Empowered by Hope

A collection of family stories
from the PWSA (USA) publication,
The Gathered View

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

*Compiled by Diane Seely, Carolyn Loker,
Melanie Keller, Janet Li and Karen Vogt*

INTRODUCTION

By Diane Seely

It is our hope that this publication will encourage you to see past the diagnosis and see your child through your eyes, and not a definition of PWS. Each child with PWS will be affected in different ways by this syndrome. We are on the cusp of many breakthroughs for treatments, and the future is very optimistic. These are just some of the stories* that you will likely hear and read, from some of the wonderful families that will embrace and support you through your journey. One of the biggest gifts from PWS is the community: the fact that you are NOT alone in this. We have a community that celebrates every victory, and applauds even the smallest successes! This community and PWSA (USA) will always be here for you.

**These stories have appeared in the PWSA (USA) publication called* "The Gathered View".

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Foreward - A Personal Glance

By Diane Seely, mother of Reagan Seely, with PWS

We were not supposed to see his chart. Our four-week-old son was in the NICU and we were arriving that morning with hopes that the nurses were successful at feeding him with a preemie bottle rather than tube-feeding him through the nose gavage. We read the notes on how the night feeding went; we also read the summary describing our little boy, which was so heartbreaking. At a mere four pounds he was so fragile. It was then that we saw the words scribbled in the margin by the attending physician: suspected Prader-Willi syndrome. And then, more words that were incomprehensible, such as: Hypotonic (low muscle tone), dysfunctional feeder, micrognathia (a lower jaw that is smaller than normal). Yes, we could see some of these things too. But that didn't mean that there was anything "wrong" with him. As the doctor explained to us that individually a lot of these things didn't mean much; however, collectively they are signs to something bigger.

The medical professionals said "your child has PWS." What does that mean? He will have difficulty reaching his milestones, he will need therapies, medications. He will, at some point, develop an insatiable appetite. That conversation was hard to hear. Truthfully, those early days were really, really hard. What's amazing to us is that the professionals can only generalize, and hypothesize. What the doctors don't know about our son is that:

- He learned sign language and then later talks non-stop. Questions. Oh, the non-stop questions!
- He learned to pedal a tricycle, and later learned to ride a bike.
- He will stand on the stage with his classmates year after year and sing in a school musical.
- He learned to ice skate, and held his own at the school roller skating party; he never held back!
- He will run his first 5K in 4th grade. He will never stop, nor give up.
- He will learn to play the drums and compose his own songs.

What we have come to know is this: PWS will not define our son, PWS will not destroy our family, PWS will not defeat us.

KWON DO for Ramon

By Kelly Gibbs, Spring, Texas

My grandson, Ramon Madrid, age 6, has been an inspiration to our family. Ramon was born prematurely; for weeks we did not understand why he had an issue with nursing. His twin sister was fine except for being premature. Luckily we live just north of Houston, Texas, and its wonderful Medical Center.

After much testing, we were saddened to hear that he had Prader-Willi. My daughter worked through the gastric tube feedings like a champ, and we all learned how to take care of him. Eventually, Ramon was able to graduate from the g-tube to regular bottles.

Yes, he has always been physically a little behind, but he is catching up by leaps and bounds. We were fortunate to learn about Human Growth Hormone and its benefits with kids with PWS, and his mother began it early. He is actually passing up his twin sister!

Ramon is now in first grade in the school where his mother teaches. He is in regular classes and pulled out for the classes where he needs some extra attention. He is a smart little cookie and just has problems with a speech impediment and sometimes attention issues.

At his doctor's suggestion, his mom tried him out in soccer and gymnastics; that wasn't his cup of tea. Ramon's inability to concentrate made it too hard to get his cooperation. Brandy, his mother, then tried him in a trial class of martial arts and was told that it wasn't working out.

