PWCF NEWS

pwcf.org Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

The Newsletter of Prader-Willi California Foundation | AN AFFILIATE OF PWSA (USA)

January ~ March 2013
Volume 24, Number 1

In this issue:

Go Green this Spring
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PWCF Proudly Announces Our New Website!

www.PWCF.org

Our vision is that people with Prader-Willi Syndrome may pursue their individual hopes and dreams to the full extent of their talents and capabilities and that we will help them achieve their goals

Prader-Willi California Foundation (PWCF)

Welcome to the Prader-Willi California Foundation's (PWCF) website. Since 1979 we have been dedicated to supporting people with Prader-Willi syndrome (PWS), their families, and the professionals who serve them.

This site will help you learn more about PWS. At the top of this page are tabs targeted to each viewer that will provide information especially designed to assist and support that viewer.

If you are a parent whose child has been recently diagnosed with PWS, we suggest you begin by clicking the **"For Parents"** tab at the top of the page.

PWCF is funded by donations, grants, membership dues, and events. We invite you to join us.

No products in the cart.

Announcing the 13th Annual Walking for PWS Events!

PWS Camp Registration Now Open!

Read in Spanish

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PWCF is recognized by the IRS as a 501(c)(3) tax-exempt organization.
Donations to PWCF are tax deductible as a charitable contribution to the extent permitted by law.

Years of behind-the-scenes work have gone into PWCF's new website. The site features a special tab for **Parents** who have just received the diagnosis, and information that is age-specific (birth to 5 years; school age; adult years). Another tab is for **Relatives and Friends** that contains information about how to be supportive, general food and behavior management strategies, and social skills information. A third tab contains information for **Professionals** such as teachers, physicians, nurses, attorneys, residential care providers, vocational work site and day program providers, and Regional Center case coordinators.

There's a **Research** tab where you can learn about the latest research, where the next research conference will be held, and how you can participate in a research study. Every tab contains a wealth of information designed to educate, inform, and support the reader.

Though clearly not enough, some important information has been translated for our Spanish speaking families, and even our Arabic and Vietnamese speaking families.

Special thanks go to **Tom McRae**, **Julie Casey**, and **Lisa Graziano** for working on the design and population of the site.

We thank our countless other volunteers who also wrote, reviewed and/or edited content: **Kimberlee Morgan, Patti McRae, Katherine Crawford, Dan Casey, Daniela Rubin, PhD, Paula Watney, Mary Hill, Michelle Donaldson, Fran Moss, June-Anne Gold, M.D, Roger Goatcher,** and **Shandra Beer.**

PWCF gives special thanks to **Ryan Delane** of **Web Site Maintenance & Design** who worked hard to help us create and support our new site. www.WSmad.com (310) 316-5393 ryan@WSmad.com
Web Site Maintenance & Design will get your Web Site working for you!

Please let us know what you think of the new site, particularly if you find a goof or an area in need of improvement.

PRADER-WILLI
CALIFORNIA FOUNDATION

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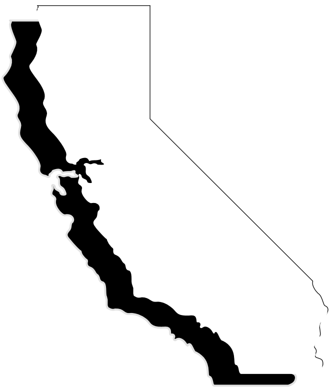

"The mission of the Prader-Willi California Foundation is to provide to parents and professionals a state network of information, advocacy and support services to expressly meet the needs of children and adults with PWS and their families."

PWS Support Contacts And Groups

Northern California

San Francisco Bay Area	Patti McRae	408-920-8003	pattimcrae@sbcglobal.net
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On-Line Support

PWCF Online Information Sharing Group for Members. This online information sharing group is for PWCF members. To join the group, go to www.yahoogroups.com. In the search box under the heading "Join a Group" enter *PWCFmembers*. When the *PWCFmembers* group name appears, click and follow instructions to join.

PWCF Online Information Sharing Group for Professionals. This online information sharing group is for professionals working with individuals with Prader-Willi syndrome e.g., Regional Center caseworkers, residential staff persons, etc. To join the group, go to www.yahoogroups.com In the search box under the heading "Join a Group" enter *PWSProfessionalsExchange*. Click and follow instructions to join the *PWSProfessionalsExchange* group.

