our materials helpful and that you consider a donation to PWSA (USA) to assist in developing more good work(s) like this. Please see our website, www.pwsausa.org

Being Pro-Active with Law Enforcement

By Evan Farrar, M.A., PWSA (USA) Family Support Counselor

http://www.disabilityscoop.com/2015/06/18/new-tool-police-response/20392/

Some encounters with law enforcement can be scary for adults and children with PWS – and their families. This is why we recommend parents and guardians pro-actively reach out to their local police department to let police officers and other law enforcement professionals know their child has Prader-Willi syndrome. This can include giving your child an opportunity to meet some local officers so they establish a relationship and are less fearful if approached by a police officer. Some parents also create a simple one page handout with their child's picture and a little about PWS and unique characteristics and qualities of their child. PWSA (USA) has a great resource we encourage all families to keep on hand: a statement for law enforcement - one for children and the other for adults with PWS. The statement can be given to a police officer and it explains why a person with PWS might become involved with law enforcement for disability related reasons such as a behavioral outburst or taking food. These law enforcement statements are available on our website at http://www.pwsausa.org/Family-Support/legal-issues

In addition, many local police departments have some type of special needs database where a parent can voluntarily share information about their loved one with a disability so that officers know in advance when a person has a disability and what this might mean for their behavior and how to approach them. Check to see if your local police department has something similar and consider registering your loved one with PWS as another preventive measure. Most people with PWS never have any significant involvement with law enforcement. But, just in case, it is good to be prepared. ■

A Balanced Life

Hi, my name is Kathryn Lucero. My husband and I have an 18-month old son named Ronan and we live in Albuquerque, New Mexico. After my husband and I received our son's diagnosis of PWS, it became clear why I chose the schooling path that I did. With a Bachelor's degree in exercise science and a Master's degree in social work, I could help my family and others by becoming a Health and Wellness Coach. I am currently a student with the Institute for Integrative Nutrition (IIN).

I want to share information to offer balance in your life, tips to help with stress, and suggestions for fun and family activities.

As parents to a child with PWS, we love that person so much we always want what's best for them. This means that first you must take care of yourself. At IIN, Primary "Foods" (not actual foods) are four areas that make up your environment: relationships, career, physical activity, and spirituality. Each of these "foods" nourishes our minds and bodies. If one of these is out of balance, you may feel it and your Secondary "Foods" (the ones you eat!) will also go out of balance.

Take a moment and think about how you nourish your mind and body: what makes you feel good? What gets you through the day? As you make this journey with me, we always circle back to your Primary Foods; this is what drives each of us.

If you have a question or a topic you would like addressed via *The Gathered View*, please contact me through pwsaeditor@pwsausa.org and include "a balanced life" in the subject line. I look forward to inspiring you and helping you find your balance. ■

ATTENTION Federal Employees!

If you work for the Federal government, the Combined Federal Campaign (CFC) is a program through which you can give to the charity of your choice. The campaign's mission is to provide "all federal employees the opportunity to improve the quality of life for all." **PWSA (USA) CFC ID# is 10088.**

For more information about the CFC program and how it works, go to their Web site at http://www.opm.gov/cfc/index.asp, or contact the PWSA (USA) office at (800) 926-4797 and ask for Debi Applebee. ■

Editor's Note: *In previous issues of* The Gathered View*, you have read about the other seven members of the PWS Advisory Board. Here is Abbott Philson's piece, which he very much wanted to write, to illustrate how much a young man with PWS can accomplish.*

My name is Abbott Philson. I am 31 years old. I live in Cumberland, Maine with my mom and dad, occasionally my sister, Adrienne, my cat Jonah, and our dog, Cassie. I walk her every day for forty minutes of exercise for both of us.

You might know me from the Public Service Announcement (PSA) I made in my Media Day Program about PWS on You Tube. I have served on the PWS Advisory Board from its inception and work to bring awareness about PWS every way I can.