About a year and a half ago, my daughter enrolled Ramon in a Tae Kwon Do class. After looking around, she found Olympia Tae Kwon Do and Master Bruce. It was most fortunate that Master Bruce had worked with other kids with challenges, and so he was more than willing to give Ramon a go. Now I am not here to say that it has all been sunshine and peaches, but he has progressed very well with the principles imparted by the instructors at the studio. Ramon is so crazy about his degree belts that Master Bruce found that a very good way to entice good behavior. There have only been a couple of times that he has had his belt taken away for bad behavior and then he had to work to get it back.

It has been amazing how much better Ramon's respectfulness and attitude has become. He has learned at class that you must respect your parents at home as well as your instructors. When he enters the studio, he bows and declares, "Hello, Master Bruce". This is expected of all the kids. Also when he enters the actual workout room, he must remove his shoes and socks, open the door, and ask "May I enter, Coach Lance."

In just a year, Ramon has gone from white to yellow to orange belts. He has had such great support, not just from the instructors but the kids also. Where it takes some of them just two kicks to break the board with their feet during a test, it could take him a dozen. When it looks like he is tiring, the whole class starts cheering him on. He really looks forward to his two evenings a week at the studio and being with his instructors. Ramon is also very careful with his uniform and belts. He goes home, takes them off and hangs it all up, and folds his belt like it was made of gold. His self-confidence has greatly increased.

I think Ramon and all of us in the family would highly recommend Tae Kwon Do to any kid with PWS who is looking for a sport.

Waiting for the other shoe to drop

By Kristi Rickenbach, Blaine, Minnesota

Sometimes parents of kids with PWS talk about how worried they are for the "other shoe to drop"--the first shoe being the diagnosis, the other the many challenges that come with PWS. This shoe comes in many shapes and sizes and, at times, can become so consuming that we forget everything else. We just sit and wait, analyzing anything different that our kids do, fearing that this is the day. To some "the shoe" is a fear of the meltdowns and temper tantrums; to others it may be food seeking or skin picking. We all have our "shoe" that we fear; overcoming this fear is difficult, but crucial. I have known this fear, and I have succumbed to it on many occasions. Until one day it was all so clear, I was missing out on so much while waiting in fear. The joy that I had with all of my other children at times seemed to be nonexistent with Justice Faith. I read all I could about PWS and tried to imagine my life in the shoes of those who had already walked this lonely road. I would get lost in dark thoughts of what would become of my beautiful baby. I worried so much about the future that I lost the present. My sadness, grief and fear had taken away precious moments that I should have been enjoying with my baby, moments I can never get back.

It was at a national conference in Florida when my head cleared and my fear no longer consumed my every thought. I met so many amazing people who taught me to live for today and enjoy every moment with my child. I no longer wait for the other shoe to drop. We live every moment to the fullest and cherish each day. If I could, I would go back in time and redo all those desperate moments when Justice was a baby. I look at her now, and I wish I could have had a crystal ball to see into the future so I could see how amazing she was going to be.

I can't get back the time I lost, but I can encourage others to live every day to the fullest and not miss out on one precious moment. We don't know for certain the future of our kids or when the other shoe will drop. We do know that time passes quickly and children grow fast. Cherish every moment with your child and don't let fear keep you from truly enjoying your amazing, beautiful child. ■

A Dad Speaks Out

By Pete Pomeroy, New Fairfield, Connecticut
proud father of Luke (2, PWS), Samantha (6) and Rayna (4)

My son Luke turned two yesterday. The most difficult part for me was the three-month period after he was born and before we knew he had PWS. The uncertainty was very stressful - what is wrong with my son? Will he be OK?

Does he have a chance to be 'normal'? I remember that I was willing to give up just about anything in the world at that point in time just for my son to have a CHANCE at a normal life. By the time we got his diagnosis, I think I was more relieved than upset. At least I knew what we were dealing with. I also remember times of sadness in those first couple of months - I think I was mostly sad for the loss of the boy and the man that Luke will likely never become - the star athlete, the popular kid in school, the husband and father, the accomplished professional. That still makes me sad sometimes when I spend too much time thinking about it.

Finally, I was sad for myself because I would not be able to do many of the things that I always envisioned doing with my son. Thinking back now, I can't even remember what specifically I thought I would be missing out on - I just had some self-pity that my relationship with my son would not be 'normal'.

