The Gathered View
National Newsletter of the Prader-Willi Syndrome Association (USA)
PRADER-WILLI SYNDROME ASSOCIATION USA
Still hungry for a cure.

IMPORTANT: New School Discipline Resource for Parents and School Professionals

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

Due to behavioral issues, students with PWS are at risk for suspensions and even expulsion. Preliminary results from PWSA (USA)'s national school survey indicates that 25% of students with PWS have been suspended at least once and 5% of students with PWS have been expelled. This experience is not unique to students with PWS. A 2014 report from the U.S. Department of Education Office for Civil Rights reported overall:

- Students with disabilities are more than twice as likely to receive an out-of-school suspension than students without disabilities.
- With the exception of Latino and Asian-American students, more than one out of four boys of color with disabilities (served by IDEA) – and nearly one in five girls of color with disabilities – receive an out-of-school suspension.
- Students with disabilities (served by IDEA) represent a quarter of students arrested and referred to law enforcement, even though they are only 12% of the overall student population.
- Students with disabilities (served by IDEA) represent 12% of the student population, but 58% of those are placed in seclusion, and 75% are physically restrained at school to immobilize them or reduce their ability to move freely.
- African-American students represent 19% of students with disabilities served by IDEA, but 36% of these students are restrained at school through the use of a mechanical device or equipment designed to restrict their freedom of movement. Source: http://ocrdata.ed.gov/Downloads/CRDC-School-Discipline-Snapshot.pdf

These statistics reveal what many parents in the PWS community already know – when it comes to suspensions and expulsions of students with disabilities, we have a serious problem in the public school system. There are many reasons for the disproportionate application of suspensions and expulsions for students with disabilities. Several resources and reports are available to explain the problem. But now we have a resource designed to prevent suspensions and expulsions and to keep students with disabilities in school where they belong.

The new resource is titled: ***Keeping Students with Disabilities in School: Legal Strategies and Effective Educational Practices for Preventing the Suspension of Students with Disabilities.*** Produced by the Southern Disability Law Center, this publication explains ways to use some of the discipline provisions and other IDEA requirements to prevent the use of suspensions, expulsions, and removals to alternative education programs (Disciplinary Alternative Education Program) of students with disabilities.

...help parents and IEP teams to work together...

What I love most is that this is resource is ***written for both parents and school professionals*** to use. Therefore, it can and should be an important tool to help parents and IEP teams to work together to prevent overuse of suspensions and expulsions when helping students with disabilities overcome challenging behaviors. For example, the sections on Functional Behavioral Assessments (FBA) and Behavioral Intervention Plans (BIP) provide a comprehensive review of the importance of these interventions and practical tips for how to create and use them effectively.

So, if you are the parent of a student with PWS, I urge you to share this resource with your child's IEP team and review it together. This way, everyone will be working from the same preventive playbook if a behavioral issue arises, promising better behavioral outcomes for your child. You can download this **FREE RESOURCE** by going to the School Issues page of the PWSA (USA) website www.pwsausa.org and clicking on the link titled: Prevention Suspension of Students with Disabilities. ■

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Prader-Willi Syndrome: When Client's Rights and Medical Necessity Conflict

Foreward: The question of "rights" vs. dietary management and restricting access to money (which can buy food) first reared its head in the 1990s just as many of our young people with PWS were starting to enter group homes. This resulted then in several deaths and many obesity-related medical crises. In response, the PWSA (USA) Board in 1998 approved a strongly-worded policy paper entitled "Adults and PWS and Decisions Regarding Least Restrictive Environment and the Right to Eat" – which seemed to successfully address the problem.

Sadly, the issue has emerged again, stronger than ever because of 2014 Federal Statutes mandating access to food whenever an individual served by Medicaid and community-based services wants it. Predictably, there have already been severe medical repercussions in some places where the rule has been implemented.

Some hard work has been done at PWSA (USA) to update this paper. Dr. Barb Whitman offered to create the initial draft which has been revised by our Family Support Team and Jackie Mallow. It was then approved by our national board. The following is the final draft which will be vetted by our PWSA (USA) Clinical Advisory Board during their meeting in July. After this meeting it will become our official consensus statement. It is included in this newsletter for you to read and make use of should you need it. We all know the danger that unlimited access to food poses to our loved ones with PWS.

Introduction: *Among the achievements to be celebrated for those providing care to persons with cognitive challenges is the improved quality of life for those so challenged, along with the recognition of "client's rights" to make many of their own choices as well as to live in the least restrictive environment. Thus, the now common concepts of "community inclusion" and "supported living arrangements" have opened new avenues of opportunity and enjoyment previously denied affected adults. While specific medical etiologies for any given disability may not always be of overriding importance in determining services and supports, at the same time, more intensive research regarding genetic and behavior phenotypes has documented that for certain genetic disorders, one size does not fit all; specific genetic syndromes and recognizable neurobehavioral patterns that present serious considerations that must be addressed in the development of a service plan. Uncritical application of "rights" without regard to the consequences resulting from failure to adhere to medical needs may lead to tragic outcomes.* ***There is no more tragic example of this than the horribly painful death from rupture of the stomach of adults with Prader-Willi syndrome when a misunderstanding of the proper application of "clients rights" resulted in a complete disregard of their medical needs.***

The Right to Decide Not to Diet: The issue of adults with Prader-Willi syndrome deciding whether they "want to diet, or not" is just such an issue. The dialog that raises this issue is framed by the concept "least restrictive environment" or "client rights." The argument generally is that strict dietary management is "too restrictive" or that locking food abrogates "rights." Although easier access to food may be a strong desire for individuals with Prader-Willi syndrome, it is a dangerous and medically neglectful practice. In too many cases, such practices have led to medical emergencies and premature deaths. This growing trend is both alarming and tragic. Failure to restrict access to food is tantamount to medical neglect. To illustrate, let us draw a parallel with diabetes. Diabetes results from a failure of the pancreas to produce adequate insulin. Thus, the person with diabetes must maintain a calorie- and carbohydrate-restricted diet while taking supplemental insulin. Failure to rigidly follow this regimen leads to elevated blood sugars and, ultimately, death. No caregiver home would think of telling diabetics that their diet was "too restrictive" or that restricting access was an abrogation of rights. ***The management of the eating behaviors in persons with Prader-Willi syndrome is based on similar physiologic failures and is equally medically critical.*** In this instance, there is a genetically based inability to sense satiety, combined with a decreased utilization of calories, results in an elevated production of fat tissue. A brain based failure to experience satiety (know that they are full), combined with a decreased pain sensation that does not provide them with volume induced discomfort (brain fails to tell them that their stomachs are too full) has resulted in medical emergencies from choking while "quickly stuffing down" food that is not on their diets, while others have died from rupture of the stomach when the volume of intake was not appropriately restricted. This physiologically driven eating behavior is no more under cognitive control, nor amenable to cognitive remediation, than is the failure of the pancreas to produce insulin in diabetes. Further, there are, to date, no medical, pharmacologic, or behavioral treatments that fix or cure this biological malfunction.