PWSA Online eSupport Groups. www.pwsausa.org Click Enter. Click Support.

for Families of Children Ages Birth-5 Years
for Families of Children Ages 6-12 Years
for Families of Teens
for Families of Adults
for Siblings
for Spanish-Speaking Families
for Military Families
for PWS + Autistic Symptoms
for Persons with PWS
for Grandparents

International PWS Organisation

IPWSO offers information about PWS in other languages. www.ipwso.org

Parent to Parent

Today I lost my temper with my son. I didn't just yell at him, I screamed *at him. I feel ashamed and sorry for how he felt. How do you express regret or apologize after an event like this?*

Honesty is the best policy. Tell him that you are so very sorry that you lost your self control. Let him know that you love him and that there is absolutely nothing he could ever do or say or think that would ever stop you from loving him. If you lost your cool over a behavior, let him know that it was the behavior, not him that upset you and then set about devising a plan (with him if possible) to correct the behavior. Another point, I always take responsibility for my part in the behavior. For example, if foraging is involved, I know it happened because I didn't fortify the boundaries well enough. I hope this helps. *Susan Shannon, mother of Shannon, age 36*

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Oh boy. This question hit home. A few days ago I walked out of the kitchen for one second to use the bathroom and my son proceeded to fill his oatmeal bowl to the brim. This amount of oatmeal will at least double if not triple in size after it is cooked. I was so tired and disgusted with his food issues (he was caught stealing tortillas the evening before). I called him a name that I could hardly believe came out of my mouth. I was angry. I immediately felt like the lowest scum of the earth for calling him that name. All day I beat myself up. I did "own up" and apologize, right away, and then all day, probably a dozen times. I do think that "owning our short comings" is the best way to be humble. Admitting that we fall short is a good policy. I am working on trying to focus on MY own behavior in the relationship rather than the focus being on the other person. Truly we only have control over ourselves. My son could be offensive ten times to my one time. I have to get over that. It doesn't justify my "one time." Unfortunately our kids learn by example. That is truly what speaks louder than words. Sometimes I want to put duct tape over my mouth. I do not want to be a "yeller." I don't want my children to remember me as a mom who lacked self control. I have been trying to start my day in prayer and give myself respite here and there. We have a very hard calling as care takers and it feels almost humanly impossible at times. If we are screaming at our kids we need to take personal inventory. Ask for help. Get some respite. Call on friends. Call on family. Hire a new worker. Set up an occasion to look forward to. Give yourself a break. *Cherie Sakschewski, mother of Lance, age 28*

Next issue's Parent to Parent question is *"My child is in the 4th grade and still cannot read well at all. Is this very common?" For those of you with children who have very poor reading skills, how did or do you help them?*

PWCF'S CAMP AT
EASTER SEALS CAMP HARMON
JUNE 20-25, 2013
Register at www.PWCF.org

Don't miss PWCF's 3rd annual PWS Camp at Easter Seals Camp Harmon that *exclusively* serves persons with PWS ages 8 to 65.

Camp Harmon is located in Boulder Creek, California in the beautiful Santa Cruz Mountains. Prior years' programming included campfires, daily swimming, arts & crafts, a hike, impromptu basketball games, quiet time, horseback riding, a dance and the *best* camp counselors! Male and female nurses are onsite to administer all medications. Staff to camper ratio is 3:1, with 1:1 available.

The menu is all healthy low cal/low carb, and exceptionally delicious. Access to food is strictly secured. Camp Scholarships are available to PWCF members in good standing that bring registration costs down to $500 (PWCF will pay $226 of your registration!). Non-member price is $726. Campers LOVE PWCF's PWS Camp!

Space is limited. Register online www.PWCF.org. For more information about programming, menu, or if you need help registering contact PWCF 310.372.5053
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Food Tip

This food tip is submitted by Cameron Graziano of Redondo Beach

Cascade Ice beverages have no calories, no carbs, 0 grams of sugar, no caffeine, no sodium, and no gluten! They come in a wide variety of flavors and each is delicious!

There are over twenty **Sparkling Water with Juice** flavors including Acai Pomegranate Dragonfruit, Blueberry Watermelon, Strawberry Guava, Raspberry Lemonade, Cherry Guava Berry, Key Lime Lulo Pear, and Coconut. All are available at Albertsons.

Available online at www.cascadeicewater.com are **Sparkling Water** flavors include Citrus Twist, Lemon Lime, Mixed Berry, and Lemon Zest.

Also available online for those with more “sophisticated” tastes are **Sparkling Cocktail Mixers**. Enjoy a 0 calorie AppleTini, Mojito, Pina Colada, or Cosmopolitan. For a mere 5 calories enjoy a Lemon Drop or for just 10 calories savor the Margarita flavor.

Gadget Tip

Mobo Triton -The Ultimate Three Wheeled Cruiser

The **Mobo Triton** is an exciting and ultra maneuverable three wheeled cruiser for children and adults. With a very unique, yet simple steering mechanism, not only is the Mobo Triton fun and enjoyable to steer, it is also easy to ride, durable and a great way to obtain a brisk work out resulting in increased cardiovascular health and hand-eye coordination. The Mobo Triton sits low to the ground, which makes it safe to ride and is designed to be simple, reliable, and fun! The Mobo Triton also includes an adjustable frame which makes it comfortable for riders of various heights. The caliper hand brake makes slowing or stopping quick, smooth, and easy. A front free-wheel mechanism, a generously padded seat, and inflatable tires provide a smooth ride. The relaxing recumbent seating position means minimal pressure on the wrists, elbows, and hands. There’s even a Mobo Tot for smaller riders! Made by ASA Products www.asaproducts.com . Toys R Us carries this cruiser for about $330. Happy riding!