I remember talking to my brother (who has a 12-year old autistic son) about being worried that Luke's condition would change our family's lives forever. He told me that many things would NOT change. He told me that I would still love my son, and that I would still be proud of my son. The things that make me proud may not be the things I envisioned, but the pride I felt would be just as real.

I have thought about that a lot in the past two years. I know our hardest days are ahead of us. But I am trying to think of it like this: My son will do things that make me proud (like when he began walking a few months ago), that make me laugh, that make me angry, and that make me sad. But isn't that true for every father?

We may think that our anger or sadness will be greater than that of other fathers, or greater than it would be if our sons were 'normal'. I am not sure that is true. My anger and my sadness are for the most part controlled by me. Not by my son. So if I am angry and sad, it is MY problem and my responsibility. My son is who he is, and right now he is an adorable loving little Tsunami that likes to hug and play with his daddy and make messes. ■

A Very Special Accomplishment

In her speech to her son, Aaron Fisher Carvajal at his Bar Mitzvah in April, Susan Fisher said, "It is truly an honor and privilege to be your mother…In your short 13 years, you have taught me more than I could ever have learned in a lifetime with you… When you were a baby, I cried every time I went to a Bar Mitzvah…because I thought you would never be able to have a Bar Mitzvah. I was so very wrong."

Aaron, a seventh grader, had to learn to read Hebrew and was able, Susan says, to make the blessings over the Torah before and after the readings. Also, he got a new suit and was chosen for the store's advertising in the paper, he collected

800 pounds of dog food for a no-kill animal shelter for his mitzvah project, and he contributed a portion of his Bar Mitzvah gifts to PWSA (USA).

In his speech Aaron said, "I love being Jewish because we pray a lot, and when I pray, God listens to me." ■

How Kids with Prader-Willi Survive College

By Colleen McMaster

Hi everyone, my name is Colleen and I am 20 years old. I was born with Prader-Willi Syndrome. The worst part of having PWS is being hungry all the time. I found support is the best way to deal with the hunger issues, but when I was in high school, it was hard to get all the support I needed. I wasn't able to tell others that I had PWS. I graduated in 2009 with a high school diploma. After I graduated, I was hired at Lifetime Assistance where I scanned documents for car dealerships. I worked there for two years when I learned about a program known as LifePrep at Nazareth College, Rochester, New York.

I have been in this program since September and I just love it. The teachers teach in a fun way and I get all the support I need with PWS. I was able to share with my teachers and peers that I have PWS. Since they know, I am able to refrain from getting food from vending machines and the cafeteria.

I have a job at the Nazareth College box office. They have a terrific theater program and I am able to attend one performance a semester for free. I finished my first college course, Psychology for the Exceptional Individual. There was a peer who attended the class with me, and I would send her my homework to make sure I was on the right track. She only made spelling changes. I belong to two clubs. Gerontology Club where I played Bingo with the elderly. I also belong to the Dance Club.

I have made many friends on campus and learned there is more freedom in college than in high school. I am able to ask for and receive support, and the teachers are flexible allowing me to do a power point versus a paper. I love college and I am learning a lot. Going to college through a special program gives me the added support I needed. The advice I would like to give you is to go to college, don't stress yourself out, and tell others that you have PWS, whether it is your teachers or friends you can trust. The support keeps you distracted from buying food when you shouldn't. Try it, I guarantee it works! ■

LifePrep@Naz

The LifePrep@Naz program is a program designed to provide individuals, 18 years and up, with disabilities with an opportunity to go to college. This program is created through the collaborative relationship among Nazareth College, Victor Central School District and The Arc of Monroe County. The curriculum is created to be an inclusive program with 50% of the student's time with same-aged peers without disabilities. LifePrep@Naz students are also supported by peer mentors who are Nazareth College students. Mentors provide academic *support to students and promote the inclusiveness of LifePrep students in the campus community. For more information or questions about LifePrep@Naz please contact:*

Jaime Dermody, Community Outreach Coordinator, The Arc of Monroe County
2060 Brighton Henrietta Townline Road, Rochester, NY 14623
Phone: (585) 730-6037   Email: Jdermody@arcmonroe.org

The Swim Coach and the Silent Waltz

by Lisa Peters

"Hello, er yes," I said rather nervously over the telephone, "I am looking for some swimming lessons for my son this summer."