A second issue is whether restricting spending money (to limit ability to buy food) violates the personal rights of adults with Prader-Willi syndrome. In many states, the agencies and group homes that specialize in Prader-Willi syndrome are increasingly criticized as being too restrictive, and as violating consumer rights. Many programs have been ordered to increase client access to food, to move clients into less restrictive settings, and to give clients decision making control of their access to food and money to buy food. In addition to the short-term consequences that can lead to death from these practices, there are long-term medical consequences that also lead to an early death. It is well established that individuals with Prader-Willi syndrome gain weight on ½ the calories allowed for an unaffected individual. It just takes a few short weeks of increased caloric intake to lead to rapid and morbid obesity. This rapid obesity overtaxes the heart and

continued on page 3

ED View, *continued from page 2*

leads to complications that can include sleep apnea, diabetes, hypertension, and cardiopulmonary compromise. Current data reported to the national Prader-Willi Syndrome Association (USA) documents 148 deaths directly attributed to obesity related complications.

The Right to Decide Revisited: Bioethicists dictate that informed consent requires the capacity to consider, and fully understand, the pros and cons of both sides of an issue prior to making a decision. Since by their own physiology, persons with Prader-Willi syndrome cannot decide "not to eat," therefore they cannot responsibly decide the converse: "to eat, or not to diet." This is most recently exemplified by the death from multiple organ failure of a 28 year old whose weight rapidly rose to over 500 pounds after a judge ruled that he had a right to eat. This young man's death is not the only example of the outcomes of such rulings. Clearly to allow such decisions under the guise of "restriction of rights" is both medically and ethically unsound.

The Least Restrictive Environment for Persons with Prader-Willi Syndrome: Developing an appropriate social milieu for individuals with Prader-Willi syndrome means creating an environment where the least restraints are present, remembering that environments of least restraint do not maximize freedom in an unbridled sense, but are designed to help individuals achieve their fullest possible potential. In planning the care-giving environment for persons with Prader-Willi syndrome, some contradictions are evident. While persons with Prader-Willi syndrome need extensive food support, they show fewer needs for support in other aspects of their lives. Indeed, many persons with Prader-Willi syndrome show competencies and decision making abilities outside the food arena. Nonetheless, until there are medical or pharmacologic interventions for this physiologically driven eating behavior, structured environments with restricted access to, and intake of, food must be standard care for persons with Prader-Willi syndrome. Environments must become more restrictive when lesser restraints fail to protect the physical or emotional well-being of the person or to ***protect the person from doing avoidable harm to themselves or to others.*** For individuals with Prader-Willi syndrome, failure of the care-giving environment to maintain a rigidly managed diet or to supervise food access inevitably leads to the previously described consequences that can in the short term lead to stomach rupture and death, or in the somewhat longer term will lead to rapid weight gain, cardiopulmonary compromise and death. There is nothing "least restrictive" about a person who is so morbidly obese they are in a wheelchair and on oxygen.

In a medical setting, failure to provide the appropriate dietary and food access limitations would lead to charges of malpractice. Such a failure in a certified living environment can, and has, led to equally serious legal consequences based on medical neglect. ■

~ Ken Smith, Executive Director, PWSA (USA)

PWSA (USA) Moving Forward With Research

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

Dr. Robert Nicholls' Research - Collaboration at its Finest:

Thanks to a major designated donation from the Storr Family Foundation, PWSA (USA) approved funding ($100,000) to Dr. Robert Nicholls' research. The Storr Family Foundation has provided research support for 2014-2016 to Dr. Robert Nicholls for novel directions in his research on the basis of Prader-Willi syndrome. This support emanated from Dr. Nicholls ***"Ride for Research --One man One bike One ride across America for a Cure"*** in October 2013, an event partnered with PWSA (USA). Subsequently, the Storr Family Foundation made a major designated donation to PWSA (USA) towards Dr. Nicholls' pig model research. The following is a short explanation of the original partnership between the Storr family foundation, PWSA (USA), and Dr. Nicholls – and the new partnership.

A Pig Model of PWS: Previous research on mouse models had shown that these do not develop hyperphagia (constant desire to eat) and obesity. It remains critical to develop a clinically accurate animal model of PWS to understand the pathogenesis and for assessing new therapeutic approaches, and **Dr. Nicholls first proposed that the minipig should be ideal since they have a similar physiology, biochemistry, anatomy with similar body and organ size, pathology, and genome compared to human.** Reagents for genome editing of pig chromosomes were developed and optimized using a novel cell culture model followed by similar assays in pre-implantation pig embryos (the latter in collaboration with researchers at the University of Missouri). The collaborative team is using artificial reproductive techniques in attempts to establish pregnancies with the goal to produce litters with some piglets having the PWS genetic change.

Hormone Secretion Deficits in PWS: The current project is to develop new cell-based models to determine the endocrine (hormonal) basis of PWS. From clinical studies and Dr. Nicholls' prior mouse model studies, the genetic deficits in PWS are known to lead to reductions in the release of numerous hormones, including from the brain's hypothalamus and pituitary (hormones that control growth and reproduction) and from the pancreas (insulin and glucagon). Indeed, it is well known that the most dramatic therapeutic intervention for PWS has the been the advent of growth hormone (GH)-treatment beginning in infancy, leading to improvements in muscle function, body composition, height, and the overall clinical outcome in PWS. Nevertheless, GH treatment is not a cure and many clinical issues remain including hyperphagia, episodes of low blood sugar (hypoglycemia) and behavioral problems. **Therefore, Dr.**

continued on page 4

Research, *continued from page 3*

Nicholls proposed that numerous hormone deficits occur in PWS as a consequence of endocrine cell secretory abnormalities, and that understanding the underlying basis will allow additional hormone or small molecule therapies to be identified for clinical features not helped by GH treatment. Dr. Nicholls is using established hormone-secreting cell lines to determine the molecular and cellular mechanisms by which PWS genes control hormone secretion. The engineered PWS cell lines are being examined for deficits in hormone secretion, gene expression changes, and for defects in the way that hormones are produced, traffic through the endocrine cell and are secreted from that cell. Dr. Nicholls' studies will lead to an understanding of how hormone production goes wrong in PWS endocrine cells and which PWS genes are responsible. The studies will also produce functional PWS cell models that will allow future screening for additional hormone or small molecule therapies for PWS. ■

Oxytocin Phase 2 clinical trial:

