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

PWSA of Iowa Office
15130 Holcomb Avenue
Clive, Iowa 50325
515-770-5297

Website: PWSAIowa.org

Email: edieiowa@gmail.com

PWSA of Iowa is a chapter of the Prader-Willi Syndrome Association (USA)

8588 Potter Park Drive, Suite 500
Sarasota, Florida 34238

Toll Free Number:
1-800-926-4797 or 941-312-0400

Fax: 941-312-0142

Email: national@pwsausa.org

Website: www.pwsausa.org

Share this newsletter!
Find it online at
PWSAIowa.org/spring2015

Spring 2015

Music to my ears!

I have said long ago, even though our son Zachary's speech and language skills differ greatly from his school-aged peers, his ability to communicate and be heard has no boundaries. Zachary had the wonderful opportunity to participate in an after-school choir club which set the stage for his "show choir" performance…glittery costume and all! As a nervous parent in the crowd of hundreds, I held my breath and prayed he would complete the performance, not fall off the riser, trip over the mat and most important, have fun!! Unbeknownst to me, Zachary's performance inspired one particular audience member who wrote a blog post the following day. It was a beautiful moment to see our son through a stranger's eyes. We have included Lisa Lavia Ryan's precious words in this newsletter. Speech deficits are just labels for diagnosis or treatment; our loved ones living with PWS communicate, have much to say and do impact the world!

-Edie Bogaczyk
Co-President, PWSA of Iowa

In This Issue:

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

What is Prader-Willi Syndrome?

Prader-Willi Syndrome (PWS) is a genetic birth defect, which occurs 1:15,000 Births. This genetic accident causes lifelong conditions affecting growth, metabolism, behavior and general well-being. Those affected by the syndrome are very individual, having varying degrees of strength and challenges brought on by this disorder.

Prader-Willi Syndrome (PWS) is, perhaps best understood as a multi-stage syndrome. The initial stage is "failure to thrive" with sever muscle weakness (hypotonic) and delayed developmental milestones. Infants re often unable to nurse or suck because of weak, limp muscles and may require special feeding techniques. Motor milestones re also delayed because of muscle weakness.

The next stage is "thriving to well." A compulsion to eat becomes more apparent in toddlerhood. Previously agreeable and compliant behaviors may also give way to stubbornness and temper tantrums. In many cases, the drive to forage and seek food increases at varying rates and degrees requiring lifelong supports in order to control caloric intake and prevent morbid obesity. While insatiable appetite and aberrant behaviors are the two most dominant characteristics of PWS, other issues are also part of the complex syndrome and require ongoing management and empathetic understanding. They may include: abnormal growth, incomplete sexual development, temperamental changes, cognitive limitations, abnormal caloric utilizations, reduced balance and coordination, speech and language difficulties, social isolation, dental problems, high pain threshold and irregularities in body temperature mechanisms.

May is PWS Awareness Month!

(Be on the lookout for fun events!)

Thanks to Waukee teachers, there's no "right" way to celebrate music

By Lisa Lavia Ryan

Originally posted on Friday, February 27, 2015: http://lisalisanocultjam.blogspot.com/2015/02/thanks-to-waukee-teachers-theres-no.html

Every child needs a place to be, a place where he/she not only feels comfortable, but owns his/her surroundings. Last night at a middle school show choir end-of-season performance in Waukee, Iowa, two teachers showed us how to make that happen.

In addition to the show choirs they direct as part of their jobs teaching middle school music, educators Shelly and Michelle started a smaller choir this year for students who wanted to do some extra performing. The group choreographed its own music and spent a lot of extra time practicing, and they performed for the crowd last night.

Front and center was a boy named Zach. Zach has obvious cognitive delays, and maybe some physical ones, too. And Zach clearly loves, and deeply feels, music.

The group performed songs from "The Lion King," and Zach knew every word, every dance move. He formed the words differently from the way the other kids formed them, and they didn't sound the same. He danced differently, too. But he matched the other kids beat for beat, and he performed joyfully, head back and eyes open wide.

He also sang loudly, so loudly that at times, we couldn't really hear the other kids. But here's the thing: The other kids didn't mind. In fact, their smiles encouraged Zach. He smiled and they smiled. They sang together, each in his or her own way.

And when it was over, Zach wasn't quite finished with his joy. He hugged every other student in the group, and every other student hugged him back. He nearly tackled one of his teacher, and she returned his enthusiasm. He clearly belonged.

I think back 39 years ago, to my own seventh-grade year. We had no classmates with cognitive or physical delays; they went to "special" schools. If I had encountered such a classmate, I'm sad to say I would have felt awkward and maybe even a little afraid.

But because districts like Waukee and teachers like Shelly and Michelle know there's no such thing as a "different" child, Zach is truly just one of the kids. He doesn't sing like everyone else, but no one makes

Photo courtesy of www.jessiesfund.org.uk

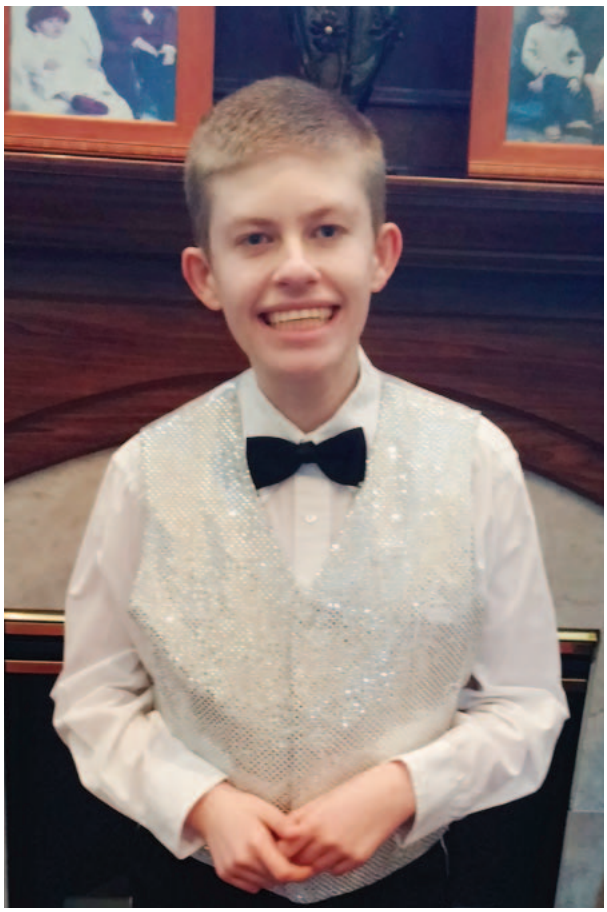
"Music" con'd on next page

"Music" con'd from previous page

him feel as though the way he sings is wrong. They rejoice in the sounds he makes because he so clearly loves making them.

In these sad days when middle-schoolers in other parts of the city are mourning classmates who have taken their own lives, it's all the more critical that every student find his or her place -- a place to receive acceptance and affection and affirmation. Thanks to teachers like Michelle and Shelly and districts that know the fine arts can save lives, Zach has such a place, and his classmates are that much stronger for embracing him for who he is.

I'm overjoyed that my daughter is part of such a district, learning from peers like Shelly and Michelle. Thanks, Waukee middle school vocal music teachers, for all you do, daily, for hundreds of kids. And thanks, Zach, for reminding us what music should really sound like.



Slow Motion Mothering

Original posting: http://www.hopefulparents.org/2014/10/slow-motion-mothering.html

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

I am a fast moving kind of a gal.

I like to go, go, go and get things done, done, done.

I like making lists and checking things off.

I guess it would be safe to say that I am most happy when I am moving.

But this fast moving, freewheeling, on-the-go lifestyle is not very conductive to raising children diagnosed with things like sensory processing disorder and poor motor planning issues.

In fact, I have discovered, somewhat reluctantly, that raising my children is all about learning how to slow things down, way down. It is a painful life lesson often delivered to me with blunt force trauma to the brain.

But applying the brakes has never come easy for me. For a long time, I resisted this notion of slow motion mothering. I continued to run faster than a speeding bullet, slowing my pace only slightly as I dragged my overwhelmed children from one chaotic event to another.

I was surprised, even angry, when my children began to scream and cry/

I thought at first, that the trouble was them.

What I have learned most recently..... is that the trouble is me.

As many of you know, Nicholas has been diagnosed with Prader Willi Syndrome. Many individuals diagnosed with this disorder are also diagnosed with dyspraxia.

Dyspraxia is a developmental coordination disorder that causes weakness in comprehension, information processing and listening.

It is a disruption in the way messages from the brain are transmitted to the body.