I go to day programs during the week, which offer three areas of concentration, art, media and music. The programs are called The Art Department (art and media) and Listen Up. Each of them incorporate daily exercise such as significant walks to places of interest about Portland for necessary materials, for library research to support our art projects, for museum visits and for Maine College of Art visits to coordinate with art students. What I enjoy most about these programs is how we take our work out into the community, performing our music at real venues, selling our artwork at First Friday Art walks, a popular City of Portland monthly event that draws large crowds, and showing movies at Space Gallery that we write, act in, and film ourselves. The movie night is called TV Show. Recently I was The Art Department's Artist of the Month. Tuesdays and Thursdays I attend a music program called *Listen Up*. We write and record our own songs, record cover songs, or we record our own scores for our movies. My band is called Dysfunctional Mayhem. I sing and play piano. The rest of the week I'm at The Art Department where I make art to sell and I make movies.

Embedded in the day programs is the opportunity to develop and practice leadership skills. I have enjoyed pursuing positions of leadership most of my life. During my high school years, I joined the Civil Rights team, and was elected to the Executive Council. After high school, I was elected to the Executive Board of *Strive,* a center for teens with disabilities, for 7 years serving as an officer most of those and as President for the last three years. So it was natural for me to serve on the PWSA (USA) Advisory Board from the start.

I heard that a lot of PWS families have been asking the national association about self-advocacy. I am in a national self-advocacy group called SUFU, which stands for **Speaking Up For Us.** SUFU is made up of people with disabilities who choose to speak up for themselves about issues or concerns that are important to them. I am on the Advisory Committee that I got elected to by my day program and represent them at state gatherings. I also participate in a SUFU sports group that promotes participating in a sport you are interested in within your community on a local team. The SUFU organization commissioned The Art Department to write and film some fun educational videos about healthy cooking and training videos on our rights. All our cooking episodes are on YouTube or you can access them at www.theartdepartment.me. The show is called "Start Cooking Yo." See what you think. The training videos can be accessed through the SUFU Maine website. If you would like more info about self-advocacy, feel free to contact me through the PWS national association. Remember, lots of disabled people are interested in healthy attitudes about food and exercise, not just PWSers.

...for the last 27 years I ...walk 20 miles as part of Boston's Walk for Hunger to raise money for people who are truly hungry all the time.

...Kind of brings me full circle around food issues!

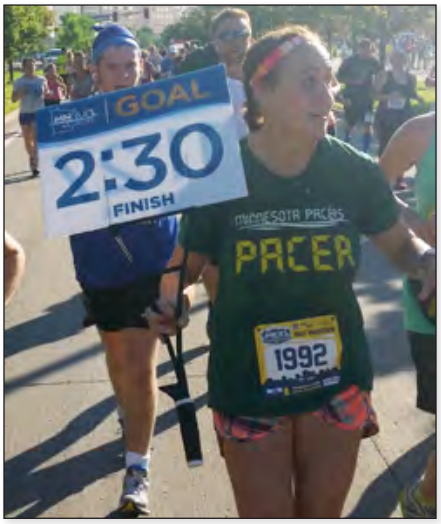
I graduated from high school with Highest Honors that I worked really hard for, especially in light of moving from New York to Boston to California before ending up in Maine. Four different ways of handling my PWS! I like to go geo-caching with my dad, sail in Casco Bay, ride recreational dressage as well as compete in horse shows and I especially enjoy line dancing. I also play Special Olympics basketball and floor hockey. Of course, I like crossword puzzles, too. Each year for the last 27 years I also walk 20 miles as part of Boston's Walk for Hunger to raise money for people who are truly hungry all the time. I needed to ride in a baby carriage my first years, but now I walk faster than my parents. Kind of brings me full circle around food issues!

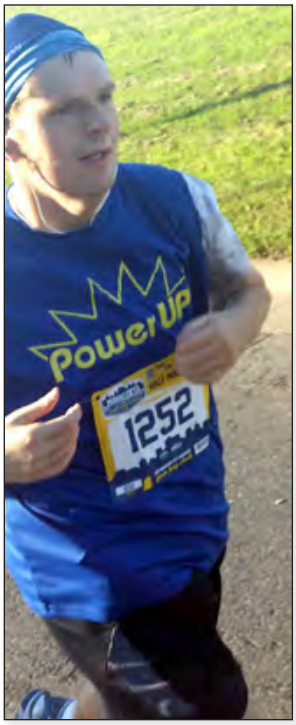
Recently, I attended my 4th Para Equestrian Training Camp which my riding school, Carlisle Academy, hosts each year. I get to work with world-class trainers and coaches from Europe and para-riders from all over the U.S. who want to make it to the International Para Olympics. I have been classified as grade 3 and I hope to ride in regional and national para-equestrian competitions and dream about making it all the way to the Para Olympics some day, too. ■

There is No Quit

By Denise Servais

On August 1st, 2015, Adam Lebeck, 25, did something few of us have done. He finished the MN Half Marathon.