Thanks to the amazing efforts of many PWS families, the PWSA (USA) sponsored oxytocin phase 2 study has raised over $600,000, and the clinical trial by Dr. Miller and Dr. Driscoll will be moving forward soon. The phase 1 clinical trial results have been submitted for publication. Although we cannot say much until the results are published, I will confirm that the statistical outcomes are very encouraging. Oxytocin is a hormone which is synthesized in the hypothalamus (a part of the brain not functioning properly with PWS) and has the potential to reduce anxiety and improve social interactions. ■

Blood clot survey:

Thanks to a $20,000 grant approved by Zafgen, PWSA (USA) has been able to do an extensive survey on thrombosis (blood clots) in PWS. We had an online survey, and did a mailing to approximately 6000 families. At this time, we have the completed results from over 1000 families so are in the process of analyzing the data. We have recently become aware of the higher risk of blood clots in PWS which can create a deep vein thrombosis (DVT) or a pulmonary embolism (PE) which can be immediately life-threatening. We want to do more than alert and scare our families and professionals – we want to figure out the risk factors and how to prevent crises. ■

Data Management Coordinating Center (DMCC) at the University of South Florida in Tampa:

PWSA (USA) has approved a second year's funding of $25,000 in order to support the database center in Tampa which houses an extensive 10-12 years of natural history on PWS. The funding was awarded after the NIH-RDCRN grant funding ended. The information that can be gleaned from this natural history study is important, and this will ensure that the staff at the database center will be able to put the time into working on the statistical information needed. ■

The International Consortium to Advance Clinical Trials for Prader-Willi Syndrome:

PWSA (USA) has approved a $10,000 donation to support the mission of the consortium which is to accelerate clinical trials for PWS through the establishment of a collaborative, pre-competitive and international consortium that will leverage expertise and perspective of stakeholders from industry, academia, governmental agencies and patient organizations to address unmet scientific, technical, clinical and regulatory needs for clinical trials for PWS. ■

A Massive PWS Awareness Campaign for Geneticists

By Janalee Heinemann, M.S.W.

PWSA (USA) had an awareness booth at the American College of Medical Genetics (ACMG) national meeting in Tampa, Florida, March 8-12, 2016. **During this conference, they had the first-ever symposium on a single syndrome (Prader-Willi syndrome) and had approximately 2,000 geneticists and genetic counselors attending.** The symposium lasted 2 ½ hours with five speakers on PWS. What huge awareness! The moderators were Jennifer Miller*, M.D., and Christian Schaaf, M.D., Ph.D. It was a special time for us because Suzanne Cassidy*, M.D., also presented and received the Pruzansky Lecture award.

Dr. Cassidy provided an excellent overview and explained the importance of PWSA (USA) for education and support services. She recommended people stop by our booth and get the flash drive we were distributing free that had a tremendous amount of information on the syndrome – booklets, brochures, and articles. We heard very positive comments on

continued on page 5

Geneticists Awareness, *continued from page 4*

the presentations at the symposium, and their amazement at the amount of services provided by our organization. **One physician stated that PWSA (USA) should be the prototype for every rare disease organization.** We were swamped at our booth and ran out of the flash drives, had more made quickly at the office, and ran out again! We also distributed other information, including the new Medical Alert booklet, and promised those who did not get a flash drive that we would send them the information. PWSA (USA) was mentioned 18 times in the program booklet – further great awareness.

Janalee Heinemann and Carolyn Loker, at the ACMG national meeting

Carolyn Loker helped me host the booth for the first time, and told me that after all these years, she now truly understood the importance of doing these educational booths at major medical conferences. Although we are worn out by the end, the enthusiasm of interacting with hundreds of specialists who will ultimately make a difference in the care they give to our children thanks to the information we distribute, keeps you on a high throughout the entire conference. Carolyn also got to experience how special it feels to help physicians from other nations that have little information on the syndrome.

PWSA (USA) recently had another major educational effort by mailing 1,041 packets of information on the syndrome to PWS clinics, geneticists and genetic counselors around the nation. A special thank you goes to Pfizer for funding this massive educational effort.

The above are just two more examples of how PWSA (USA) is saving and transforming lives – and why I am so proud to be a part of this wonderful organization. ■

*PWSA (USA) advisory board members

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, http://www.pwsausa.org/

Webinar Review: Advocating in the ER

Reviewed by Andrea Glass

As an emergency department physician, Dr. Daniel Beaver may look at events in the ER a little more critically. A board certified ER physician with 30 years' experience, and the parent of a child with PWS, Beaver familiarized the viewers in the recent webinar "Advocating For the Person with PWS in the Emergency Room" with the ER process - the different kinds of staff you may meet and their roles, as well as provided strategies and resources you can use as you advocate for the person you care for with PWS. The main talking points in this webinar were helpful to parents and caregivers when finding themselves in this situation.

Dr. Beaver encourages all parents/caregivers to:

- carry the PWSA (USA) Medical Alert booklet http://www.pwsausa.org/medical-issues-a-z/
- download the PWS phone app (available on iTunes and Google Play) ***See details on page 6***
- access website articles for emergency room staff at: www.uptodate.com.

It is very important to collaborate with the ER staff throughout the emergency. **Be prepared to provide the phone numbers for the individual's primary care doctor, endocrinologist, psychiatrist, etc. as well as all medications. This adds credibility to your presence.**

Try to generate urgency in an objective way. For example, you may say; "People with PWS who vomit stand a high risk of dying from gastric wall rupture."

Request a specialist be brought in if warranted.

Share your knowledge!

There are many reasons that our individuals with PWS are more challenging for ER staff to diagnose:

- Increased pain tolerance
- Poor temperature response (lack of fever) or temperature disregulation (spikes)
- Increased sensitivity to drugs
- Poor muscle tone
- Hypothyroidism
- Respiratory vulnerability
- Lack of vomiting
- Thick saliva
- Staff that is unfamiliar with PWS

continued on page 6

Webinar Review, *continued from page 5*

Some of the reasons our individuals need to utilize the ER are:

- GI Issues – An overeating binge significantly increases the risk. Manifest by **nausea, vomiting, pain, bloating, fever and other signs are an intra-abdominal catastrophe until proven otherwise.** Caretakers need to watch for signs of over eating and proceed to the ER if this is suspected.
- You may have to insist that the individual does not just have the flu.
- Choking (the average age of choking deaths in PWS is 24).
- Bone and Joint Issues.
- **Due to high pain tolerance, any pain in a bone or joint or change in use of a joint or gait or bone requires an X-ray. CT can be useful to identify hairline fractures. MRI is rarely useful.** A CT scan is better than an MRI.
- It was also suggested that if your person with PWS is a wanderer or is in the community by themselves that you have a wrist ID made. One company is www.roadid.com. You may want to consider putting a reference to PWS on the band. ■

PWSA (USA) Phone App on mobile devices!