Often children diagnosed with dyspraxia also have issues related to the processing of sensory information.

Too much sight, sound, smell, touch or taste information delivered too fast to the body overwhelms the brain resulting in emotional overload.

What I have learned is.....this behavior is not telling me ...."I want to be defiant"

It is telling me....."I'm overwhelmed"

Slowing things down and minimizing the amount of sensory input is crucial to enabling my son to be successful in this world. It enables him to enjoy loud events, boisterous activities and large crowds.

As a mother of a child diagnosed with this condition it is my responsibility to slowly build Nick's sensory endurance. Introducing events and new experiences slowly, building each time in intensity so that he can finally begin to function and relate better to our fast-moving world. This is a necessity if he is ever going to be able to live on his own, go to school or secure a job.

And so it is with much difficulty that I am learning how to slow down the eager speed demon.

Now if I can just get the rest of the world to understand this important lesson.

Zafgen Clinical Trials: A letter from Janalee Heinemann

Dear PWSA (USA) chapter leaders,

By now you are all aware of the Zafgen phase 3 clinical trial on beloranib. In spite of all the announcements of the clinical trial and all of the excitement about the positive results of the phase 2 study, **they are still struggling to get enough teens and adults with the syndrome in the trial.** We (and they) know that part of the problem is that a person with the syndrome has to have a fairly high BMI, and that the hyperphagia scale is eliminating some that would participate even though the person with the syndrome has a strong drive to eat. Unfortunately, at this point the only hyperphagia scale the FDA will approve is in this day and age somewhat outdated. Many of our children are slim thanks to external controls, and are less likely to show drastic acting out to obtain food due to good parental management. Although we know most of our children of all ages still struggle with weight and food control, for the study the criteria has to be fairly strict to eventually get FDA approval for this drug.

In light of all that, **we are asking your help in promoting this clinical trial to families who have a child with the syndrome ages 12 to 65 and who are still living at home.** We are going to send individual families who we are aware of at PWSA (USA) that fit into this category a special mailing. (We cannot give the information directly to Zafgen – or to any other company) If you are aware of families that you would like to see get this mailing, please send their mailing information to info@pwsausa.org. We will double check our list to avoid duplication. If you are uncomfortable sending us the names, you could personally send the families information. One of the best ways to do this is to send them our latest newsletter, The Gathered View, which has two pages on this clinical trial and the different sites participating.

The ultimate goal is to ultimately have a drug that will help all children and adults with the syndrome, but we will only get there through clinical trials and the support of families, which is why I consider working with the pharmaceutical companies who are paying for these clinical trials an important part of my role with research.

Warm regards,

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

More information can be found here:

www.pwsausa.org/app-latest-news/zafgen-announces-positive-results

‘Food Is a Death Sentence to These Kids’

By Kim Tingley Jan. 21, 2015,
Published in the New York Times

“Are you ready to go to teenager college?” Rhoda Ross-Williams asked her 13-year-old daughter. “You really want to leave us?”

“Mm-hmm,” Rachelle said. She had pulled off her pajamas and was sitting on the toilet so her mother could bathe her. At 4-foot-7 and 278 pounds, she could no longer step over the side of the tub to take a shower.

Rhoda soaped a washcloth and began to scrub beneath the folds of her daughter’s skin. “They’ll have all kinds of stuff for you there,” she went on.

“Fruit?”

“Oh, yes, they have plenty of fruit.”

“Jell-O?”

“Definitely, going to have the Jell-O.”

Rhoda helped her daughter towel off and pull on a pink T-shirt, black leggings and purple socks, which Rhoda worried aloud didn’t match. She combed Rachelle’s hair — freshly trimmed and blown out at a local salon — into a ponytail and added pink butterfly clips. She wanted her to feel stylish. “I need to lose weight more,” said Rachelle, who has cognitive disabilities. “I don’t want to eat too much food.”

When Rachelle was born, her limbs flopped, she couldn’t suckle or cry and her heart and lungs were weak. The diagnosis was a rare chromosomal abnormality called Prader-Willi syndrome, which causes low muscle tone and impairs signaling between the brain and the stomach. For several years, Rachelle would show no interest in eating, doctors told Rhoda; then she would crave food intensely for the rest of her life. No matter how much Rachelle ate, she would never feel full. To make matters worse, she would also have an especially slow metabolism, predisposing her to morbid obesity. Though people with the syndrome now routinely live into their 50s and 60s, their average life expectancy in the United States is 30; most die of obesity-related causes. Frighteningly, because no sensation of satiety tells them to stop eating or alerts their body to throw up, they can accidentally consume enough in a single binge to fatally rupture their stomach.

In the South Georgia town of Valdosta, where Rachelle’s family lives, elaborate spreads of high-calorie fare are the centerpiece of every social activity. Rhoda, who grew up as the daughter of a Southern Baptist minister in Valdosta, is obese, as is most of her family. But Rachelle’s health problems are far more complicated. By the time she was 8, she weighed close to 200 pounds and had diabetes, pulmonary hypertension, asthma and sleep apnea. Rhoda knew that people blamed her for her daughter’s size. She consulted a nutritionist, tried to limit portion sizes and kept rigidly scheduled mealtimes; she took Rachelle and her older sister, Raquel, walking at a local track for exercise, and she got Rachelle physical therapy. But she couldn’t seem to halt Rachelle’s weight gain.

Desperate, Rhoda began to avoid family gatherings, where relatives, thinking her too strict, would sneak Rachelle treats. One Sunday, their church announced a “light snack” for the children of fried chicken, macaroni and cheese and cupcakes; after that, she stopped attending. Finally, through a

“Food” con’d on next page

"Food" con'd from previous page

Google search, Rhoda — who was briefly a biology major in college and has an M.B.A. — discovered an inpatient program at the Children's Institute of Pittsburgh that promised to treat the most severe cases of her daughter's disorder. When she applied to her insurance company to cover the cost, however, it declined, arguing that Rachelle's medical problems were not "acute."

Over the next four years, Rachelle gained 100 pounds. She fell and broke her ankle at school, putting her in a wheelchair, and often needed to wear a nasal cannula, a tube to deliver oxygen. In violent tantrums — a common feature of Prader-Willi that stems from both the frustration of feeling hungry and a limited ability to control behavior — she hit, scratched, spit at and even hurled her oxygen tank at her teachers. Once, when her sister teased her, she grabbed her by the hair and threw her to the ground. At home, she started sneaking food scraps from the trash can. Then Rhoda lost her job on the support staff of the Valdosta city school system. With her income gone, she was able to get Rachelle on Medicaid, which approved two months of treatment at the institute's Center for Prader-Willi Syndrome. Wanting Rachelle to get excited, she told her she was going to college just like her sister soon would.

On the last Saturday afternoon in May, after Rachelle's bath, Rhoda piled suitcases into a rented minivan. Her mother, Edith Ross, took the wheel. Rain spattered the windshield, blurring the view of pecan groves and blackberry fields. At a convenience store, Rachelle's sister helped her out and, walking backward and holding both of her hands, led her up the curb. To move forward without falling, Rachelle rocked from side to side, inching her feet ahead a little at a time. Inside, she maneuvered toward the restroom between shelves of rainbow-wrapped candy and glowing glass cases of soda. Her mother let her pick out a bag of pistachios. Back in the van, her breathing was still ragged from exertion. The next morning at a Waffle House, Rhoda ordered Rachelle a waffle with sugar-free syrup and a side of bacon. "Bacon good!" Rachelle remarked. "Not too much."

Rhoda is 39, an optimist with a self-effacing sense of humor and a bright, vulnerable smile. All her life, food has meant joy and, in times of trouble, comfort. Denying her daughter a treat when she was about to leave her for the first time, somewhere far from home, felt like denying her solace. She

Rachelle Ross-Williams, who has Prader-Willi syndrome, with her mother, Rhoda Ross-Williams. Credit Stephanie Sinclair for The New York Times

"Food" con'd on next page

"Food" con'd from previous page

feared that she was failing Rachelle. Yet she was convinced that without intervention, the way she was breathing, she would die before Christmas.