Adam running the MN Half Marathon August 1, 2015

What makes Adams's story so special is that this young man has PWS. Adam currently lives at a PWS residential facility in Hastings, MN.

Six years ago Adam Lebeck was at his peak weight of 345 pounds. Then he found *Stepping Out,* a residential treatment facility to help those with Prader-Willi syndrome manage a healthy lifestyle, in 2009. The staff encouraged Lebeck to start running and lifting weights. Eventually, Lebeck lost 200 pounds. "I like running because it makes me feel good and proud of myself," Lebeck told *Runner's World Newswire*. Lebeck's story was featured in a *Runner's World* article. He was also featured in the local TV and newspaper media.

Adam before his weight loss.

Adam after

Andrew Johnson, Operations Manager for *Stepping Out*, told *The Gathered View,* "there is no quit in him." Lebeck told Johnson, a half hour after the race, that he (Lebeck) *was going to run a marathon next year*. "He is a true competitor with compassion and has great leadership," said Johnson. Apparently, Lebeck's efforts have inspired other residents at *Stepping Out* to try a marathon. Congratulations, Adam! ■

¡HOLA!

By Nina Roberto, E.D. of the New York Association and on the State Chapter Leaders Team as representative to Spanish-speaking families with PWS.

¡Hola! Me llamo Nina Roberto y soy la especialista para familias hispana. Estoy disponible para ayuda, apoyo y informacion sobre el Syndrome de Prader-Willi. Yo tengo tres ninos. 20, 10 y 9. Mi hijo que tiene 10 anos tiene SPW. Yo vivo en NY pero ayudo familias en los estados unidos que nececitan informacion y ayuda. Les quiero directar a www.pwsausa.org donde vas a encontrar informacion en espanol. Si tienes algunas preguntas me pueden llamar a (718) 846-6606 o email, ninaroberto@verizon.net. ¡Hablamos pronto! ■

*Thanks to our new PWSA (USA) board member Leon Caldwell and his family, more awareness on Prader-Willi syndrome was brought to the set of the hit TV show, **"The Big Bang Theory"**. Pictured in back are Leon and his wife Celika, and on the couch are their daughter Kendi, actress Mayim Bialik (Amy on the show) and son Kahlil, with PWS. More pictures and the rest of the story will be featured in the next issue of* The Gathered View.

Now Available! from the PWSA (USA) Adults with PWS Advisory Board

Important New and Unique School Handout

By Evan Farrar, M.A., PWSA (USA) Family Support Counselor

During PWSA (USA)'s Adults with PWS Advisory Board meeting in January, we spent some time with the group discussing their school experiences. The conversation with this bright and engaging group was fascinating and informative. We celebrated successes at school and also the challenges they faced. Many of those challenges still exist for students with PWS today. ecause what Advisory Board members had to say is so important, and very helpful information for school professionals, with their permission we created a brand new handout called, "Supporting Students with PWS: Information and Advice for School Professionals from the PWSA (USA) Adults with PWS Advisory Board." Topics covered include:

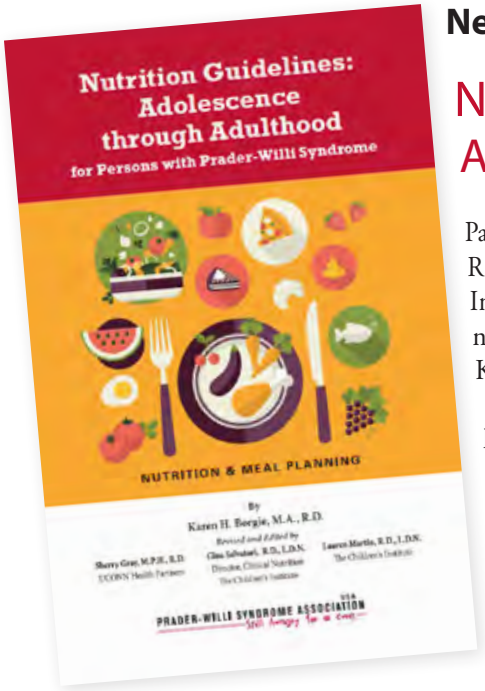
- What works best for students with PWS
- What kind of accommodations can help
- What school professionals should know to better serve students with PWS