Thanks to the Settles family, enjoy freedom to browse any and all information on our website from the ease of using your iPhone/ iPad/iPod app. ■

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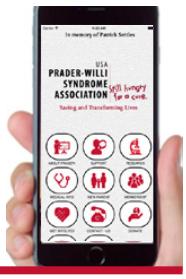


From the Home Front

My name is Sara Grosso. I am the mother of Grayson Grosso, who was diagnosed with Prader-Willi syndrome at just one month after birth. He is a thriving two-and-a-half-year-old boy now and it has taken me nearly his entire life to put his story into writing, because, frankly, it makes me extremely emotional. As a young, first-time mother, his entrance into the world was traumatic. I have put this writing to the side countless times, neglecting it for months at a time because I have to muster up the courage to continue to allow myself to go "there", that painful place in my soul. I began penning out his story to release the mix of emotions stirred by his birth, to heal, and to serve as an explanation to him one day of my love for him.

I felt compelled to share my personal account in the hopes it would find its way to as many families of children diagnosed with PWS as possible, particularly, new families within the PWS community, to let them know there are others out there who know the storm and can attest to the fact that they will find a way to weather it, in spite of any obstacles that may be looming ahead.

Thank you for taking the time to read Grayson's story.

While in college, years ago among a group of elementary education peers during a discussion about the reasons I had chosen not to minor in early childhood or special education, I was asked what I would do if I was faced with raising a mentally impaired child.

"Give it away."

Ugly words spoken jokingly, but there was a fragment of truth hidden in them. How would a cognitively or physically impaired child reflect on me? A child with special needs did not fit the image of perfection I was striving for my future.

The guilt I felt for my selfish remark was brief; after all, what were the odds? Maybe the odds weren't much higher than winning the lottery and I had never won the lottery before.

3,952,841 babies were born in 2013...

In 2013, I would be sitting pregnant on an examination table while my midwife asked, "Would you like to do screenings for Down syndrome or other defects? ...Or would it matter?"

"It wouldn't matter."

I was struck with guilt again for my gilded words. It would matter! I wanted a picture perfect family. But after all, what were the odds?

For days I sat in in the dark on the only piece of furniture in my son's NICU room; a cold, hard, plastic recliner. There was no television, so I watched the screen of his monitor and worried. I would stare at its flashing neon numbers until the colors bled together and its rhythmic beeping created a deafening silence that allowed me to slip away into the darkest corners of my own mind. More selfish thoughts, the most disgusting "what if's": What if I had opted for screening? What would I have done with the results? I can't bring myself to write out the options, but I am telling you, in the days between his birth and his diagnosis, my imagination painted vivid pictures of each scenario. I have never felt more guilt than admitting the places I let my mind wander in time I spent alone with him at the hospital.

...150,000 of them born with some form of a birth defect

Nearly two weeks earlier I had given birth to an adorable and seemingly healthy little boy, only to be readmitted to the hospital at his first check-up just a few days after being home. Why wasn't he eating? Why was he floppy and lethargic? All of a sudden, he was undergoing a series of genetic screenings. We had been given a list of possible diagnoses, all of which were terrifying.

I was caught in a bizarre time warp where I felt as if life was moving in fast forward, but time was dragging. Worry was wreaking havoc on my resolve. I had done most things carefully and purposefully in preparation for the future only to realize - It. Meant. Nothing. I had

continued on page 7

Sara Grosso, *continued from page 6*

no control, and was left only with this huge question mark looming over the future. And grief. Overwhelming grief. I was able to kiss his warm face and see his heart beating on the monitor he was connected to, but I was grieving him; or at least, the idea of him, the dreams I had for him, in the way you would grieve a loved one's passing.

I remember once, after being transferred to the PICU, I left Grayson's room to make room for visiting family. I crossed the waiting room between the NICU and PICU in search of coffee, when a televised sermon caught my attention. The sermon was based on the power of positivity. The message was essentially: The will it requires for one to choose positivity in the face of adversity creates feelings of power and strength within. These feelings of control, in turn, generate peace for the soul.

The preacher's words resonated with me.

Several more days passed. Visiting family and friends came and went but I stayed. It didn't matter who came to visit or for how long, I always felt alone. I was trapped inside my own mind pondering the outcome of the screenings that would have us in a three-week long limbo as we anxiously awaited an answer.

0.5% of newborns have a chromosomal abnormality.

I had taken to watching videos on the Internet to entertain myself between Grayson's feedings. I must have watched a video of Paul McCartney seated at a glossy black piano singing "Let it Be" under a single stage countless times over the next several days. When we were alone, I would cradle my baby in my arms and sing this song to him, my tears falling on his forehead, running along the contour of his nose, and getting caught by the barricade formed by the NG tube taped to his cheek.

He flat out wouldn't eat for anyone but me, and feedings weren't a cakewalk; he had no sucking reflex. Six. Nine. Noon. Three. Six. Nine. Midnight. Three. His hour-long feedings took place every 3 hours. What he didn't drink from his bottle was pushed through his NG tube. I would pump between his meals, which left enough time to eat quickly, but little time to rest. I didn't dare close my eyes in fear of sleeping through a feeding despite being worn ragged. He was required to be able to drink an 80% minimum of his bottles without it being pushed through the NG tube before doctor's would even entertain estimating when we could take our baby home. He didn't do nearly as well when nurses fed him and I couldn't stand the effect those feedings would have on his discharge, so I lived three hours at a time.

The stress, lack of sleep, and lack of eating made me nearly unrecognizable. I was skeletal and my hair starting to fall out in large clumps. I stayed at the hospital, only leaving between early morning feedings to venture over to my room at the Ronald McDonald House to grab a change of clothes and snacks for the next day or to do Grayson's laundry.

Normally, I did as advised and took the shuttle that ran between the hospital and the house. Large cities aren't notorious for being the safest of places at the hours I was traveling, but on one particular night, I decided to brave the city streets. I knew it could be dangerous, but the air was fresh and it was quiet. I weighed my options and I decided my sanity needed the stillness more than I needed safety.

As I walked the lit path through the hospital playground, I found myself humming The Beatles.

Let it be. Let it be. Let it be. Let it be. There will be an answer. ***Let it be.***

Suddenly, the events of the last month shifted sharply in to focus. Each passing day was bringing us closer to an answer whether we were prepared to accept it or not. I chose in this moment to embrace that answer rather than spend another second being fearful. I chose to trust that whatever diagnosis we were faced with, it was purposeful. There was a reason I was given THIS little boy! We were made for each other! This pairing was no accident; it was carefully orchestrated! I was left with chills from my revelation and peace filled my soul. A huge weight, the fear of what was to come, had been lifted from my shoulders and my heart was changed.

The next morning, we received Grayson's diagnosis.

1 in 10,000 babies are born with Prader-Willi syndrome. That is equivalent to less than 1%.