Ride to Fly

Ride to Fly in Palos Verdes

For those of you who live in or near Palos Verdes, California, there’s a wonderful therapeutic horseback riding organization you should know about.

Ride to Fly is a non-profit organization dedicated to providing therapeutic horseback riding and the associated learning experiences to children and adults with disabilities in a safe, nurturing environment. RTF believes in the inherent worth and dignity of all people and wishes to share the special gift of horsemanship with those with special needs. Ride to Fly is a PATH International (Professional Association of Therapeutic Horsemanship International) member operating center that has been serving the South Bay area since 1994.

RTF’s instructors have been specifically trained and certified in therapeutic riding techniques. Their dedicated volunteers also go through training and safety classes. Their horses are carefully selected for their calm, gentle natures and are highly trained. According to their abilities, participants perform traditional horseback riding activities. They use traditional English, Western, and Bareback riding styles. Games, trail rides, and exercises provide fun and challenging sessions to meet each rider's individual needs. For more information visit www.ridetofly.com

Executive Director's Column

Lisa Graziano, M.A.

Have you ever gotten to a place where all of a sudden *everything* is a priority and it *all* must be completed *at the same time*? And the more you work to get these critical tasks completed, the more fatigued you become? But the more pooped you feel, the less capable you are at actually completing the tasks? This is my experience and one reason why you're receiving this newsletter edition so late. So from the get-go, let me express my personal apologies for my part in the lateness of this newsletter edition.

I imagine, actually, that what I've experienced (ok, am still experiencing) during the first few months of this New Year isn't too terribly different from what you experience from time to time. Here's how I believe it goes: the more we learn about PWS and connect with experienced others, the more aware we become about successful medical and therapeutic interventions and strategies and techniques that are successful at managing behavioral symptoms. Then, as we become aware of and learn more about each of these potential interventions, we want our child to receive the benefit of them. And so we drive our child from this specialist appointment to that specialist appointment, try to figure out how to add hippotherapy and craniosacral therapy to the already full daily regimen of therapies, address in-school issues and attend to homework matters, research this potential employer and train-up that work environment or day program so that our loved one has a full and fulfilling quality of life. It's often difficult to prioritize the day-to-day tasks required of us in order to meet the moment-to-moment needs of our loved one with PWS. Each need is real, persistent and pressing, and multiple needs must often be addressed simultaneously. The harder we work to meet these needs and create a safe *and* emotionally rich environment, the more exhausted we may feel, leaving us less capable of actually meeting those needs, especially when our loved one's need is for us to maintain a calm, low-key, patient demeanor.

Organizationally, we've worked hard and come a long way since PWS was first identified in 1956. We have an International PWS Organization (formed in 1991) to assist families all over the world. We have a national Prader-Willi Syndrome Association (formed in 1975) and a state Prader-Willi California Foundation (formed in 1979). Most other states in the union now have their own PWS chapter to offer their state's families guidance and support. Most recently (2003) the Foundation for PW Research was formed to focus its resources on research efforts.

Hard work has brought us a long way in our understanding of the medical aspects of Prader-Willi syndrome and the management of many of its symptoms. The FDA has approved growth hormone treatment for children with PWS, though we must still battle for this treatment for our infants, adolescents, and adults. Dry mouth symptoms can all but be eradicated with Biotene toothpaste. Instituting the Principles of Food Security will reduce many problematic behaviors. Implementing PWS Behavior Management Strategies will improve the flow of day, every day. Psychotropic medications can help reduce anxiety and improve other psychiatric symptoms. Today more than at any other time in history, people with PWS can maintain a healthy weight.

And yet there are still too many critical aspects of PWS that remain elusive: appetite regulation, mood regulation, digestive regulation. This issue of the newsletter contains new and important information about digestive issues. We don't yet have all the answers about *why* things occur, but like other symptoms of PWS we are getting closer at identifying how to manage them.

PWS is still considered a rare disorder and so we are fortunate that it catches the attention of many talented and skillful professionals from all over the world. Researchers, scientists, physicians, and clinicians work hard every day to unravel the mysteries that cause the symptoms of PWS. Many who work directly with patients and families absolutely understand the urgency, the absolute priority to develop some intervention that manages the hyperphagia – drive to eat – symptom. And at the same time, there is a critical need to develop some intervention that improves the digestive process that eliminates the heartbreak that gastroparesis causes. And everyone touched by PWS knows how critical it is to develop across-the-board successful interventions that improve control over feelings and behavior so that individuals with PWS can feel calmer and respond more calmly to their environment. These and others are all absolute priorities that demand attention *now.*

I believe, and I hope that you do too, that we *will* reach each and every one of these goals. We get closer every day. Like this newsletter, these tasks will be checked off the list. And when this occurs our hard work and perseverance and even our fatigue will have been worth it because life as we know it for people with PWS will be changed forever.