Prader-Willi syndrome was first identified by Andrea Prader, Heinrich Willi and Alexis Labhart, researchers at a Swiss children's hospital, in 1956. But for 25 years, no one knew what caused the strange suite of symptoms that, in addition to low muscle tone and insatiability, characterize it. These include short stature, disproportionally short arms and legs and small hands and feet; a tendency to pick skin until it bleeds; a high pain tolerance; infertility; excellent spatial memory; and cognitive disabilities, including low I.Q. and difficulties processing emotions akin to those common in autism. People with Prader-Willi are prone to troubles with empathizing, to obsessive thinking, to dismay over slight changes in plans and to problems regulating behavior. Many symptoms affect some people more than others — for instance, not everyone with the disorder is intellectually impaired — but all children with it show an early failure to thrive, followed by obesity, unless their diet is aggressively managed.t

In 1981, researchers at the Baylor College of Medicine made a significant discovery: Errors on the chromosome 15 segment — which occur at conception and for which there are no clear risk factors, except in a fraction of cases — produce the syndrome, making it one of few known genetic causes of obesity. No other genetic disorder incites the same extreme lack of satiety or urge to obtain food. Researchers now know that the damaged stretch of chromosome affects at least a dozen genes, but which of those genes govern hunger and fullness — and how — is still a mystery. What is certain is that Prader-Willi disrupts the functioning of the hypothalamus, a region of the brain that is involved in appetite control.

One result is a heightened, permanent sensation of hunger. "They describe it as physical pain," Jennifer Miller, an endocrinologist at the University of Florida who treats children with Prader-Willi, told me. "They feel like they're going to die if they don't get food. They're starving." Parents must lock their pantries, refrigerators and trash cans, and their children frequently lie and steal to get something to eat. They have been known to memorize credit-card numbers and secretly phone for delivery, use a drill to remove the door from a locked refrigerator and break into a neighbor's garage and eat, uncooked, an entire frozen pizza. Experts aren't sure how many people are born with the syndrome; estimates range from one in 15,000 to one in 30,000. That means that as many as 20,000 children and adults in the United States could have it, yet doctors are often unfamiliar with the symptoms, and fewer than 8,000 cases have been diagnosed.

Researchers believe that hundreds of genes, combined with environmental factors, have the potential to influence whether a person in the general population overeats and how easily he or she gains weight. But in almost all cases of obesity, the body eventually fails to properly process leptin, a hormone produced by fat cells. Leptin and other hormones signal the hypothalamus to prompt you to eat or alert you that you're full, but in obese people these systems break down, preventing them from feeling sated. In some cases, including Prader-Willi, resistance to leptin appears to come first, leading to insatiability and weight gain. In others, the reverse happens: Weight gain causes resistance to leptin, which increases appetite and perpetuates the cycle. "As people gain weight, they inflict a chronic injury to the hypothalamus — to the cells

"Food" con'd on next page

"Food" con'd from previous page

in the brain that sense whether their body weight is appropriate," says Rachel Wevrick, a professor of medical genetics at the University of Alberta who studies Prader-Willi.

That lasting damage is a major reason weight loss is often so difficult to sustain. In Prader-Willi, the cause of the hypothalamus dysfunction is entirely genetic, but the resulting problem — an inability to sense fullness — is similar. Figuring out how to restore proper signaling in the hypothalamus of people with Prader-Willi, according to many researchers, could translate to a treatment for almost all cases of obesity. "I feel that Prader-Willi holds the key," Miller says. "If you could control their appetite, you could control the appetite of anyone."

In recent years, pharmaceutical companies have begun testing substances that they hope will curb the appetites of people with Prader-Willi — and by extension those of others struggling with obesity. One drug, beloranib, seemed in a small pilot study to reduce weight, body fat and, for the first time, insatiability in Prader-Willi subjects — results that its maker, Zafgen, is now trying to reproduce in larger trials. Ferring Pharmaceuticals recently completed Phase 2 clinical testing of a drug that it hopes will improve fullness-signaling in the hypothalamus. And Rhythm Pharmaceuticals is initiating the first trials of RM-493 in people with Prader-Willi; that drug also targets the hypothalamus, and compounds similar to it have reduced appetite in mice whose condition approximates the syndrome.

What is control, and where does it come from? That is perhaps the most complicated, and controversial, question raised by Prader-Willi. How does the drive to seek food, for people who have it, differ from the urge to overeat that anyone might face? Medicine has no definitive answer, but so far studies seem to suggest that people with Prader-Willi are experiencing an amplified version of the cravings we all have when we're hungry.

Our impulse to eat is linked, via the hypothalamus, to the reward centers of the brain that are also activated by drugs and alcohol. In brain scans, those centers light up if anyone who has been fasting sees pictures of food. But when subjects of normal weight are given glucose, to simulate eating, before they view images of food, their reward centers are quiet; in obese subjects, those regions become slightly more active, and in Prader-Willi subjects much more so — in fact, they are particularly stimulated when people with the syndrome who should feel full see high-calorie foods. "I think Prader-Willi makes you appreciate when we fault people for being obese," says Janalee Heinemann, the research director of the Prader-Willi Syndrome Association. "What's to say other people don't have different hunger-full messages? It's certainly not just a matter of willpower." But most families of children with Prader-Willi find that they are the victims of stereotypes associated with obesity — schools, employers, medical professionals and even their own relatives simply can't believe that the condition is just as intractable and potentially lethal as a peanut allergy.

In 2004, Peter and Gayle Girard held their annual Christmas Eve party for family members at their home in Orlando, Fla. Before dinner, they set out chips, vegetables and dip, shrimp, a bowl of punch and sodas. Their 17-year-old son, Jeremy, had Prader-Willi, and they often hosted events at their home so he could join in while they kept an eye on him — as they believed they were doing

"Food" con'd on next page

"Food" con'd from previous page

that night. But the next morning, Jeremy's belly was distended, and he complained of pain. At the emergency room, doctors pumped his stomach, but his condition worsened. A day passed before surgeons discovered that his stomach, which had been distended long enough to lose blood flow and become septic, had ruptured. Jeremy died that night. Only afterward did the Girards learn that other family members saw him eating more than he should have but didn't alert them.

"I think the problem with most people's perception of Prader-Willi is: It's just a fat kid," Peter Girard told me. "They don't understand that food is a death sentence to these kids. He was usually really good with us at parties — until the last one. You can't take your eyes off these kids for a second. They're good at what they do, gathering food, and before you know it, it's too late."

"Teenager college!" Edith announced, halting the van outside a squat brick building on a shady residential street. A case manager met the family in the lobby and led everyone to a long hallway lined with bedrooms. Rachelle's had a hospital bed covered in a pink flannel blanket. There were plastic shelves bolted to the wall and a bathroom with a walk-in shower and a button to push for help cleaning up — her shorter arms meant that, like most people with Prader-Willi, she couldn't reach to wipe herself.

The family perched around the room, anxiously scanning Rachelle's face. She sat on the bed while a staff member in scrubs named Nicole Smith unpacked her suitcase and logged each item, a subtle way of checking for contraband. The floor that housed the Prader-Willi program was kept food-free and locked. Trays were delivered just before mealtime and removed as soon as everyone finished eating. Accommodations for heavy patients were prevalent but understated: In a central recreation room, extra-wide chairs were filled with sand to prevent them from tipping over or being thrown.

After a while, Nicole suggested that Rachelle follow her, so she could get her picture taken and meet some new friends. But about 30 feet down the hallway, Rachelle slowed, and Nicole pulled over a chair and had her sit down. Gregory Cherpes, the program director and a psychiatrist, appeared and slipped a monitor onto her finger to measure how much oxygen her tissues were getting. A healthy reading is 95; Rachelle's was 70. She was close to fainting, and potentially even cardiac arrest. Nicole went to get a wheelchair while Cherpes waited to see if resting would bring the number back up. "That's a pretty shirt," he said gently. "Rachelle, have you ever been to camp before?"

Cherpes is 49, tall and thin, with the muted voice and thoughtful expression of an experienced maître d'. He wears black-framed glasses and collared shirts but never neckties, because patients can grab them in a fit of temper. He and the staff were prepared for Rachelle to become aggressive, but she seemed remarkably content. Cherpes wondered if she was simply not feeling well enough to act out. The next day, a new patient hit him in the face; it took four staff members to restrain her.

As Rachelle left with Nicole, her family went to a conference room to meet with Cherpes and other staff members. They explained that Rachelle would be on a 600-calorie-per-day diet while at the institute and that she would need to eat 800 or fewer calories per day when she returned home if

"Food" con'd on next page

"Food" con'd from previous page

she was to continue to lose weight. To help make the meals look big without adding calories, they recommended offering a bowl of salad greens with lunch and dinner in addition to a medley of other vegetables, a small amount of protein, Jell-O and skim milk. Thinking about just the cost of the produce — and the gas required to restock vegetables that quickly go bad — made Rhoda's stomach hurt. She said she would have to start budgeting. As the family prepared to leave, Rhoda warned Raquel and Edith that they had better not let Rachelle see them cry. "Don't say 'bye,'" she said. "Say 'see you later.'"