Grayson has proven himself to be a resilient and determined little boy fueled by curiosity. And his personality… It's breathtaking! Honestly. He has this infamous head of curly, wild hair, an ornery, infectious smile, and shrieking laugh that turns strangers into friends in a matter of seconds. He's sweet and silly… and stubborn! He just has this way of lighting up an entire room.

Did we hit the "jackpot" genetically? No.

Being a parent of a child with PWS is hard. Being a parent of a child with any disability is hard.

But that falls to the wayside because we are blessed beyond words in so many other ways. His existence has enriched life to an unimaginable magnitude. I have quickly moved beyond paying much attention to what the odds tell us; they will bury you if you allow them to. I have stopped mourning the life he would have without this genetic disorder, simply because he is too beautiful inside and out not to admire. I am so grateful for the way his uniqueness has opened my heart. There is not a day that goes by that I don't wake up in a world completely saturated in pure love and happiness because, somehow, through this crushing game of numbers and percentages and odds that we were forced into, he was entrusted to me.

Today, we are not just surviving; we are thriving!

I never knew I could find so much love and joy in "winning" at a seemingly luckless lottery, but he is mine, and I feel as if I have won the jackpot. ■

Ben Karp - on a mission to serve and grow

By Denise Servais

You can ask anyone at the PWSA (USA) office about Ben Karp, and you will likely hear what an exceptional employee he is. Karp has worked on and off for PWSA (USA) since 2011. "I was pulled in by the mission and the amazing PWS community," he reported. Karp initially worked in communications, fundraising, and social media before he started working on his most recent project.

He is currently working with PWSA (USA) on a short-term basis to assist with school-related family support projects. "Ben's commitment to helping the families we serve and his creative skills and technical expertise have been essential to the process of developing and implementing these projects," said Evan Farrar, Family Support Counselor. He credits Karp for advancing these initiatives. Farrar adds, "...our hope is to keep him connected to our Family Support Program by enlisting his services for special family support projects in the future."

Karp recently spent some time off from working at the PWSA (USA) office to go hiking in Nepal last year. While hiking in the Himalayas, the earthquake hit. "Once we saw the damage, we realized we couldn't leave it and ended up staying for the next four months in Nepal doing disaster relief work," he said. "In that time we raised money to build four classrooms, one year's worth of school supplies for over 300 students in Gorka, and helped construct and fund 50 earthquake-resistant homes and 16 temporary shelters, (as well as other disaster relief projects)." he noted.

Karp will be leaving for graduate school in mid-May to pursue his Master's in Social Welfare. He and his girlfriend, Christina, will be moving toward the western part of the US, either California or Colorado. "I will continue working with PWSA (USA) as long as I am needed."

We wish Ben great success in his move, studies and future connections to our community. ■

PWSA (USA) Adds National Special Education Consultant

PWSA (USA) is pleased to announce that Jennifer Bolander has been serving as a National Special Educational Consultant for PWSA (USA) since October of 2015. She is a graduate of John Carroll University and lives in Ohio with her husband Brad and daughters Kate (16) and Sophia (12) who was born with PWS. Over the years, as a special-needs parent navigating the Special Education system for Sophie, Jennifer became interested in learning as much as possible about that process. She began by attending PWSA (USA)'s first Wyatt Special Education Advocacy Training in March of 2013 and went on to complete a rigorous 9-month Special Education Advocacy Training course with the Council of Parent Advocates and Attorneys in May of 2015. This included successfully completing an advocacy internship with PWSA (USA). Jennifer is referred school cases by PWSA (USA)'s Family Support Counselors, and then works closely with parents and schools to review education records, assess the child's situation at school, provide further information about how the syndrome affects the school experience, and create as needed improved IEPs and behavioral plans. Jennifer was excited to take on this role of helping parents in the PWS community to work collaboratively with school professionals and parents to create positive, effective learning environments for children with PWS across the country. ■

CHUCKLE CORNER

The PWS Spirit that we all know and love!

About an hour after the doctor told Davis he will need to be in the hospital longer because he needs two surgeries instead of one, the following conversation took place:

Davis: I am lucky!

Me: Why are you lucky?

Davis: They sent up two chocolate milks with lunch!

~Mary Raymond, North Reading, MA

El cuidado de los demás - Caring for others

PWSA (USA) has donated boxes of three different types of Spanish brochures to Cuba, Mexico and Colombia. Approximately 600 brochures have been sent to each country to help with education and awareness on the syndrome. Both PWSA (USA) and IPWSO are assisting Columbia where they are working diligently to put together their first PWS conference. During our communication, I received the following from Kevin Quinn:

"Johana and I would like to express our tremendous gratitude for the work you have done, and all those associated with these incredible organizations. We know Katie's (4 years old) development and future have been positively impacted through your diligence.

We hope that this conference will serve well the Colombian families and associated doctors, and that it will, in small part, expand the foundation so faithful set through PWSA (USA) and IPWSO." ■

~ Janalee Heinemann, MSW
Coordinator of Research & International Affairs, PWSA (USA)
Vice President, IPWSO

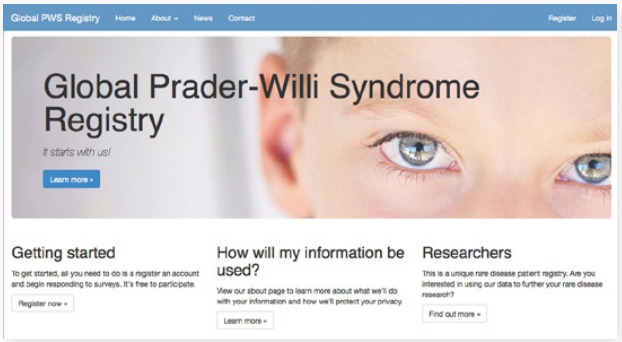
Save The Date- Ninth IPWSO Conference

July 20-24, 2016 , Toronto, Ontario

Every three years, IPWSO holds an international PWS conference held in a member country. IPWSO conferences are unique! Scientists, researchers, psychiatrists, psychologists, geneticists, endocrinologists, physicians and all other medical professionals are our delegates. Jeremy Veenstra-VanderWeele, M.D. is the keynote speaker. Dr. Veenstra-VanderWeele is the Mortimer D. Sackler, M.D., Associate Professor of Psychiatry at Columbia University, the New York State Psychiatric Institute, the Sackler Institute for Developmental Psychobiology and the New York Presbyterian Hospital Center for Autism and the Developing Brain. Professional caregivers and residential managers, parents, teachers, caregivers, relatives and friends attend. Children, babies, and adults with PWS, their siblings, and volunteer caregivers all enjoy IPWSO's fantastic international conferences.