> **Live with intention. Walk to the edge. Listen hard. Play with abandon. Practice wellness. Laugh. Risk love. Continue to learn. Appreciate your friends. Choose with no regret. Stand by your family. Celebrate the holidays that make sense. Lead or follow a leader. Do what you love. Love as if this is all there is.**
>
> ***~ Mary Anne Radmacher***

Gastroparesis: The Newest Threat

by Lisa Graziano, M.A., PWCF Executive Director
Janalee Heinemann, M.S., PWSA (USA) Director of Medical Affairs
Ann Scheimann, M.D., MBA, Gastroenterologist and PWS Specialist

If you're a member of the Prader-Willi California Foundation and the national Prader-Willi Syndrome Association (USA) then you have read about or discussed at a meeting of some sort this thing called gastroparesis. There have been articles about the fact that it exists, alerts about it (*Medical Alert: Gastrointestinal Issues in Individuals with PWS*), and now a peek at the likely incidence rate (this issue page 7). What we haven't yet received enough information about is how do we know if our child/adult may has it and what can we *do* about it. This is the focus of this article.

Please know that this article will likely be a difficult read for those of us who care for and love someone with PWS. Knowledge is power, however, and so if the information contained within this article helps inform care providers enough that they can keep someone with PWS safer, then the read is worth it.

In 1999 PWSA (USA)'s *The Gathered View* included an article about PWS specialist Rob Wharton's, M.D. discovery of what he termed Acute Idiopathic Gastric Dilation. What Dr. Wharton saw in his patient was that for some unknown (idiopathic) reason the stomach (gastric) was quickly (acute) pushed out (distended) and caused the stomach tissues to die. If not immediately treated with surgery this condition may lead to death.

Over the following years, particularly with closer examination by PWS and GI specialist Ann Scheimann, M.D., it has become clearer that a great number of people with PWS have a stomach that empties too slowly. In fact, Dr. Scheimann now believes ***it is highly probable that a significant number of people with PWS have some degree of a slow emptying stomach***. The medical name of this disorder is gastroparesis: the muscles in the wall of the stomach work poorly and prevent the stomach from emptying properly. As a result, food stays in the stomach longer than it should. Over time, the volume of accumulated food in the stomach can cause the stomach to become full. Like a balloon that has too much air, the stomach of someone with PWS that contains too much food can respond in one of two ways: it will rupture, or the food will push so hard against the stomach lining that it "strangles" the cells in the stomach. Both of these conditions cause massive internal infection and can quickly lead to death.

Other important factors to consider are that some medications such as narcotic pain relievers and anticholinergic medications can also cause the stomach to empty too slowly (as well as cause dry mouth symptoms). Abnormally high blood glucose (sugar) levels or undetected hypothyroidism can also slow stomach emptying therefore it is important to control blood glucose levels and screen periodically for hypothyroidism.

At the same time the stomach empties too slowly, the intestinal tract (bowel) also seems to empty too slowly. This means that digested food that the body turns into waste product and must eliminate from the body as feces/stool is not entirely eliminated leaving too much stool in the intestinal tract.

I've spoken with many parents and care providers who've believed that because their child or adult has a bowel movement every day that this means they don't have a slow emptying bowel. This is not necessarily true. Even with a regular daily bowel movement the intestinal tract may not empty appropriately. As the colon becomes more backed up with retained stool, the ability to evacuate stool is less effective. Over a long period of time, continuous, constant hard pushing has resulted in some people with PWS to experience rectal prolapse. The feeling of constant fullness and pressure on the anus or itching of the skin from irritation from bile acids present in the stool may contribute to reasons why some people with PWS insert their fingers into their anus or pick at it.

As the colon becomes more impacted with retained stool, emptying of the stomach commonly slows down. This means that gastric rupture or dilation are at dangerously elevated risks.

How to Detect Gastroparesis and Slow Emptying Bowel

How do we know if the individual with PWS we're caring for has gastroparesis or a slow emptying bowel? What are the signs? What are the symptoms? What do we look for? The answers are, unfortunately, that there probably aren't many easily recognizable signs or symptoms.

The symptoms of a slow emptying stomach are primarily nausea, vomiting, abdominal fullness after eating, and/or pain. But for persons with PWS who often have a blunted pain threshold and an absent vomit reflex, symptoms of gastroparesis or Acute Idiopathic Gastric Dilation can be extremely difficult to detect.

Because the abdominal core muscles are generally weaker in persons with PWS, the stomach can often appear to be more rounded. If food is not emptied quickly enough the stomach can look rounded (distended) and feel "too firm" to the touch. On the other hand, for those who are taking growth hormone medication and are therefore more lean, the stomach can already feel "firm" to the touch.

The definitive test to identify delayed stomach emptying is the Gastric Emptying Study which measures the amount of time it takes for food to empty from the stomach and enter the small intestine. The test is done in the nuclear medicine section of a hospital.

Continued on page 7...

Gastroparesis continued from page 6 ...