"Okayyyy," said Beth, our local swim coach, who owns a pool and for many years has taught all of the neighborhood children how to swim. I closed my eyes and waited for the next inevitable question.

"How old is your son?"

"Well, um, er..." I replied uncomfortably.

How do I do this? I wondered to myself. ***How do I explain why it took so long for me to consider swimming lessons for Nicholas? How do I explain about Nicholas? How do I tell her about his diagnosis? But more importantly, will she be willing to teach him how to swim?***

"He, um, has very low muscle tone and struggles with issues related to coordination." My pathetic attempt to try to educate her on some of Nick's challenges.

"Okayyyy, how old is he?" she asks again patiently.

"He's ten," I replied and felt my cheeks start to redden.

"No problem," she said, "we will probably need to place him in a class with younger children."

Oh no, I thought to myself, she does not understand. Inside my head, I pictured a school of flopping, screaming children splashing her pool into a seething whirlpool of doom and destruction. I could see the slow moving Nicholas overcome by a monstrous wave of blackened pool water.

"Perhaps this isn't going to work," I answered, frustrated with my inability to explain what Nicholas needed.

"I have taught several children diagnosed with special needs to swim," she replied trying to assure me she had done this before. I started to breathe a little easier.

How many children will be in the class?" I asked.

"About 6 or 7, but I would need to take a look at him in the water first."

More images of a floundering Nicholas gulping mouthfuls of chlorinated water.

"I don't know," I said, "I am not sure this would be a suitable class for Nicholas."

Again my fear and inability to communicate.

"Once I see him in the water, I will have a better idea of what he needs," she reassured.

"Oh," I said feeling a little better but still picturing Nicholas and Beth floating out of the pool on a giant kid-made tsunami.

"Why don't you just bring him by on Monday," she said. I could sense she was getting frustrated with me.

I hung up the phone and questioned the value of my degree in communications.

As the days passed, Nicholas looked forward to his first swimming lesson.

We all tried to prepare him for the arrival of the big day.

"Nicholas, you're going to love swimming in the pool, it's so much fun," Weston said, anxious to reassure his younger brother.

"I am?" Nicholas asked.

"You are!" Weston answered.

"Beth is soooo nice!" I told him enthusiastically.

"She is?" Nicholas asked.

"She is!" I answered.

Monday finally arrived and Nicholas awoke. He donned an old pair of Weston's "surfer dude" swim trunks, anxious to begin his new adventure.

We arrived at Beth's pool. A mass of tiny, wet children was exiting the churning pool, laughing and shivering. What was I ***thinking?*** I thought to myself as they clamored around me and Nicholas looking for their towels. It wasn't long before each chilly child found their mother and headed home. The pool and surrounding area became quiet, the water stilled. A tanned, gray-haired woman walked up to Nicholas and extended her hand.

"Are you ready, Nicholas?" she asked.

"I am!" he replied enthusiastically. She held his hand and led him to the edge of the pool. They did not speak.

Within minutes, Beth had the sensory-sensitive Nicholas in the pool and smiling. I sat stunned on the side of the pool. I watched as these two strangers silently connected. They glided through the water in an effortless motion of trust and mutual respect.

Beth pulled Nicholas slowly around the pool. He let her gently guide his body.

"Ok, now try to put your legs behind you," she instructed softly, and the compliant Nicholas allowed his body to float. They swirled silently together through the water from one side of the pool to the other, softly, gently, quietly. Nicholas bonded easily with this patient woman. There were no dangerous waves or whirlpools. There was no fear or anxiousness, no difficulties communicating; submerged in the clear, tranquil water of the pool, they were dancing. As I watched their graceful movements together, I could almost hear the music.