This conference (hosted by the FPWR) in Canada will offer the latest research presented by scientists, the best possible strategies to help parents, caregivers and teachers support the person with PWS, and a platform for professional caregivers and professional residential providers to meet and expand their already internationally acclaimed "Best Practice Guidelines for Residential Care". ■

To register: http://bit.ly/1OUJua9
To learn more: http://bit.ly/1MVStKF



Every Person Matters

Register Now Global Prader-Willi Syndrome Registry

If you are a parent or guardian of a person with PWS, join the movement today to build the Global Prader-Willi Syndrome Registry by visiting **www.pwsregistry.org** ■

2016 eWalk

By joining today, you can help transform someone's tomorrow.

Help raise awareness and important funds for Prader-Willi syndrome by joining our online fundraiser, **eWalk**. Each year PWSA (USA) experiences an increase in the volume of crisis and support calls we receive from the PWS community. In 2015 we received 2,013 calls for help from families and individuals like you concerning issues ranging from medical and GI, school, law, behavioral and many other issues. We worked with 173 new diagnoses in 2015 and expect to help 200+ more families in 2016 whose child will be newly diagnosed with PWS. We assist these families every step of the way.

Help us continue to provide the educational, medical, and staff counseling resources necessary to assist these families by creating your personalized **eWalk** fundraising page today! It only takes a few minutes of your time. Sharing your family's fundraising page by email and social media will not only raise funds, but it will also help raise awareness for PWS.

To register, please go to: https://www.firstgiving.com/pwsausa/2016-ewalk ■

A family enjoying a grand time with the Pirates mascot and Clint Hurdle at the 2016 Hot Stove event. Many thanks to the Pirates, sponsors, donors and attendees who together made the event a great success!

on the MOVE Events

UT	FITNESS FUN-RAISER	5/21
AR	OTM VIRTUAL WALK	ONGOING
MA	HUNTER LENS GOLF TOURNEY	6/4
WI	GOLF TOURNAMENT	8/20
WI	BOWLING FUNDRAISER	9/17

On the Move events aren't just for chapters. Many individuals have hosted very successful events in their local areas. We will help you throughout the entire process. An ***On the Move*** event can take place ANY TIME of the year and can be anything from a walk or golf tournament to a dress down day at your child's school. Help us spread awareness while raising funds. Interested in hosting an event? Please contact Leanne Gilliland: 941-312-0400 or lgilliland@pwsausa.org. ■

Other 2016 Chapter Events

NY	STATE CONFERENCE - ALBANY	5/13-5/14
NY	GOLF FOR PWS - MT. SINAI	5/16
IN	MIDWEST CONFERENCE - INDIANAPOLIS	October
PA	PIRATES VS. REDS GAME - PNC PARK	9/11-13
PA	MINI-CONFERENCE - WASHINGTON	11/13

On March 19th, PWSA (USA) and Clint Hurdle, manager of the Pittsburgh Pirates came together to host the 2nd Annual "Hot Stove Dinner Event" at the Courtyard Marriott in Bradenton, FL. The night featured a lovely dinner, auction and presentation given by Clint about the 2016 baseball season prospects. The local community, PWS community as well as many individuals from Pittsburgh came together to make the night an outstanding success! Together we raised 25% more than last year bringing in over $55,000. PWSA (USA) sends a big thank you to Clint Hurdle and his family, the Pittsburgh Pirates, our sponsors, many generous donors and all those who attended. Funds from the evening will allow PWSA (USA) to continue saving and transforming lives. ■

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: https://www.opm.gov/combined-federal-campaign/ or contact the PWSA (USA) office at (800) 926-4797 and ask for Debi Applebee.

Chapter Spotlight – Wisconsin

In 1991, a group of parents met in the waiting room of a small medical clinic in McFarland, Wisconsin. They all had one thing in common: they were parents of a child who had Prader-Willi syndrome and felt very alone. In 1992, these parents formed a non-profit organization called Prader-Willi Syndrome Association of Wisconsin, Inc. (PWSA-WI, Inc.) and became a chapter of PWSA (USA).

Prader-Willi Syndrome Association of WI, Inc. has an extensive vision and a well organized approach to ensure this vision is achieved:

- All infants born with Prader-Willi syndrome will receive a diagnosis within their first year of life so that they can receive early intervention services, treatment for health conditions, and begin a life that promotes health, wellness and success for them and their families.
- All children and adults who have Prader-Willi syndrome will successfully play, learn, work and live in their communities with the knowledge and understanding of their disability so that the appropriate educational, environmental and behavioral supports are in place that allow them to have a positive quality of life and live as independent as possible.
- All persons with Prader-Willi syndrome, parents, care givers and others who support and assist persons with Prader-Willi syndrome will receive the necessary support, education and tools needed to become informed advocates and educators so the proper supports are in place that allow them to have a positive quality of life and live as independent as possible.
- PWSA of WI, Inc. will strive to provide awareness and knowledge of Prader-Willi syndrome to all who reside in the state of Wisconsin.
- PWSA of WI, Inc. will work collaboratively with other organizations and professionals to advance our knowledge and understanding of Prader-Willi syndrome through various research endeavors.
- PWSA of WI, Inc. will provide social opportunities to enrich the lives of people with Prader-Willi syndrome.

The Chapter successfully lobbied to get PWS listed as a "developmental disability" with regard to the Department of Health and Human Services in 1998. Additionally, we joined a successful lobby against decreasing funding for the Family Care program.

In 2008, PWSA of WI, Inc. hosted the PWSA (USA) national conference. A few years later, a mini conference was co-hosted with the Illinois chapter. I (Crystal) am also a Co-Chairperson for the PWSA (USA) Chapter Relations Committee and work closely with PWSA (USA) and other chapter leaders. Our Educational and Training Consultant also works closely with PWSA (USA) with regard to publications. Each January, we host the annual Snowflake Ball with 200-250 people in attendance. Our Educational and Training Consultant hosts various trainings throughout the year at the Waisman Center and at the residential homes. In April 2016, our chapter brought in Dr. Ann Scheimann to do a Grand Rounds presentation at the Medical College of Wisconsin and then provided a parent-attended presentation. In the past, we have also hosted mini-conferences with speakers such as Dr. Forster and Dr. Gourash.

Our members are encouraged to also become members of PWSA (USA). We use a number of tools to communicate with our members, including our *Facebook* (FB) page, quarterly newsletter, and email blasts. We also have a close relationship with the group homes and they share information about our chapter with appropriate persons. In addition, we send out packets about our organization to various physicians within the state such as endocrinologists, geneticists, pediatricians, internists, and gastroenterologists.

There are many group homes located throughout the state and 17 of the providers are currently members of our organization. Also, many of the providers attend our social functions and fundraisers. PWSA-WI, Inc. maintains a list of physicians in Wisconsin who see patients with PWS. This list can be shared with parents, guardians, providers, etc. via phone, email or FB.