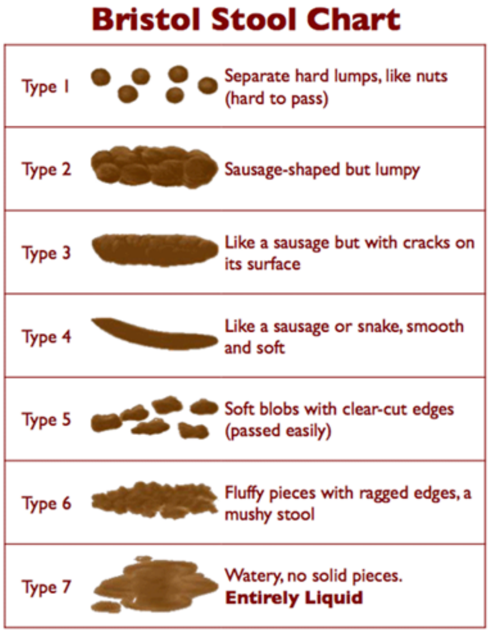
The patient fasts overnight and eats a breakfast that contains a tiny amount of radioactive material. The patient then lies flat and still on an exam table under a large "arm" that measures the amount of food particles that evaporate from the stomach over a period of time, generally four hours is the appropriate amount of time for the emptying study, following a mixed meal of liquid and solids. There are no side effects from a gastric emptying study; the radioactive material is not absorbed into the body and is eliminated in the stool. The test can be difficult for kids under the age of 10 to complete because it is critical that the person lie perfectly still throughout the duration of the test. It is important to make certain that other factors such as constipation and/or thyroid disease are well controlled prior to completion of the test.

The most likely answer to how we treat the potential for gastropareisis and slow emptying bowel is to presume they exist and treat them as if they exist.

Treatment Strategies

1) As with all treatment of PWS symptoms, the first approach is to always provide Food Security: a) provide a healthy, low-calorie, low carbohydrate diet; b) serve meals and snacks at structured times/sequences of time throughout the day; and c) restrict all access to food.
2) Request from the PWCF or the PWSA (USA) information about GI issues in persons with PWS.
3) If there are GI concerns present, consider consultation with either a pediatric or adult gastroenterologist, dependent upon age. Provide the physician with your GI issues documents.
4) Discuss the pros and cons of a Gastric Emptying Study.
5) Discuss the use of medications such as metoclopramide (Reglan) and erythromycin to improve stomach emptying.
6) Discuss an assessment for stool buildup (e.g., palpitation, x-ray). The Bristol Stool Chart can be used to screen/track progress of the management of constipation. Normal stools should be Bristol Class 4 (See Chart).
7) Discuss the use of over-the-counter medications such as Miralax to improve stool elimination and over-the-counter probiotics to help regulate the balance of helpful organisms (microflora) in the intestines
8) If there are challenging issues for your primary GI specialist physician, suggest the GI specialist contact a PWS GI specialist by contacting the PWCF or the PWSA (USA).

We continue to learn more about the gastrointestinal and bowel emptying issues of Prader-Willi syndrome and as we do, we will inform you. Maintain your membership in the PWCF and the PWSA (USA) so that you stay as informed as possible about the management of gastroparesis, slow emptying bowel, and all other PWS-related medical issues.



Delayed Stomach Emptying in PWS

RE: Gastric Emptying Study Sponsored By PWSA (USA)

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I have completed the final control for the patient's gastric emptying portion of the PWS study. Gastric emptying was delayed for nearly all the Prader-Willi subjects and was normal for all the obese matched control subjects. We will be analyzing the PWS subjects to review the impact of the type of diet upon gastric emptying, the time/strength of gastric muscle contractions over the meal duration in addition to review of the GI peptides collected during the course of the meal.

As gastric emptying appears significantly delayed in nearly all patients with Prader-Willi syndrome, I would suggest for now controlling other factors, such as constipation, which are well documented to slow gastric emptying due to downstream effects.

Ann O. Scheimann, M.D., M.B.A., Associate Professor of Pediatrics Division of Pediatric Gastroenterology and Nutrition, Johns Hopkins Hospital; PWSA (USA) Clinical Advisory Board member

Soothing Your Child's Heartburn And Acid Reflux

by Katherine Crawford, Family Support Coordinator

A number of individuals with PWS have acid reflux. They could have an odd feeling that food is "stuck behind the breastbone", or they could experience a burning pain in the chest ("heartburn"). This feeling can sometimes be soothed by antacids, but what can you do to help prevent it in the first place? The first rule of thumb is to keep a food journal over a period of time. Record what, when, and how much is eaten, as well as activities done after the meal, and whether or not there was heartburn as a result. There is no one-size-fits-all approach. Keeping a food journal allows you to tailor a diet to an individual based on what works for them, moderating consumption as needed.

Heartburn Foes:
Spicy foods are notorious heartburn triggers, but if your family loves delicious Mexican food like mine does, you'd be sad to give it up! Luckily, heartburn control isn't an all-or-nothing thing. If you know spicy food triggers heartburn, you may still be able to enjoy a milder version of your favorite foods or have a plan to take a preventative antacid. Keep that food journal to find out what works! **Tangy citrus fruits** (like oranges or orange juice) are classic heartburn-causing foods because of their high acidity. They are worst when taken on an empty stomach. **Tomatoes** are in this same high-acid category. Certain vegetables, including **bell peppers, garlic** and **onion** can trigger reflux depending on the person; keep a food log to see if it affects your child.