This calm, silent scene was a sharp contrast to the loud, nervous noise inside my head. My needless worry seemed silly to me now, and I wondered if perhaps the word "disabled" was a more accurate description of me. I was the one who was awkward and afraid. I was the one who had trouble trusting.

I was the one who couldn't dance.

It is my son, not me, who hears this inner music, a song that connects him silently and fluidly to others in this world who also vibrate to that beautiful sound.

As I watched my son dance to this silent music, I realized I have a lot to learn.

■

A Golden Granddaughter from the Gods

By Michael Tate

She arrived as a Christmas gift in December 2003. My sixth grandchild. Blond and delicately beautiful with the requisite blue eyes. All was well. Then – the SHOCK. There was a possible problem. Questions were asked. Does anyone else, except her mother, in the family have blond hair? Yes, I did as a child as did my brother. A week later it was confirmed. Ashley was a child with Prader-Willi syndrome!!

"Prader-Willi" – What was that? No one knew. Never heard of it! The Internet description gave detailed and alarming coverage of every detail of what might be Ashley's future. Our daughter Suzanne, Ashley's mother, said later that Ashley's birth date was the day that changed her life forever. She also said that God had chosen her to be the guardian of this little girl. That being so, it followed that He had chosen me to be her Grandfather.

In those early days I watched as Suzanne coped with an infant that would not feed normally and to whom she had to give nightly Hormone Growth injections. I was impressed with the ways she sought information and direction from the many medical facilities, while at the same time I was horrified at the lack of awareness of the syndrome, both in the general public and in the day-to-day medical profession. As Ashley grew, I found myself constantly looking for signs that would confirm the descriptions of behavior as outlined very explicitly online. Thankfully, outwardly, there was very little to distinguish Ashley from any normal little child, which confirmed my intent to treat her as such whatever may happen. Yes, Ashley had floppy limbs, speech problems, but Suzanne worked continuously to get the correct help. Early on, a speech therapist worked wonders.

Ashley now has a sister Meghan, a fish and half shares of a kitten, Belle. She is very active, swims and does Yoga. She played softball and tried soccer. I see that she does tire easily and is ready for bed early, perhaps because she wakes full of energy early each day. She will ask me when I am having dinner or whichever meal is next. I do not make a big fuss about her frequent requests for food as she is aware that her intake must be limited. So far there has been no serious need to lock the fridge. I am delighted that she loves her school where her teachers and school leaders have been briefed on her condition and her needs. She does well scholastically, and her reading is excellent. She is inquisitive and asks many questions. She is the right height for her age with weight only slightly high.

Two possible concerns. She does have "meltdowns" both at home and in public which Suzanne deals with expertly, making it clear that it is not appropriate behavior. Second, she is extremely friendly and will readily ask questions to complete strangers. OK now but will it be later?

Suzanne asked me to write something about being a grandfather to a child with PWS. I don't look at it that way. I see a bright, pretty, healthy little blond girl who has her own personality! Just as important I see a mother who has schooled herself to get her daughter the very best of attention and medical opinion, who despite the stress is always positive and cheerful and treats Ashley just like her younger sister.

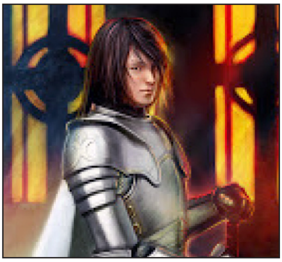
Ashley looks after me, too! If she's around, she will bring me my pills saying "Here, you must not forget to take your medicine." Recently we travelled to New York to visit with one of the top specialists in PWS – about 85 miles each way. She visits him every 4 months. For 30 minutes all three of us played "I Spy" in the car; then Ashley fell asleep. The doctor put her through various tests, weighed her and recorded her height. Ashley answered questions without hesitation. At the close he proclaimed how delighted he was with her progress and congratulated Suzanne on attention to all Ashley's requirements. It was good to get official confirmation.