Three weeks later, at 8 on a Monday morning, Rachelle started her breakfast: scrambled eggs, which she dressed with ketchup and pineapple. Sunshine poured through the windows of the common room. That day, there were eight patients on the Prader-Willi floor. The youngest was 10, the oldest 35. Rachelle sat at a place near the door, her cheeks pink and her eyes bright. "Hi, beauty queen," Luke Kanish, a 26-year-old Penguins fan, called to her as he came in. Alexandra Rudzitis, a sweet, bipolar 17-year-old with corn-silk hair — the patient who had hit Cherpes — wandered over to tell her a knock-knock joke. Rachelle had a deep, hiccupping laugh that everyone found contagious. Danielle DiCola, a bright 14-year-old homesick for her guinea pig, Lightning, called her "the giggle monster." Surprisingly, even at mealtimes, the patients never talked about foods they missed, or asked for more to eat, or complained about feeling hungry. Some even left food, mostly vegetables, on their trays. That didn't mean they were full, though. Whether they ate it or not, Cherpes explained, they wouldn't feel any different.

All the patients had a green sheet of paper with the day's agenda on it and boxes for points they could earn by completing each activity. Many refused, at least a few times, to participate. But that morning, as she had every day, Rachelle marched cheerfully through her schedule. In nutrition class, she filled in outlines of food with stoplight colors: green for near-zero-calorie products, yellow for more substantial items and red for things like ice cream or French fries, which she would be allowed to have once a month as a single 350-calorie serving. In physical therapy, she walked for 12 minutes, climbed up and down a flight of stairs and pedaled a seated exercise machine while singing along to Miley Cyrus's "Party in the U.S.A." "Tell Mama I'm doing good?" she said to her physical therapist.

The tight structure of Rachelle's days, combined with the lack of food anywhere, led to a complete absence of her tantrums. Once, after an argument over cards, she put her head on the table and refused to participate in therapy. Another time, she was clipping ads from the paper, a favorite activity, and said she didn't want to go to class. Cherpes sat down across from her and watched as Constance Casey, a staff member, encouraged her to go earn her points.

"I'll keep your stuff here for you," she told her. "I'll make sure nobody bothers it." A moment later, Rachelle got up and walked toward her classroom.

"Good choices!" Cherpes said.

The Prader-Willi program at the Children's Institute of Pittsburgh began in 1982 with a single patient. Until 2012, when HealthBridge Children's Hospital in Houston started a program, the institute was the only place in the country, and one of few in

"Food" con'd on next page

"Food" con'd from previous page

the world, to offer inpatient treatment for the syndrome. It now houses roughly 10 patients at a time — both adults and children — for stays of four to 10 weeks, depending on their medical needs and what an insurer will cover. The cost of care, per patient per day, averages about $1,500. Over the past few years, patients seem to be coming to the institute sicker than before, sometimes arriving in wheelchairs and on gurneys — a fact that the staff attributes to insurance companies' increasing their requirements for inpatient rehabilitation while misunderstanding the disorder and what it takes to treat it. "As soon as they hear 'obesity,'" says Kwaj Overton, the nurse case manager, "they think, Well, they need to try Curves."

Actually, much of what the institute does — restricting patients' caloric intake and getting them to exercise — would help any obese person lose weight. For people with Prader-Willi, though, it is impossible to make those changes without also managing grave health complications and out-of-control behavior, which is hard to untangle from exposure to food. People with the syndrome can resist raiding an unlocked cabinet, especially in the company of others. But this effort at control often erupts later in aggression. The institute's philosophy is that eliminating any exposure to food — except at rigidly scheduled mealtimes for which menus are posted weeks in advance — is the only way patients can forget their hunger and anxiety so they can enjoy other food-free activities: crafts, gardening, dancing. There are no punishments for acting out, only incentives for participating. "If the words are 'You have to do this,' maybe I do or maybe I don't, but I'm going to test you and see," Cherpes said. "In a battle of wills, the person with Prader-Willi is always going to win."

A major part of the program is teaching parents how to create a similar environment at home. The staff members also talk to schools about making accommodations, including securing classmates' lunchboxes, finding a place for a child to eat alone outside the cafeteria and providing a one-on-one aide for transitions between classrooms — measures that administrators, especially those in strapped districts, often resist. Over all, the results appear to be positive and lasting. Patients discharged in 2012 lost an average of 27.5 pounds during their stays, and 96 percent continued or sustained their weight loss after 18 months. Nine months out, a vast majority had not needed emergency medical or psychiatric treatment.

For obesity researchers, the uniqueness of Prader-Willi presents a paradox: The causes of obesity in the general population are far more complex and varied than those of the syndrome, but Prader-Willi's specific genetic roots, while not expected to explain all forms of obesity, could offer universal truths about the biology of hunger and fullness. Robert Nicholls, a geneticist at the Children's Hospital of Pittsburgh who studies Prader-Willi, believes it is "very unlikely" that our species evolved multiple, separate systems to govern eating. Understanding why people with Prader-Willi switch in early childhood from an extreme lack of interest in food to insatiability could offer clues about the nature of appetite — which might eventually help scientists minister to a person's specific type of overeating or prevent it altogether. It's possible that it could do the same for conditions of undereating and malnutrition, like anorexia. Whether damage to the hypothalamus can be undone at all, regardless of its cause, is still an open question, but one that a successful treatment for Prader-Willi could

"Food" con'd on next page

"Food" con'd from previous page

answer. "Taking that genetic condition — if that is curable, there could be hope there," says Joan Han, an endocrinologist at Le Bonheur Children's Hospital in Memphis, Tenn., who conducts research at the National Institutes of Health. "It may not tell us everything about obesity in general, but it's an essential part of the big picture."

One promising avenue of exploration illuminated by Prader-Willi involves a gene disrupted by the syndrome, Magel2. During the last 10 years, Rachel Wevrick, the University of Alberta geneticist, and colleagues discovered that mice lacking the gene develop many of the same symptoms that people with Prader-Willi have, including behavioral abnormalities, low muscle tone and obesity. And though they are less active than normal mice, they do not eat less, so they gain excessive amounts of fat. By analyzing samples of their brain tissue, Wevrick found that the ability of their hypothalamus to sense the leptin produced by the body's fat cells was impaired, disabling a neural pathway that tells the animals whether they need to conserve energy and consume more calories. Within the past year, researchers have also identified more than a dozen children in whom only the Magel2 gene on the chromosome 15 segment is mutated. At least several of the children have abnormally large appetites — all have low muscle tone — reinforcing the idea that the gene may play a central role in producing those same Prader-Willi symptoms. The Rhythm drug, RM-493, uses a synthetic protein to bypass the neural pathway (in humans) that should be governed by leptin but does not work in the mice that lack the gene. When a similar compound is given to those mice, they eat less food.

And yet the drug that has progressed furthest in human clinical trials, beloranib, highlights what an enigma Prader-Willi still is. Originally designed to treat cancer, beloranib had the unexpected side effect of decreasing hunger and increasing weight loss. Though it has shown preliminary success in curbing the appetites of people with Prader-Willi, no one is sure exactly how it might be doing so.

In fact, the only drug available so far for managing the weight of people with Prader-Willi — human growth hormone — replaces a deficiency in the pituitary gland that is not directly related to general obesity. Approved for use 15 years ago, the hormone improves muscle tone and increases metabolism, helping people with Prader-Willi stay thinner. When administered early in life, it also appears to improve cognitive ability. This could partly be why more young adults with the syndrome are graduating from high school. Afterward, though, they're often stuck. They can't go away to college, because food is everywhere there. Likewise, it is almost impossible to find a job at which there isn't, at the very least, access to an employee fridge — and they can't be allowed to manage money, because they can use it to buy food. There are a few adult group homes around the country equipped to manage the disorder, but not enough to meet demand. Noah Thorner, who is 23, graduated from high school with honors and now lives with his parents. In lieu of a steady job, he makes wooden toys that he sells on Etsy. Finding friends has been difficult. "Everywhere you go, you see people eating," he told me. "And I realize that I can't participate, and that's really hard."

Another young high-school graduate, Rachel Crowley, attends community-college classes while her mother, Debra, waits outside to prevent her from straying to the vending machines or campus cafe. "She's a great candidate for someone who

"Food" con'd on next page

"Food" con'd from previous page

could have her own apartment," Debra says, "but she can't prepare her own food — that's the main stumbling block. We're hoping some of these new medications they're researching could open that door for her." But questions remain about whether even a miracle drug would be enough to safeguard against a fatal binge: What if it doesn't work perfectly? What if, one day, a person forgets to take it? "It gets exhausting trying to keep your daughter in the world, but a world that just doesn't get it," Duane DiCola, the father of Danielle, one of the girls in Rachelle's program, told me. "We really struggled with 'No, my child is different.'"