PWSA-WI, Inc. hosts an annual walk-a-thon, bowl-a-thon and golf outing. The walk-a-thon is held in May as part of the National awareness campaign. The golf outing is held in August and the bowling event is held in September. The walk-a-thon and bowling event double as social events for individuals with PWS; whereas, the golf outing is strictly to raise funds. We are fortunate to employ a full time program director whose background is in special education. When school related issues arise, our program director works with the schools via telephone, email or in-person by traveling to schools to attend IEPs or conduct trainings.

At the beginning of March, PWSA-WI, Inc. reinstated paid dues and, as a result, we have 42 paying members; however, we reach between 300-700 people when it comes to our special events. We service about 180 individuals with PWS located in Wisconsin and these individuals range from a few days old to 70 years old.

The current Board of Directors includes: Crystal L. Boser, President, Jackie Mallow, Vice President, Amber Gaulke, Secretary, Tom Hughes, Treasurer, Bobbi Pogrant, Melanie Laur, Jamie Milaeger, Nancy Burlingame, Andrew Gaulke, Dr. Nicollette Weisensel, and Claudine Hoverson. The chapter leadership also includes, Barb Dorn, R.N., B.S.N., Education and Training Consultant and Joshua Escher, as full-time Program Director. ■

PWSA of WI has a website at www.pwsaofwi.org, a FB page that is open to the public, and a closed FB page for PWSA of WI, Inc. families with children 0-9.

~ Crystal Boser, President, PWSA-WI, Inc.

Carter

Every school day morning, I watch my sweet boy climb the stairs onto the big yellow bus and wonder…will anyone greet him? Share a seat with him? Is he okay sitting alone, or does it make him sad?

From my curtained viewpoint inside the house, I watch as Carter ascends the steps and heads to the back of the bus. He'd waited three years to be able to sit back there, as the hierarchy dictates that 8th graders get to enjoy that coveted area. At first it saddened me to see Carter sitting alone each morning. I'd occasionally ask him if he sat with anyone that day, and he'd answer with a simple, "No, but it's okay." Perfect… if he doesn't mind, then why should I, right? I've since become accustomed to seeing him plop down onto an unoccupied bench – more room for his backpack, less chance for trouble, I tell myself.

This morning, I watched Carter stroll down the aisle, my pulse steady as I hoped for him to find a seat quickly and not hold up traffic. I glanced toward the back of the bus and was concerned when it looked like all the seats were inhabited. I could feel my heart skip a beat. Carter paused. On a few previous occasions, I had seen him turn around and head back to the middle of the bus to scurry into the first seat he encountered. Was he

going to turn around this time? "Stand your ground," I think to myself. "Those seats can serve two people. Just politely ask someone to scooch over, and sit down." It's quite possible that I actually said this out loud to no one but the dogs, who looked at me with tilted heads and inquisitive eyes.

Seconds tick by, feeling like minutes. What will happen? Who will budge? I hear the old western twang in my head that often accompanies a duel scene in a movie. The only weapons Carter has are his voice and his manners; will he wield them today, or turn and walk away? I imagine what is being said, what the others are thinking, how Carter is feeling. Imagination sometimes produces less-than-ideal scenarios, and this was one of those times.

To my dismay, I watched as another child stood up, pushed past Carter, and sat down with someone else, leaving an empty seat for Carter to rest his laurels. While I'm happy that Carter didn't retreat to the middle of the bus, I am sad that, from where I stood, it appeared that this child felt it beneath him (or her) to have to sit with my son. I felt defeated, heartbroken, sad.

I wanted to run outside, climb those bus steps, and tell that child what a jerk he (or she) is for treating my son this way.

I wanted to teach the whole lot of them a lesson about inclusion, empathy, compassion, and friendship.

I wanted to preach about the Golden Rule - treat others the way you want to be treated.

I wanted to cry.

Since I was still in my pj's, I did just one of those things.

I cried.

P.S. As it turns out, Carter reported that the child who got up and pushed past him actually did so because another child told her she had to move so Carter could sit down. My interpretation of the situation was way off. Instead of Carter being ostracized as I had feared, a fellow student had stood up for him on the bus. My feelings were unfounded this time, though they were based on prior experiences.

~ Michele Shingleton
Mom to Kylie, age 16 and
Carter, age 14 with PWS
Burlington, CT

Counselors Corner

Supporting Students with PWS in Summer Camps

By Amy McTighe, Ph.D.

CABLE Coordinator/ Inpatient Teacher, The Children's Institute of Pittsburgh / Center for Prader-Willi Syndrome

Summer camp should be a relaxing, fun, and exciting time for students with Prader-Willi syndrome. It is a time to meet new friends and engage in activities that students may not have been exposed to during the school year. However, a summer camp atmosphere can also create anxiety and behavior problems for a student with PWS if they are not supported well during the camp experience. Additionally, parents may have even more anxiety about their child's participation in this environment. Therefore, it is important for parents to determine if the camp staff is able to support the child and provide food security in this setting.

The Americans with Disabilities Act (ADA) requires all camps to make reasonable accommodations so that students with special needs can attend. This means that many camps that you may have thought are not an option, may actually be an option for your child. However, it is important to remember that many camps may have started by serving the general population of students without disabilities and educating the camp staff about PWS and your child's needs is important for your child to be successful.

View summer camp exposure for children with PWS as a way to create an environment for your child where they will have fun

Here are some recommendations for determining if each particular summer camp is appropriate for your child, how to educate the camp staff about Prader-Willi syndrome, and recommended strategies for you and the staff to support your child with this experience.

Gathering Important Information and Training:

Interview the director of the camp to ask questions about how the staff is hired, background of the staff, staff trainings, camp staff to camper ratio, and emergency protocol. If it's necessary for your child, ask if it is possible to have 1:1 adult support.

1. **Arrange with the director a time to train the staff** about Prader-Willi syndrome and provide one-sheets or pamphlets about PWS to each staff member - available from www.pwsausa.org

2. Ideally, it is recommended to **create a resource that describes PWS**, how it manifests specifically in your child, and supports or strategies that have been effective for your son or daughter.

3. **Explain the importance of food security.** Work collaboratively to create a plan with the camp staff as to where food will be stored and locked throughout the day.

Preparing for the Camp Experience:

1. **Ask the camp staff** about the daily schedule and any special activities that may occur during the time that your child is present. **Ask about special events or activities that may involve food.**

2. **Create a story to read to your child about what they will experience at camp.** Include the times they will have meals and snacks on this schedule in order to prepare. This will give them a clear structure and predictable schedule of when food will be served. A visual schedule that the child can bring to camp each day will also assist as a reminder during the day of what to expect.

3. **If meals and snacks are provided or if food is used during activities, problem solve with the staff.** Is there a place for the child to eat in an alternative location with adult supervision and then return to the group when food has been disposed of? Or, can a small group of campers eat with your child in an alternative location where adult supervision is provided to decrease the amount of food exposure?