[We are delighted to receive an article from a grandfather and encourage other grandparents to consider sending a piece about their grandchild with PWS.] ■

Battle Fatigue II

By Lisa Peters

Sanity Saving List



Battle Fatigue I *appeared in the March-April issue of* **The Gathered View,** *Lisa Peters' description of being a mother of a child with PWS. Here is Battle Fatigue II, Lisa's "Sanity Saving List", which she says is "an ever-changing record of helpful tools that help to preserve my emotional strength."*

1) Hire a Babysitter: Important to finding some alone time for myself, a time to do the things that I enjoy, alone and uninterrupted. (Time hiding locked in the bathroom does not count.)

2) Alone Time with Hubby: An important time to reconnect with my husband and remember what brought us together in the first place.

3) Let Housework Slide or Hire a Helper: The pressure and time involved in keeping a clean house is a thief of time and can interrupt those precious few moments needed for rest and relaxation.

4) Cancel Appointments: Nicholas visits with so many specialists that I could literally spend all of our time just seeing them. When times get tough, I try to take an entire month off from any specialists and non-emergency visits.

5) Listen to Music: A new one that I have discovered. Locking myself in my bedroom with the door closed and an iPod filled with my favorite music has done wonders for calming my spirit.

6) Meditate: Another new one for me. I have found that purchasing a few good meditation CDs is a helpful tool. It took a while to find the right CDs that resonated with me. Meditation is a lot like homework--difficult at first to make it a routine, but when I did, I noticed an improvement in my mood.

7) Nature Walks: I learned this one from my son, Weston. Long walks outside amidst Mother Nature is another winner for relieving tension.

8) Talking: I find it very cathartic to talk with others about how I am feeling. It is when I repress my thoughts and feelings that I notice a darker side to my disposition. However, there is a huge warning here. I must be very selective in my choice with whom to speak, for some individuals are not instinctively designed to handle such a heavy load; speaking with these individuals can actually make my pain worse. I try to speak with only those who are thoughtful and willing to listen with a sense of kindness, compassion and void of any judgement.

9) Therapist: Early intervention services in our state included the services of a family therapist. I am continuing with this incredibly helpful intervention.

10) Mini Vacations: I try to plan several mini family vacations throughout the year. Looking forward to time away from the rat race has worked wonders for us all, especially Nicholas who loves new adventures. A few days away works wonders in creating a restful diversion.

11) Write, Write, Write: Even if I do not share these thoughts with others, the process of getting it out on paper (or computer screen) has been particularly cleansing to me.

12) Sleep, Rest and Relaxation: During times of increased stress, I try to sleep more. If I can't sleep, I try to just rest and listen to music.

13) Special Needs Groups and Individuals: No one understands me better than those who share my struggles. Reaching out to these groups or individuals can provide some interesting and effective solutions.

14) Positive Reflection: This, to me, is the most important. With every stressful event that has ever occurred while raising Nicholas, if I dig deep enough, I can always find an important lesson. So, when my mind wanders back to disturbing events of the past, I force my brain to explore a positive aspect that occurred because of that experience. I do not repress the event, since I believe it is important for the mind to rewind the experience and reflect upon it.

Implementing these strategies is painful. Maintaining them...even worse, feeling like a type of special needs homework, a dreaded but necessary evil. But by calming my spirit and accepting my child and his diagnosis, I am in a way helping myself to live a happier and more fulfilling life. Ironically, however, of all my life-saving strategies, it is my son's soothing sage-like spirit that effortlessly balances my warrior woman energy. It is interesting to me that when I physically tire from the heavy load of caring for him, it is he who comforts me most, and I wonder if perhaps this is no accident. ■

Special Olympics

By Denise Servais

Through the power of sports, Special Olympics has had a positive impact on the lives of people like Logan Melton. Logan, age 12, is from Surprise, Arizona. In October of 2013, Logan, and his friends Hannah Wilkinsen and Andrew Kuskie (all with PWS) competed in the Special Olympics regional swimming competition in Surprise.

This was Logan's first swimming competition. Logan's mom, Tiffany Shafer, explained how at first Logan wanted to take a break shortly after swim practice had begun. "His (swim) teacher didn't let him. She was very encouraging." Shafer explained how Logan began to really like practice, "He would swim back and forth…he didn't give up…He kept wanting to go back." Shafer said she would speed walk around the pool as Logan swam to keep him motivated.