Thirty-four days after she dropped off her daughter, Rhoda flew to Pittsburgh for a visit. She would stay for 10 days — in housing offered by the institute — and attend meetings to help prepare for Rachelle's return home. When she arrived, her daughter was waiting for her almost shyly by the door. She had lost 18 pounds and was wearing an olive outfit her grandmother had sent her. A nurse had cornrowed her hair. Rhoda kissed her and petted her cheeks. "Do I know you?" she said. "Who is this pretty girl?"

It was lunchtime on a Sunday. Rachelle led her mother to the rec room, and Rhoda sat near her table to watch her eat. On her tray was sliced turkey breast, steamed cauliflower, a salad, sweet potatoes and cucumbers; a carton of skim milk; a cup of decaffeinated coffee; a cup of Crystal Light; a packet of Splenda, ketchup, salad dressing and Mrs. Dash seasoning; and a cup of sugar-free Jell-O. "I didn't realize they needed all this other stuff to go with it," Rhoda said.

In thinking about how she had managed Rachelle's illness so far, Rhoda told me, she graded herself 65 out of 100. But she believed she recognized where she went wrong. "She'll have a big bag of nuts," she said. "I knew nuts were high in calories, but I was looking at the sugar. Now I'm like, that was a horrible choice. Planning would be the way to avoid that. Those slip-ups add up. If I had not been slipping up, she would not have gained that weight." Rhoda had never met anyone else with Prader-Willi before, and as Rachelle ate, she surveyed the room. Some of the patients were as heavy as Rachelle, but others were barely overweight. Nearby, Danielle was chatting about Disney movies. "You wouldn't even know anything was wrong," Rhoda said.

The next morning, Cherpes, Heather Roach, the program psychologist, and Amy McTighe, the program teacher, took part in a conference call with the director of special education for the Lowndes County school system, where Rachelle is a student. The administrator seemed mostly agreeable to the recommendations they offered, but when Roach suggested celebrating holidays and other events without food, the administrator balked.

"Realize this is South Georgia," she said, before quickly adding, "But if we could teach all of us not to celebrate events with food, we'd be better off."

Still, she suggested that Rhoda simply keep her daughter at home on the half days before school breaks, when cake and candy were rampant. McTighe and Roach shook their heads at the phone. "We're thinking it's best that the accommodation happen at school, rather than her having to stay home," McTighe said.

Later, Roach explained to Rhoda that if her daughter veered off her dietary schedule, even once, not only would she be ingesting calories she couldn't afford, but the exception would become an expectation.

"Food" con'd on next page

"Food" con'd from previous page

If a family member slipped her a treat, for instance, she would probably throw tantrums wanting to see that person again. Spontaneity would be impossible. If Rhoda wanted to take the family to a restaurant, she would need to tell Rachelle several days in advance where they were going and exactly what she would be having there; she would need to speak to the servers and ask that they not put breadsticks on the table or offer specials or sodas or desserts; and if Rachelle acted out, Rhoda would need to be prepared to leave and try again another time.

Rhoda nodded and jotted notes on a sheet of loose-leaf paper. "Regarding the movies," she said, "what is the action to get past the concession stand?"

Almost a month later, on Rachelle's second-to-last day at the Children's Institute, Cherpes found her in the rec room. Rhoda was coming to take her home, and she was too distracted to cut ads or color. "Where's my mom?" she kept asking.

"She's going to get here, don't worry," said her tablemate, Lana Aliff, a motherly 19-year-old from West Virginia.

Rachelle put her head down on her arm. "Airplane — you hear it?" she said. "I think I hear it in the sky."

Cherpes asked her if she would come chat with him. As she followed him to a private meeting room, her gait was noticeably quicker. She had lost just over 30 pounds and was off insulin. She had also begun to say more, probably in part because her brain was getting more oxygen. They sat at a table, and Cherpes asked Rachelle if she was excited about going home. She nodded. He started to explain that her mom would be doing some things differently.

"I don't like boys," Rachelle said, changing the subject. "Boys at my school laugh at me."

"That doesn't feel very good, does it?" Cherpes said.

"Boys tell me I'm fat. Fat and ugly."

"Do you feel fat and ugly?"

"No."

Cherpes suggested ignoring the boys and telling her teacher. Rachelle just kept repeating the problem: "They don't stop. Call me names."

"It gets kind of hard not to cry sometimes," Cherpes said after she left.

If Rachelle had said she did feel fat and ugly, he said, he would have pointed out how much she had changed — something she could control: "What would you like to do that you can't do? Well, just a couple weeks ago you couldn't walk down the hall." Now she could walk for 30 minutes on the treadmill.

That evening, at dinnertime, Rachelle heard the doorbell and speed-walked — she still couldn't run — toward the door. "Mama, guess what?" she said when Rhoda greeted her. "I lost some weight!"

"I know you did," Rhoda said, cupping her face. "You did teenager college like a champ."

Rhoda debriefed with Cherpes and the rest of the staff the next morning. She and Raquel had cooked meals for the week. Rhoda had found an inexpensive gym membership for her and her daughters and discovered cheap frozen vegetables at Walmart. She had tried, via Facebook, to implore her relatives again not to eat in front of Rachelle or sneak her even seemingly healthful snacks.

As she went to collect Rachelle for the airport,

"Food" con'd on next page

"Food" con'd from previous page

though, Rhoda just hoped she could make it home without her daughter melting down over all the available food she would see. In the rec room, Rachelle was starting lunch. Once the trays were passed out, Roach, the psychologist, waved a certificate. "It's Rachelle's last day today, and I want to give her her physical-therapy award," she said. "She has done 65 days of P.T.! Congratulations, Rachelle!"

Everyone clapped. Rachelle, sandwich in hand, froze. Then the corners of her mouth dropped, and tears ran down her cheeks. As if unsure what to do, she took a bite. Rhoda leaned over her with a napkin and dabbed her face. "Don't you want to go home?" she whispered. Rachelle shook her head from side to side. Soon, Rhoda's eyeliner was running, and she was using the napkins herself.

Alexandra gave Rachelle a high-five. "Have a good time, O.K.?" she said. Lana pressed a goodbye card that all the patients had signed into her hand. Rachelle clutched the pink envelope, unopened, all the way to the airport.

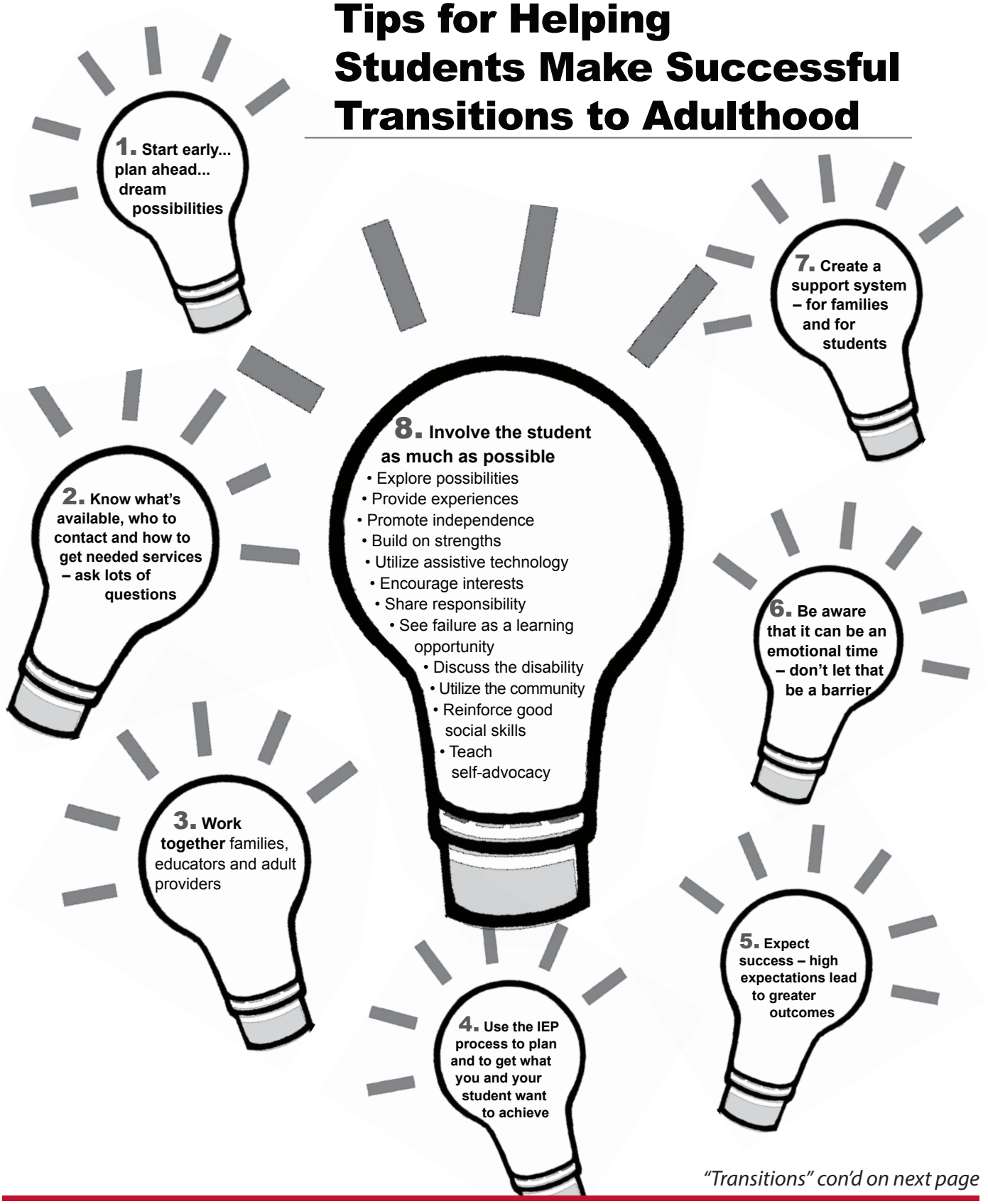
Later, I asked Rhoda why she thought Rachelle had become tearful. "I think she was emotional because she was like, 'I'm in a place where there's other people like me.' They have this understanding among themselves," she said. "I think she felt anxiety about going back into the real world. That's why I started crying, because that's what I thought she might be thinking. It was just her own little world there, and she was happy."