This is the first handout for schools that contains information exclusively from the perspective of people who've lived the experience of being students with PWS. Therefore, it is an important contribution to literature we provide schools because it is based on the first-hand experience of Advisory Board members. We recommend it to parents and school professionals. You can obtain a copy of the handout in two ways:

1. If you are subscribed to the PWSA (USA) school e-letter, "School Times," it will be included in our next issue. To subscribe to "School Times" e-mail me at efarrar@pwsausa.org **Note: We encourage all parents of school-age children with PWS, and school professionals who serve them, to subscribe to "School Times" which is the only publication dedicated exclusively to PWS school related issues.**

2. You may also e-mail me directly to receive a copy or contact our office at 800-926-4797 to request a copy by mail.

I want to say a very special thanks to the Advisory Board members who provided information for this handout: Shawn Cooper, Brooke Fuller, Conor Heybach, Kate Kane, Lauren Lange, and Abbott Philson. Without their willingness to share openly and honestly about their school experiences, this important new resource would not be available to help a new generation of students with PWS. ■

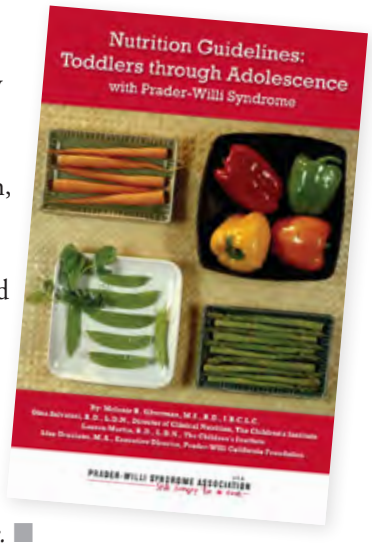


New Publication! ***20% discount for members***

Nutrition Guidelines: Adolescence-Adults with PWS

Thanks to the volunteer efforts of Sherry Gray, M.P.H., R.D., UCONN Health Partners; Lauren Martin, R.D., L.D.N., The Children's Institute; and Gina Salvatori, R.D., L.D.N., Director, Clinical Nutrition, The Children's Institute, we are pleased to offer a revised and updated nutrition booklet with guidelines and tools written by Karen H. Borgie, M.A., R.D.

These wonderful professionals donated numerous hours to revamp and update this 32-page publication, which includes sections on caloric needs, a PWS Food Pyramid, worksheets, meal plans, exchange lists, and much more. This booklet can be purchased for $7.50 by calling the office, 1-800-926-4797, or by ordering from our website, www.pwsausa.org/shop/publications.



Featured on page 14 of the March-April 2015 issue, the newly updated edition of Nutrition Guidelines for Toddlers through Adolescence *is also available for purchase.* ■

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Deadlines to submit items to *The Gathered View*: Dec. 1; Feb. 1; Apr. 1; June 1; Aug. 1; Oct. 1

Our Mission: Prader-Willi Syndrome Association (USA) is an organization of families and professionals working together to raise awareness, offer support, provide education and advocacy, and promote and fund research to enhance the quality of life of those affected by Prader-Willi syndrome.

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The Members Only section requires a password. Please enter PWS for the code.

E-mail Support Groups: We sponsor nine groups to share information. Go to: www.pwsausa.org/egroups

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can be changed, even though he has PWS?
What if he was more present? More engaging?
Participated in class? No longer wanted to play alone?
And actually cared if you don't feel well
or asked how you are?
That is what oxytocin has done for my child.

Oxytocin Phase 2 Study Campaign Update
page 4

In this Issue