Logan participated in the breast stoke, free style, and relay race. He won two gold medals and one bronze medal. Logan plans to compete in swimming Special Olympics this fall.

Logan lives with his older sister, Shanda, and his mom and dad. Besides swimming, Logan is in Special Olympics track. He also enjoys participating in his Lego class, loves video games, and playing with his dogs.

Special Olympics has active programs in over 170 countries and a growing body of more than 4.2 million athletes with intellectual disabilities. Check in with the Special Olympics office nearest you to learn more about volunteering and local events. ■

The Faith of a Champion

By Amy McDougall, mother

Noelle (age 11), our middle child and only daughter, has PWS. At first glance, she seems like a "girly girl" who loves to be dressed in her own style and loves animals. We have fostered a strong work ethic in all of our children with the stance that accomplishments aren't what is truly important, rather the level of effort that you give. Noelle rises to this challenge every day: in her schoolwork (which doesn't come easily), in therapies (many of which she no longer qualifies for), and importantly, how she advocates for herself.

What you don't see is her determination and strong-willed nature. Noelle can explain how PWS affects her and will ask for opportunities to educate others as to how others can best support her, particularly in dealing with hyperphagia.

Her participation in normal activities such as dance, soccer, cheerleading, etc. over the years has pushed her to grow even more. This year (2013?) Noelle was recognized as the Reserve Champion for her division (Lead Line) at the local horse show series, based on her place in points for the shows this past summer. Her trainer alone was aware she had received motor therapies starting in infancy, and there were no accommodations made for her at shows. This accomplishment is all her own and we couldn't be more proud of Noelle and all her hard work! ■

"The adventure of life is to learn. The goal of life is to grow. The nature of life is to change. The challenge of life is to overcome. The essence of life is to care. The secret of life is to dare. The beauty of life is to give. The joy of life is to love!"

William Arthur Ward (1921-1994)
Author, Educator, Motivational Speaker

Honor Roll Recognition

By Ann Baird, mother

I want to share some wonderful news with you. Rebecca has always been a hard worker and it has paid off...Rebecca made the honor roll!

Rebecca is 12 years old and in the 5th grade (we had her repeat Kindergarten). She has ELA and Math in a small resource room and goes to her regular class for Social Studies, Science and all her specials. An aide from the resource room goes into the classroom with her to oversee her and other kids in the class. Rebecca used to have a 1:1 aide when she was younger. As she's getting older, we want her to become as independent as she can be and she's shown us all that she can do it. We know anything can change at any time, but for now, she is doing better than we ever imagined and we couldn't be happier!

I'm also happy to report that Rebecca is not seeking food, does not always eat everything on her plate, and will tell us she's full after eating.

Not sure if it's the conditioning we've done with her all these years telling her that we are all full after we eat, so she says she's full, but whatever the reason is that she's doing so well, we'll take it! ■

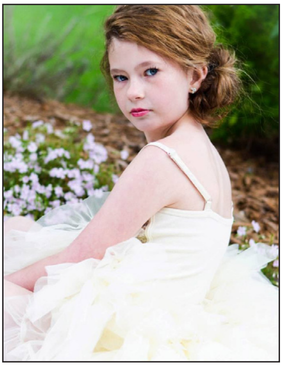
Aloha

By Clinton Soo, father

At the Hawaii 5210 Let's Go! Keiki Run 2014, a Great Aloha Run event, Corbin, age 10 and in the 4th grade, showed determination, pushed the limits and utilized the support team to help realize the thrill of victory in a win for Waikiki School. From four Soo Family participants, $15 from each registration will be going back to Waikiki School for a total of $60. We believe in the cause to continue promoting healthy eating and active living in Hawaii schools and families. ■

Happy Birthday, Justice Faith!

by Kristi Cole Rickenbach



On December 18, 2003, our lives were forever changed. As I held our sweet baby in my arms for the first time, I wondered if we would ever take her home. Those first few hours I longed to hear her cry or to see her move. The first few days I prayed for her to eat, to stay awake. When we finally took her home, I cried during those long sleepless nights, listening to make sure she was still breathing. It seems like just yesterday we were running to so many doctors trying to get an answer, something, anything to explain why our baby was so weak.