Selections from

The Transition Resource Guide: Life After High School - Ready or Not

Reprinted with Permission from the Mississippi Bend AEA

Tips for Helping Students Make Successful Transitions to Adulthood



"Transitions" con'd on next page

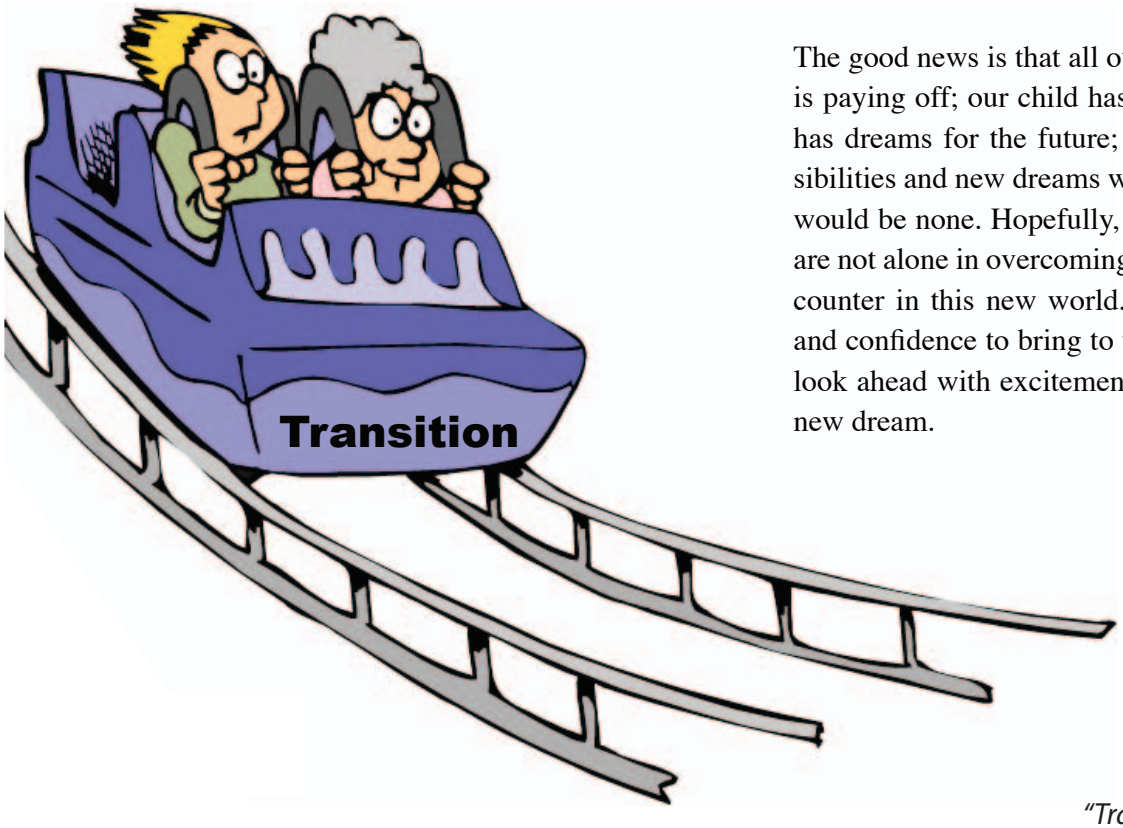
Reprinted with Permission from the Mississippi Bend AEA

Riding the Emotional Transition Roller Coaster

Isn't graduation supposed to be an exciting time for parents? And, it IS exciting! After all, this is what we've been working toward all of our child's school life! Then why do we simultaneously feel sad, anxious, fearful and even, overwhelmed???

There is research to suggest that the impact of our children's disability is greater at the time of transition to adulthood than it was at the time of diagnosis. We think of all the changes, the unknowns and the risks. We learn about a maze of new services out there with which we are barely familiar. We hear of needing to let go yet knowing we can't, not entirely. At the same time, we may yearn to let go, as we have for our other children or have seen others do for their children without disabilities. Instead, once again, we are reminded of what is not to be – that dream we had back before our child was born, that never included disabilities.

It is important to know that these emotions are not uncommon to parents when children with disabilities reach important milestones. Talking with other families who have been through the transition experience can be helpful.



The good news is that all our hard work over the years is paying off; our child has gotten to graduation. S/he has dreams for the future; we have come to see possibilities and new dreams where we once thought there would be none. Hopefully, we have come to know we are not alone in overcoming the challenges we may encounter in this new world. We have developed skills and confidence to bring to the task. We have reason to look ahead with excitement as we work to realize our new dream.

"Transitions" con'd on next page

Transition Checklist

The following is a checklist of transition activities that you and your son or daughter may wish to consider when preparing transition plans with the IEP team. Your student's skills and interest will determine which items on the checklist are relevant. Use this checklist to ask yourself whether or not these transition issues should be addressed at IEP transition meetings. The checklist can also help identify who should be part of the IEP transition team. Responsibility for carrying out the specific transition activities should be determined at the IEP transition meeting.

4-5

Four to Five Years Before Leaving the School District

- ☐ Identify personal learning styles and the necessary accommodations to be a successful learner and worker.
- ☐ Identify career interests and skills, complete interest and career inventories, and identify additional education or training requirements.
- ☐ Explore options for post-secondary education and admission criteria.
- ☐ Identify interests and options for future living arrangements, including supports.
- ☐ Learn to communicate effectively your interests, preferences, and needs.
- ☐ Be able to explain your disability and the accommodations you need.
- ☐ Learn and practice informed decision making skills.
- ☐ Investigate assistive technology tools that can increase community involvement and employment opportunities.
- ☐ Broaden your experiences with community activities and expand your friendships.
- ☐ Pursue and use local transportation options *outside of family*.
- ☐ Investigate money management and identify necessary skills.
- ☐ Acquire identification card and the ability to communicate personal information.
- ☐ Identify and begin learning skills necessary for independent living.
- ☐ Learn and practice personal health care.

2-3

Two to Three Years Before Leaving the School District

- ☐ Identify community support services and programs (Vocational Rehabilitation, County Services, Centers for Independent Living, etc.)
- ☐ Invite adult service providers, peers, and others to the IEP transition meeting.
- ☐ Match career interests and skills with vocational course work and community work experiences.
- ☐ Gather more information on post-secondary programs and the support services offered; and make arrangements for accommodations to take college entrance exams.
- ☐ Identify health care providers and become informed about sexuality and family planning issues.
- ☐ Determine the need for financial support (Supplemental Security Income, state financial supplemental programs, Medicare).
- ☐ Learn and practice appropriate interpersonal, communication, and social skills for different settings (employment, school, recreation, with peers, etc.).
- ☐ Explore legal status with regards to decision making prior to age of majority. (see pages 34, 35 & 39.)
- ☐ Begin a resume and update it as needed.
- ☐ Practice independent living skills, e.g., budgeting, shopping, cooking, and housekeeping.
- ☐ Identify needed personal assistant services, and if appropriate, learn to direct and manage these services.