Many people think of **peppermint** as a stomach-soother, but that may not be the case for acid reflux. It turns out that peppermint may even increase the chances of heartburn because it relaxes the sphincter muscle that sits between the stomach and the esophagus, the valve keeping the stomach acid down where it belongs. Other foods that can have this effect include **alcohol, chocolate, and caffeinated drinks.** Caffeinated drinks that are **carbonated** (like most sodas) have a double-hit effect: in addition to relaxing the esophageal sphincter, the carbonation increases the risk of gastric distension, which increases pressure on the sphincter. If you have a child with PWS, chances are good that you are already avoiding soda anyway.

High-fat foods are a surprise trigger for some people. These include foods like **avocadoes, nuts, and cheese.** Foods high in fat slow down the emptying of the stomach because they take longer to digest, which increases the chance of a distended stomach, which in turn puts pressure on the gatekeeper valve, the esophageal sphincter. We already know that people with PWS have slow-emptying stomachs to begin with, so slowing the emptying down even more with high-fat foods can be problematic! For this reason, it is important to exercise caution with these foods. It may be possible to mitigate the heartburn triggering effects by giving your child a smaller portion of the high-fat food, and have them eat it at the beginning (rather than the end) of the meal so their stomach has more time to process it.

Heartburn Allies:
Now on to the fun part! You've already looked at what foods can contribute to making heartburn worse, so now let's look at what can help prevent heartburn.

Since saliva neutralizes acid that may come up from the stomach, things that promote saliva are often helpful. Since saliva is often overly thick in individuals with Prader-Willi syndrome, using a product like **Biotène toothpaste** to encourage healthy saliva may help multiple problems at once. The danger of stomach acid from reflux eating away the tooth enamel is a very real concern which should be treated seriously.

Heartburn interventions need not be only food-based. **Gravity** can also be used in your favor to keep stomach acid down. If your child has just eaten dinner, have them **keep their torso upright for at least three hours** afterward to give the stomach a chance to empty. This may mean eating dinner earlier and avoiding snacks right before bedtime. If you're still concerned about nighttime reflux, there are a number of wedge-shaped foam "pillows" that can be used on the bed itself so that your child can lie down and still keep their torso at a raised angle. An even faster (and cheaper) solution can be to raise the head of the bed by placing two wood blocks under the bed stand. If your child tosses and turns, this means that they'll be more upright no matter what.

Another intervention is preventing the stomach from getting overly full. This is already a concern with Prader-Willi syndrome, so chances are you are already limiting meal calories, and you're likely also **limiting meal size** as well to prevent stomach distension. Medically, there is a wide range of **antacids** available over-the-counter. In my own personal experience it's worth trying different brands. For example, I drink a dose of one specific brand of liquid antacid right after I've eaten my favorite spicy meal. It just seems to work better for me than other antacids.

If your child's gastric reflux is unresponsive to your interventions, you'll want to schedule an appointment with a **gastroenterologist** to explore possible treatments. Given the challenges individuals with Prader-Willi syndrome face with slow-emptying stomach and GI problems, you may wish to visit one even if your child does not appear to have reflux.

Finally, I'll leave you with these three tips. The power to soothe your child's reflux is in your hands!
-Keep a Food Journal
Record *What, When*, and *How Much* was eaten
What *Activities* were done after the meal, and if the person remained upright
Record any *Interventions* needed (such as taking an antacid medication)
Bring this with you to gastroenterologist visits

Continued on page 9 ...

Reflux continued from page 8 ...

-Be aware of common Food Foes

- Acidic foods
- Spicy foods
- Caffeinated / Carbonated drinks
- High-Fat foods (eaten in large quantities and/or at the end of the meal)

-Use heartburn prevention techniques

- Use gravity to keep down stomach acid
- Limit meal size
- Use antacids as needed
- Encourage saliva production (since it helps neutralize stomach acid)
- Visit a gastroenterologist to explore possible treatments

Ken Smith Leaves The Children's Institute in Pittsburgh

We regret to inform you that after 27 years of dedicated service to Prader-Willi syndrome, **Ken Smith**'s position at The Children's Institute in Pittsburgh has been eliminated. Ken directed and oversaw the PWS & Behavioral Disorders Program at the Institute where he gained invaluable experience and information about the behavioral components of PWS. The Institute continues to serve persons with PWS who are in behavioral or medical crisis, but case managers versus a director now coordinate services. Ken remains committed to working with the national PWSA (USA) and serving families. If you want to contact Ken email him at ksmith@pwsausa.org

Ken Smith (middle) with a few members of PWSA-USA Adults

Carina Chaij Completes Research Paper

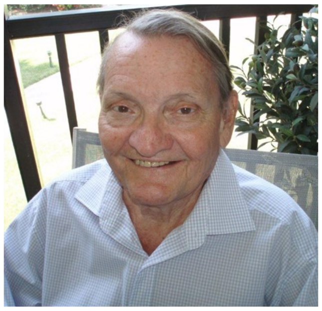
Latino Families with a Child with PWS:
Exploring Needs for Support

PWCF proudly supported the research of PWCF member Carina Chaij as she worked to learn more about the needs of Latino families who are raising a child with PWS.