4. **If food is scheduled to be a part of an activity or special event, think about an alternative item that could be substituted for the activity that does not involve food.**

For example, if candy is passed out as a reward after a great day of camp activities, ask if the camp counselors can give pencils, word search booklets, or stickers instead. If a food recipe is an activity that the campers are completing to practice following directions, ask if the activity can be revised and if the campers can practice following directions to create a craft or an art project.

Communication and developing a working relationship that is filled with the ability to problem solve ways for your child to be successful is key. PWS is a complex syndrome and it is difficult to be upset or frustrated when the staff, in any location, is not supporting your child in the best way. In reality, they don't know how. View summer camp exposure for children with PWS as a way to create an environment for your child where they will have fun, relax and make life-long friendships as well as time to educate others about Prader-Willi syndrome!

For more information regarding supporting students with disabilities in summer camp settings, visit http://www.wrightslaw.com/info/camps.summer.mil.htm. ■

Exciting Updates on PWSA (USA)'s 2016 School Initiatives

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

Wyatt Special Education Advocacy Training (WSEAT)

In 2013, PWSA (USA) completed its first special education advocacy training for parents in the PWS community. After evaluating the 2013 training, and the special education advocacy needs and capabilities of the PWS community, we are transitioning the WSEAT to an online webinar course. This **free training** will consistent of three modules: **Module One** will cover basic special education law and concepts. **Module Two** will discuss effective advocacy. **Module Three** will address the unique school needs and challenges of students with PWS. These LIVE modules will be held in June, July and August; stay tuned for registration and other details!

Rebranding of School Times

In March, 2016 we launched a rebranded version of *School Times* that includes:

- A new and unique look that distinguishes it as a school related publication.
- A new emphasis on including related videos.
- New features such as information on home schooling.
- Expanded content including a more robust section for school professionals.

There is more! Check it out and if you are not a subscriber, send an e-mail to efarrar@pwsausa.org to subscribe.

The response to the new version of *School Times* has been fantastic. Since the March issue we have added 230 new subscribers giving us a total subscriber list of 675.

School Data = Understanding

In March 2016, PWSA (USA) launched a groundbreaking new survey to capture, for the first time ever**,** the school experience of students with PWS across the United States. This survey is for parents/guardians of children with PWS currently in school **and** those who graduated in the past. **The School Experience Survey** will help us gather hard data on how students with PWS are actually doing in schools, their successes, the challenges they face, and the experience of parents/guardians as they navigate the special education system. If you have not completed the survey, please do today by going to https://www.surveymonkey.com/r/KPSPF7Sf So far 203 parents have completed the survey!

Special Education Advisory Board (SEAB)

The Special Education Advisory Board (SEAB), created in 2015, continues to develop under the leadership of the Chair, Amy McTighe, who is the In-Patient Teacher at the Center for PWS at the Children's Institute in Pittsburgh, PA. In addition to helping to plan the WSEAT, the SEAB is also conducting a review of all of PWSA (USA) school handouts and resources, discarding old versions, updating resources as needed, and proposing and developing new resources for parents and school professionals. ■

Part II: The Resource Challenge

Settling In

By Kathryn Lucero

As overwhelmed as I was over a month ago, things seem to be falling into place nicely. I have connected with a wonderful group of women in CO, all who just "get it" because they too have children with special needs. I have found myself getting out more than I ever have and now that I have a new "job" I feel as though the stress has been lifted. I have had several people tell me that I seem happier, then followed up with "moving is so stressful, how is it that you are doing well?!" I tell them that yes, I have had my share of stress dealing with insurance not cooperating with Ronan's medications, therapists not calling me back and also be homesick, HOWEVER I have found that having done a lot of the leg work prior to the move it really helped. I connected with the women I now call friends prior to moving, I began contacting doctors' offices and PWS clinics so that Ronan could be on whatever wait list was needed and then I just held my breath that everything else will fall into place.

The move has definitely had its ups and downs but I am certainly trying to turn a new leaf and not dwell on the things that were absolutely frustrating and made me want to pull out my hair; I am not perfect so I still have those days especially since I am a wife, a mom and someone who has found it difficult in the past to let go. A couple of wonderful things that occurred recently are that we went to Florida to not only meet Dr. Jennifer Miller who I found to be so wonderful and helpful, but Mickey Mouse, who Ronan found to be just as wonderful. To see the look on Ronan's face when he met the Mouse was priceless! All in all I would say that the Lucero family is settling in nicely. ■

Kathryn and Armando Lucero, with son Ronan visiting Mickey.

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

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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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MEMBERS ONLY:
Access our website: www.pwsausa.org for downloadable publications, current news, research, and more.
The Members Only section requires a password: member20

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

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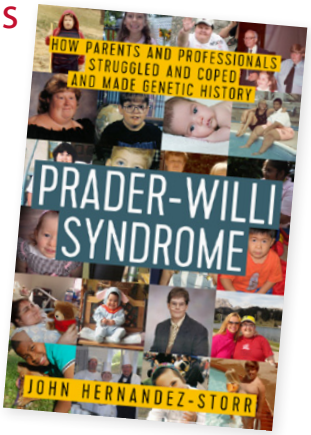
e-News...

Reminder – stay informed and stay current with PWSA (USA)'s free e-News. Sign up today at www.pwsausa.org and watch for the next update full of great info.

NEW! Prader-Willi Syndrome: How Parents and Professionals Struggled and Coped and Made Genetic History



By John Hernandez-Storr

Now available through PWSA (USA) -- this amazing 256-page book gives never-before-told historical facts on the evolution of the medical world working to understand Prader-Willi syndrome (PWS) entwined with intimate, personal stories of the original PWSA (USA) pioneers. As the BlueInk review states, this book is *"A seamless blend of case history, detective story, and medical mystery."* The author, John Hernandez-Storr, who is the father of a daughter with PWS, spent years doing personal interviews with many of the key PWS professional and parent pioneers.

The following is a review by Suzanne B. Cassidy, M.D., a world renowned PWS genetic specialist, editor of *Management of Common Genetic Syndromes,* and president of the International Prader-Willi Syndrome Organisation (IPWSO):

"A wonderful, eminently readable book about the impact, challenges and successes of living with and understanding Prader-Willi syndrome. Most impressive from my point of view, as a clinician and researcher who has observed and participated in the progress in our knowledge of Prader-Willi syndrome for more than three decades, is how clear and accessible are his descriptions of the scientific and medical progress it has undergone. Written with an audience of families and direct caregivers in mind, it is nonetheless scientifically accurate.

This is a book that can be a source of knowledge and inspiration for everyone who lives with or studies Prader-Willi syndrome, whether a parent or sibling, a care provider, a teacher, a doctor, or a scientist."

John Hernandez-Storr has very generously offered to donate all of the proceeds for books sold through PWSA (USA) back to the Association. Order your book NOW. visit: http://bit.ly/1Tz8FCi Cost: $15 plus shipping. ■

In this Issue