1

One Year Before Leaving the School District

- ☐ Apply for financial support programs (Supplemental Security Income, Independent Living Services, Vocational Rehabilitation, and Personal Assistant Services).
- ☐ Identify the post-secondary school you plan to attend and arrange for accommodations.
- ☐ Practice effective communication by developing interview skills, asking for help, and identifying necessary accommodations at post-secondary and work environments.
- ☐ Specify desired job and obtain paid employment with supports as needed.
- ☐ Take responsibility for arriving on time to work, appointments, and social activities.
- ☐ Assume responsibility for health care needs (making appointments, filling and taking prescriptions, etc.).
- ☐ Register to vote and for selective service (if a male).
- ☐ Match career interests and skills with vocational course work and community work experiences.

"Transitions" con'd on next page

Reprinted with Permission from the Mississippi Bend AEA

How Parents Can Use the IEP Process to Enhance Transition Outcomes

Successful transition to adulthood takes families, educators and students working together.

Parents, you can have a discussion with your daughters and sons, and, together, come up with your dreams and expectations in the areas of Living, Learning and Working. Ask them what they see themselves doing when they get out of school. Follow that with, "If for some reason, you couldn't do that, what other things would you want to do?" Remember, parents, it is normal if you and your child have differences of opinion. Allow for those differences to be discussed.

The Transition IEP should be built around your children's strengths, interests and preferences. Get their input; let them know what you see them good at; point out where they have been successful; talk about pursuing interests they may not yet have explored. Remind your children that they can change their minds as they explore, eliminate, and change what they hope to do with their lives.

"The Parents' concerns for enhancing their child's education" section is where you can address your child's needs. Maybe you aren't sure your child has the skills to match what she desires to do. Perhaps you are wondering what supports will be available to help him explore interests. The list could go on, and that's okay – write down all of your concerns and share them with the team.

The Transition Goals should reflect both the strengths, concerns, and the transition assessment information completed in the areas of living, learning and working. The information gathered should answer questions like:

- What information has been gathered from my child's transition assessments?
- What skills will my child need to be **successful living** as independently as possible where she wants to live? How will she learn those skills?
- What **work experiences** should be built into his program to explore jobs in which he has expressed an interest?
- What **program of studies** will be important for my daughter to have if she plans to attend a post secondary educational program?
- What **work skills** does he need to work on or develop that will help him be a good employee?

"Transitions" con'd on next page

How Parents Can Use the IEP Process to Enhance Transition Outcomes continued...

- What is being done to help my child **learn to be an independent** and responsible adult?
- How will she be helped to **understand her disability** and become a strong self-advocate for her needs?
- In what ways can we help him **develop leisure skills** that will contribute to a meaningful adulthood?
- **How much time** in my child's day will go toward addressing her transition goals?

You will be kept informed about how your daughter/son is doing with the IEP goals. You should receive that information as often as other students receive progress reports; i.e., midterm and grading times. Don't hesitate to request that your child's teacher "show you" how they know what your daughter/son's progress has been. Schools regularly collect and chart data on student progress so they will have that information for you.

IEP Meeting Attendees: Families and students can request whom they would like to have in attendance at the IEP Meeting. Adult Service Providers, like Vocational Rehabilitation, Supported Employment staff, Kirkwood Community College's VITAL staff, are often very willing and wanting to get involved early.

"Start early" and "Use the IEP Process" are two good rules of thumb for transition planning.

The following articles and checklists are intended to give you information and ideas about what needs to be done and when as you proceed with Transition Planning.

"Transitions" con'd on next page

"Transitions" con'd from previous page

Reprinted with Permission from the Mississippi Bend AEA

Learning to Make Decisions: Students and Their IEPs

When you think about your child's future do you see him being able to make decisions and take at least partial responsibility for choices in his life? Does he have the communication skills, the confidence and the desire to have a voice in the decision process?

Being involved in her own IEP meetings can be a great learning experience for the student to practice making decisions. Her thoughts and wishes should be central to the team's planning for her future. (See wheel on page 42). Student involvement can yield several results:

- Taking over responsibility for some of the direction setting about the future
- Preparation for assuming age-of-majority rights by age 18
- Coming to a better understanding of the disability and its implications for life after school
- Learning to interact with professionals who will share responsibility for the student's receiving services
- Having to learn how to resolve differences when teachers and/or parents want something different from what the student wants

A student should not be expected to walk into a meeting "cold" and effectively participate.

Before the meeting:

- Teachers can help students understand the IEP Process and the student's role in it.
- Parents can talk with their son/daughter about the kind of input he or she may want to offer to help the IEP team plan for transitional programming
- Students can be given responsibility for a specific part of the meeting – reporting goal progress since the last meeting, sharing perspectives on how their disability impacts their lives, or covering the Strengths and Concerns parts of the IEP with their interests, desires and worries

During the meeting:

- Students should be encouraged to share; have them identify their strengths from their point of view; they should have input into every decision made
- Someone who has helped them prepare should assist and prompt students through the process
- Periodically checking with students for understanding will help clarify their input
- All team members should work to affirm effort and help students feel successful

After the meeting:

- Goal progress should be reviewed with the student on a regular basis
- Parents should have on-going discussions about decisions made and the student's satisfaction with the direction those decisions are taking him/her
- Where there is failure, parents and teachers need to help the student learn from the experience
- Planning for the next IEP meeting should be a continuous process

"Transitions" con'd on next page

Reprinted with Permission from the Mississippi Bend AEA

Does Your Child Have Good Self-Advocacy and Self-Determination Skills?

Choice making, problem solving and goal setting are all a part of being a strong self-advocate. Helping children become self-determining adults begins when they are very young and is certainly a critical part of transition planning. Do your child's transition goals address self-advocacy and self-determination?

Becoming a confident person willing to speak up for one's self, express needs and seek assistance begins with an understanding of one's disability. Yet so often we avoid that topic with our youth with disabilities, not wanting to point out differences, offend or make them feel badly. We will talk with them about what they can and can't do yet we don't discuss what's behind some of what they can't do. If our children with disabilities are going to feel good about themselves, they must first feel okay about being a person with a disability. So, parents:

- Don't talk around the disability. Naming or describing the disability can demystify and disarm the power that makes some afraid and anxious about it.
- Let's raise our children with disabilities to be knowledgeable, comfortable, accepting of themselves, articulate and assertive.
- Equip them to speak frankly about their strengths, needs, wants, and feelings.
- Give them tools (information and skills) they will need to gain and keep as much control over their lives as possible.
- Consider them a part of the planning team for their IEPs and teach them to collaborate with those providing care/services.
- Give them gifts we want all children to receive – courage, self-determination, knowledge of themselves, self-acceptance and self-sufficiency.

Reminder Question: How do we as parents, teachers and community service providers empower students to make choices, solve problems and set goals?

Recipes

Sunshine Carrot Salad

Ingredients:
3 cups shredded carrots
1 cup diced unpeeled Red Delicious apples
1 cup 11 oz can rinsed and drained mandarin oranges
½ cup ultra-low fat mayonnaise
Optional sweetener to taste about 2 tsp
½ tsp apple pie spice

Directions:
Mix gently to combine. Cover and refrigerate 30 minutes. Makes 6 servings.

Per Serving: Calories 80.4; Fat 0.3 g; Cholesterol 0,0mg; Sodium 158.8mg; Carbs 20.7

Reprinted with permission from PWSA (USA)
Low-fat, Low-sugar Recipes for the Prader-Willi Syndrome Diet, By: Donna Unterberger

Omelets

Ingredients:
3 egg whites
2 chopped green onions
½ diced red and green bell peppers
1 diced tomato

Directions:
Spray of light vegetable oil in pain. Beat egg whites and place in the fry pan on medium. When eggs start to form add vegetables on top of eggs. Fold over and serve. Salsa may be added as a nice low calorie condiment. Makes 2 servings.

Per Serving: Calories 54.3; Fat 0.3g; Cholesterol 0.0mg; Sodium 91.5mg; Carbs 7.2 g

Reprinted with permission from PWSA (USA)
Low-fat, Low-sugar Recipes for the Prader-Willi Syndrome Diet, By: Donna Unterberger

Interview & Tips for Planning Your Child's Individualized Educational Plan

Originally Posted By: ASK Resource Center, Families of Iowa Network for Disabilities (FIND) Blog findfamilies.org, Reprinted With Permission
Written by Monica Rouse on February 9th

Meet Edie Bogaczyk...Attorney at Law

Posted by Monica Rouse on February 9, 2015 at 8:54am

Recently, in a RESPECT training, I met a new attorney who just hung her sign in the Des Moines area. She is a member of the RESPECT training in Des Moines, and is available to support parents when legal challenges may arise with the needs of a child conflict with the services the public school system provides or is willing to provide. I was excited to interview her and relay the information to the FIND audience.