Her work will be submitted to the Children and Youth Services Review and the Journal of Social Work in Disability & Rehabilitation. Stay tuned for a summary of Carina's findings in a future newsletter.

. David Wyatt: Legacy of a Hero

by Evan Farrar, PWSA (USA)
Crisis Intervention Counselor
Reprinted with permission from PWSA(USA)



For those who've been around PWSA (USA) – and especially involved in any way with its family support and crisis services over the years – David Wyatt is a much beloved and inspiring figure. Beginning in 2000, at the request of then Executive Director Janalee Heinemann, David began working as the first "official" PWSA (USA) Crisis Intervention Counselor. He was well suited for the task bringing 37 years of professional counseling experience and education to his new counseling role with the PWS community. In addition to his many professional gifts, David brought to our association his humble, gentle, and calming spirit that personified the best a counselor can offer to a person or family in crisis. Countless people with PWS and their families have been changed for the better because of David's work.

In 2007 it was my honor to step into David's position when he finally decided to enter a long overdue retirement – while still staying on as our Crisis Counselor Emeritus. To this day, David's hard work and spirit of person centered creativity and collaboration are the foundation of PWSA (USA)'s unique and very effective crisis intervention program. And so it is with great respect, gratitude, and thanksgiving that we named our first special education advocacy training after David who long ago – without the support we benefit from today – worked quietly and effectively with parents, teachers and schools across the country to help students with PWS claim their right to an appropriate and effective learning environment. We are excited that in his name, the Wyatt Special Education Advocacy Training (WSEAT) has been created.

> *For Everything that has been—Thanks.*
> *For Everything that will be—Yes."*
> - Dag Hammarskjold

Congratulations to

Ryan Patay,

Age 8 1/2, son of

Jessica & Chris Patay,

who ran his first 5K

race in March.

Way to go, Ryan!

Board Corner

Board Corner

PWCF Board Directors Tele-Meeting, March 12, 2013

Submitted by Whitney Bras

Board Members Present: Whitney Bras, Julie Casey, Rodger Goatcher, Jackie Lindstrom, Tom McRae, Nisha Meta, Kimberlee Morgan, and Paula Watney

Staff Present: Lisa Graziano, Executive Director; Katherine Crawford, Family Support Coordinator

Board Members Absent: June-Anne Gold M.D., Renee Tarica, Julie Tauscher

Executive Director's Report - The Executive Director, Lisa Graziano, reported that she and Katherine have been very busy in the office assisting families with various issues as well as spending a lot of time preparing for the upcoming Walk-a-Thons.

Program Committee Report - Unfortunately Ross Greene, PhD, author of *The Explosive Child*, will not be able to present this year's General Education Meeting. Katherine and Roger are working on an Agenda for their Educational Advocacy Training program. Lisa will establish dates for the PWS Behavioral Training program.

Research Committee Report - Julie Casey identified two recent research articles with potential benefits for PWS.

Executive Committee Report - There was discussion about PWSA(USA)'s new resource support for chapters. The Board elected to remain independent from PWSA but continue to provide financial support and maintain the positive and beneficial relationship we've enjoyed for many years.

Action Items - The board has been discussing creating a Board Member Profile Matrix to better identify skill sets that would benefit the Board of Directors. Deeper discussion is to take place at the May meeting. The Board is also working to create an "Elevator Speech" about the syndrome which will help with awareness and fund raising activity. The 30 second Elevator Speech will include critical components of the syndrome and will be shared with members to aide in wide-spread awareness-raising efforts.

Residential Training - PWCF is in talks with an established group home organization to open a group home that will exclusively serve children with PWS.

The next board meeting will be held on May 18, 2013.

It was with tremendous sadness that the Board learned that Yvette Tarica, daughter of one of our longest-term Board members, Renee Tarica, passed away suddenly in March. PWCF's crisis line was utilized by Yvette's physicians and surgeons in order to receive PWS medical guidance from throughout the U.S. but despite everyone's dauntless efforts, Yvette's life could not be saved.

PWCF's 2013 Board of Directors, Officers, & Staff

Name	City of Residence	Profession	Age of Family Member
Whitney Bras	Placentia	Homemaker	15
Julie Casey President	Burbank	Insurance Profession/Risk Mgmt	9
Roger Goacher	French Camp	Director of Special Education	11 & 17
June-Anne Gold, M.D.	Loma Linda	Genetics Researcher	—
Tom McRae	San Jose	Software Engineer Manager	13
Jacki Lindstrom	Burlingame	Owner, General Building Contract Firm	27
Nisha Mehta Secretary	Redondo Beach	Strategic Planning Consultant	8
Kemberlee Morgan Vice President	Burbank	Medical Administrative Services Associate	13
Renee Taricca Treasurer	Tarzana	Bookkeeper	50
Julie Tauscher	Auburn	Vocational Case Manager	—
Paula Watney	Clovis	Homemaker	29
Staff & Consultants			
Fran Moss Consultant		Former Executive Director	40
Theresa McGrath Consultant		Professional Residential Training Services	30s
Lisa Graziano, M.A. Executive Director		Licensed Marriage & Family Therapist	14
Katherine Crawford		Respite Service Provider	23