A month later when we finally got the diagnosis of PWS, our world stopped. We knew the heartache and struggles that came with this diagnosis, we knew, we had read, we had done research. The medical books were very clear on what to expect. Our world was filled with a whole new vocabulary that in the past I never cared to learn. Words like Methylation, Uniparental Disomy, NG Tube, failure to thrive, aspiration and so many more that I could fill an entire page with them.

I was so angry that I figured that if I learned everything I could about PWS I could somehow fix it. It took me a while to come to the realization that I couldn't. At first I screamed Why me? Why my baby? But then one day it all became clear. Justice Faith's future was not determined by a text book.

We decided that as a family we were going to do anything and everything to ensure that Justice had every opportunity to prove the text books wrong. Today as we celebrated her 10th birthday, my heart swelled as I listened to her read all of her birthday cards out loud. I could barely contain my joy as I watched her interact with her friends, laughing and talking about what they will wear tomorrow, just like any other 10-year-old. My heart melted again just like it did 10 years ago as I held her before she climbed into bed.

I cried again today but not because of what Justice is not, but because of all she is. Justice is an amazing, beautiful, smart, compassionate, funny, sweet little girl that has brought us more joy than I could have ever imagined.

Happy Birthday, Sophie!

By Lori Moline

Today my beautiful girl, the one the doctors told me was profoundly deaf and blind, who they said would likely never walk or even sit normally…the one I was told to take home from the hospital and love "for the time you have her with you"...turned TWELVE YEARS OLD. So far, she's kicked every one of those predictions of gloom and doom to the curb. She no longer needs hearing aids, she not only walks and sits, she is on "typical" sports team, set to take a spring tournament by storm. She's smart and kind and so funny there are days that all we do is laugh. She has a tenderness for animals and babies that is truly amazing, and they respond to her as if they know she "gets" them. I would love to make a list of all the incredible things this girl has done, WITH PICTURES, and mail it to the geneticist who handed me a list 12 years ago of all the things she would never do. So far she has climbed mountains, hiked deserts, swam in two oceans and the Mediterranean sea; she has given me far less trouble than her typical brothers, become my "partner in crime" and my bestest traveling buddy ever. Yes, we've had struggles--no, things haven't always been easy and trouble free.

But 12 years of this sweet, floppy little baby, now strong, accomplished young woman, who wakes up with a smile EVERY morning, makes every struggle worth it.. she is a blessing to everyone who gets to know her. I can't believe how fast 12 years can go by.

Imagine

Imagine -

There are no PWS educational materials for schools,
medical staff, parents, supportive living staff, and relatives

Imagine -

There is no program of support for new parents of a
child with PWS, and they have to hang on the edge of despair
of the unknown for years

Imagine -

There are no specialized supportive living homes for PWS

Imagine -

There is no one to call when you have a
medical emergency or have specialized PWS medical questions

Imagine -

There is no counselor to call when you and your child need help
with school, SSI, insurance denials, placement, the law, etc.

Imagine -

There is no one you know who has a child with PWS,
and there are no state support groups, no conferences,
and no email groups where you can meet other parents
to share your hopes, fears and questions

Imagine -

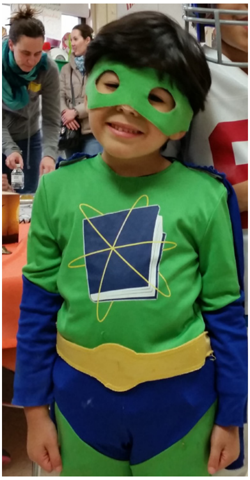
There is no growth hormone nor psychotropic medications
to help your child, and no one to educate and
advocate for their safe and effective use

Imagine -

There was no one educating large numbers of professionals
on PWS at medical conferences

I Can Imagine -

Because that was our world 30 years ago –
before the growth of PWSA (USA) and state chapters.
~Janalee



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to change lives!

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