Q1: Tell us a bit about yourself, including what drew you to the legal field, specifically special education law?

A: I've been an attorney for 20 years but an advocate my entire adult life. Blending my psychology degree with a legal background was a natural fit for my desire to continue to advocate on a broader level. After working in non-traditional legal roles for the past two years, I made a decision to return to the practice of law full time. My intention was to work in an area that embraced my passion for disability rights coupled with filling a community void and need. After speaking with various agencies and some colleagues in the legal field, the common theme in discussions was the need for legal support in "special education" law. I made the commitment and opened my practice last fall with a primary focus on special education law.

Q2: You have a son with special needs. What has been your personal experience with the IEP process as a parent?

A: Our son was born with Prader-Will Syndrome. He received early childhood services and has been a student with an IEP for the past nine years in the public school system. In my experience, being visionary is important. Encouraging the IEP team to think more visionary can be challenging. I know my child the best, and I do not hesitate to lay my aspirations and goals for his future. I believe being prepared for an IEP meeting is important. My husband and I support realistic goals for our son,

"IED" con'd on next page

"IED" con'd from previous page

but we do not waiver on our aspirations for him during school and beyond 12th grade.

Q3: Parents often feel anxious about an upcoming IEP meeting. What would you suggest parents do to prepare for the meeting to help alleviate that anxiety?

A: IEP meetings can be daunting, sometimes due to the sheer numbers of individuals in the room. Even after introductions are made, it can still be overwhelming. In advance of the meeting, ask the school to prepare name tags that identify a person's name, their respective role, and the relationship that person has with your child. It can also be helpful to draft a list of questions and forward them to the person who sets the agenda so answers can be provided during the meeting. Additionally, tab or highlight pages during the review of the IEP (preferable before if you can secure an anticipated copy of the document). When you get to those pages during the review, you will be reminded of your desire to ask your question. Finally, avoid going to an IEP meeting alone. Have someone go with you, even if it to simply take notes. Meetings can be lengthy and having to remember every detail afterwards is worrisome. In addition, the person who went with you can be a person you engage in discussion with to process the meeting to be sure there is a common understanding of what happened during the meeting.

Q4: How important is it for parents to actually read the Procedures Safeguards Manual?

A: It is extremely important and necessary. The Iowa Department of Education Procedural Safeguard Manual outlines parental rights in special education. It provides options available if a parent elects to challenge a decision or action by the IEP team or district. The manual provides direction for the manner by which to address the disagreement. There are filing time constraints as well. Therefore, reading and understanding your rights will keep you informed as to how long concerns are potentially viable.

Q5: How important is the relationship between parent and the local school in serving the child with special needs?

A: Keeping the lines of communication open is important. Like any relationship, the connection between parents and the school can and does fluctuate. Transparency is helpful, both sides being honest about concerns and, at the same time, providing suggestions and possible strategies to address concerns. It is realistic to say that a strategy that worked last week might not be effective this week. Remember, all students are "individual" and have "unique" needs. I always emphasize the "I" in IEP.

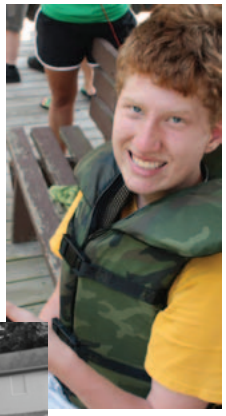
Q6: If a parent feels the need to pursue an attorney's insights, how do you suggest they begin the process of locating one?

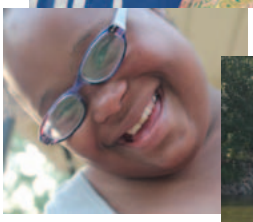
A: Contacting the Department of Education can be a great place to begin. The State Bar Association is also a helpful resource as are local agencies such as ASK and Disability Rights Iowa.

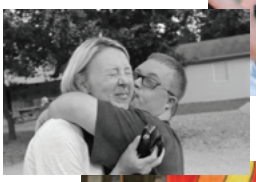
Edie is available by email at edie@bogaczyklaw.com or by phone at 515-443-9151.

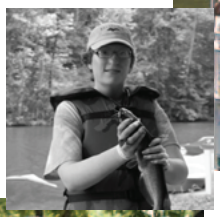
Wonderland Camp

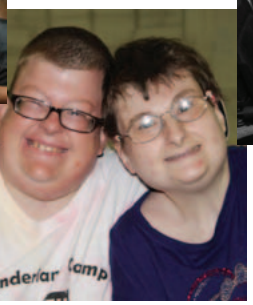
Providing a fun, educational camp experience for individuals with disabilities.











Come to Wonderland Camp!

- Specific Weeks for Individuals with Prader-Willi Syndrome (PWS):
  - ⇒ June 14th - 19th
  - ⇒ July 12th - 17th
- Individualized experience based on the campers' needs.
- Wonderland Camp's Founder, Charles Miller had a son had Prader -Willi.
- More information contact our Office @ 573-392-1000 or info@wonderlandcamp.org;
- Website: www.WonderlandCamp.org

"Life is Good… Camp is Better!"

www.wonderlandcamp.org

www.facebook.com/wonderlandcamp

HEARTLAND AREA EDUCATION AGENCY

TRANSITION FAIR
Monday, April 13, 2015
5:30-8:30 PM

Where: ADM High School, 801 Nile Kinnick Drive South, Adel, IA 50003

Who: Parents, Students ages 14+, Administrators, AEA Personnel, Counselors, and Educators who are preparing individuals to transition from high school to post-secondary pursuits.

Highlights:
Free Refreshments

Break-out Sessions (6:20-6:55, 7:05-7:40 & 7:50-8:30)
Sessions will be previewed at 6:00 in the cafeteria

Sessions may include: Assistive Technology (if interested in attending this session, please bring an iPad/iPod), Guardianships & Estate Planning, College Disability Coordinator Panel, Student Disability Panel, Vocational Rehabilitation, Iowa Workforce Development, Benefits Planning, Apprenticeships, University of Iowa's REACH program, Goodwill and Project SEARCH, I Have A Plan (Iowa's Career Planning Program), Supported Community Living Providers, Life After High School Simulation.

Informational Tables: (5:30-8:00)

Tables may include: Parent Educator Connection Consultants, Camps, Link Associates, Family Resource Center, ChildServe, Goodwill Industries, Dallas County Health Services, Iowa Vocational Rehabilitation, Courage League, Iowa Workforce Development, Job Corps, U of I's REACH, Iowa Work Incentives Planning & Assistance, Dallas County Case Management and Community Services, Optimae, REM, Military Recruiters, MetroWest Learning Academy, Gigi's Playhouse, Genesis, Mainstream Living, MOSAIC, LifeWorks Integrated Health Program, and Post-secondary Apprenticeship Options.

Items to Note: Let your child's teacher know if accommodations will be needed.

Registration: Registration is not required, but it would be helpful to let your child's guidance counselor/special education teacher know that you plan to attend by March 30, 2015.

* More detailed information will be made available closer to event.

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

We'd love to have you!

Fill out this page and 1) mail it to:

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

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

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

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

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

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

Name: _____
(required)

Mailing Address: *(required)*

_____

Street City State Zip

Email: _____
(required)

Phone Number: _____
(required)

Tell us about yourself!
(Does someone in your family have Prader-Willi Syndrome? How old are they? Would you like additional information? Etc.)

_____

_____

_____

_____

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

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

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

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

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

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

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

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

TRAINING FOR SERVICES SPECIFIC TO PRADER-WILLI SYNDROME:
Opportunities for individual or group trainings specific to Prader-Willi Syndrome are eligible for funds. Submission of full information to the Administering Board prior to the event is recommended.

GRANT FOR RESEARCH:
At the discretion of the Administering Board, an amount of up to $500 per year can be given to the PWSA-USA Research Fund.
Krumm family members serving on this Fund: Wanda Askelson, Carlene Krumm, and Valerie.

PARTING WORDS

from the Prader-Willi Syndrome Association of Iowa:

"To *effectively communicate,* we must realize that we are all *different* in the way we perceive the world and *use this understanding as a guide* to our communication with others."

-Tony Robbins

Has Your Home or E-mail Address Changed?

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

Share this newsletter! Find it online at PWSAIowa.org/spring2015