Prader-Willi Syndrome Research Opportunities

The Effect of Growth Hormone Replacement Therapy on Physical and Behavioral Sexual Development in Persons with Prader-Willi Syndrome

Drs. Myers and Whitman of St. Louis University are performing a study to examine the impact of growth hormone replacement therapy (GHRT) on the sexual/gonadal maturation and functioning, and sexual behavior of males and females with Prader-Willi syndrome (PWS). This study is supported by FPWR. The subject population will include 20 adults (10 males and 10 females ages 18 years and over) and 20 youngsters (10 males and 10 females between the ages of 10-14 years) with Prader-Willi syndrome. Adults will be divided between 10 adults previously treated with growth hormone replacement therapy (GHRT) and 10 naive to GHRT. Youngsters will be drawn from those currently receiving GHRT. GH is provided free of charge by Pfizer. A small stipend towards travel may be available for some families. For more information contact Dr. Barbara Whitman, Saint Louis University School of Medicine (314) 268-4027

Causes of Excessive Appetite, Obesity, and Cognitive Problems Associated with PWS

Children and adults with Prader-Willi syndrome are invited to participate in a clinical study sponsored by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, which is part of the National Institutes of Health (NIH). The purpose of the study is to learn more about the causes of excessive appetite, obesity, and cognitive problems associated with PWS. Participation involves providing medical records and blood samples (may be drawn locally and mailed-in), and if interested, further evaluations at the NIH Clinical Research Center in Bethesda, Maryland. There is no cost for participating in the study.

Eligible participants will be compensated for their time and transportation costs. For more information, contact: Joan Han, MD, Principal Investigator, (301) 435-7820, hanjo@mail.nih.gov or Melanie Hicks, BA, Study Coordinator, (301) 402-6762, PWSresearch@mail.nih.gov, Department of Health and Human Services, National Institutes of Health, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development.

CHLA Research Study: Can Exenatide help patients with Prader-Willi Syndrome lose weight?

Exenatide (Byetta; Amylin Pharmaceuticals, San Diego, CA) is a subcutaneous injection given twice a day which has been shown to lead to weight loss in adults. The study looks at the effects of exenatide on obesity factors in overweight patients with PWS the ages of 13-20 over a 6 month period. The study involves 5 visits to Children's Hospital of Los Angeles (CHLA) located at 4650 Sunset Blvd., Los Angeles 90027. The initial screening visit involves blood tests; if the patient qualifies there will be 4 more visits. All visits include physical exams, blood draws, and an appetite questionnaire. Two of these visits will include a mixed meal tolerance test (MMTT) and a DEXA scan. The MMTT involves placing an IV and series of 4 blood tests over 2 hours. The DEXA scan is an x-ray that measures body fat. $50 will be provided at each visit as compensation for your participation. The study is conducted by Drs. Debra Jeandron andParisa Salehi from the CHLA Endocrinology department. To participate in this study you:

- Must have Prader-Willi Syndrome; must be 13-20 years old; must have a body mass index >85th percentile; must NOT be using or have used exenatide or related medication; must NOT have a current of past history of pancreas of kidney illness or problems; must NOT have another diagnoses which may affect taking the medication of its results.

For more information contact Dr. Debra Jeandron (323) 361-8816 djeandron@chla.usc.edu

PWS and Early-Onset Morbid Obesity Natural History Study – All Persons with PWS

Conducted by Virginia Kimonis, M.D., Chief, Division of Genetics and Metabolism, UCI Med Ctr. The purpose of this study is to collect natural history information on PWS and early onset morbid (severe) obesity.

WHO: Persons with a confirmed diagnosis of Prader-Willi syndrome ages birth-60 years, receiving and not receiving growth hormone.

WHERE: UCI Medical Center and General Research Centers at UCI Med Ctr. and Children's Hospital, Orange County in Orange, CA. CONTACT: Virginia Kimonis, M.D. at 714-456-5791 or email at vkimonis@uci.edu or Sandra Donkervoort, MS, CGC research coordinator at 949-824-0521 or email at sdonkerv@uci.edu

Save These Dates!

Visit www.PWCF.org for More Information, to Register, or Purchase Tickets

May - Dec	Support PWS Awareness throughout the year www.pwcf.org/WalkingForPWS
June 15	Putt for PWS Golf Tournament, Windsor Golf Course, Windsor
June 20-25	PWS Camp, Easter Seals Camp Harmon, Boulder Creek
July 20	Family Night at the L.A. Galaxy
Sept 20-21	Ragnar Race, Napa Valley
November 2	Annual PWCF Conference, Los Angeles
November 7-9	PWSA (USA) National Conference, Orlando, FL

Medication Alert

Desmopressin

The *PWSA UK Instant News* (26-3-13) reports that they "have been alerted to a case of an adult with PWS who was prescribed Desmopressin to treat night-time urinary incontinence (bed-wetting). The person suffered a seizure due to low sodium levels induced by the medication, and was in a near-death situation. Care should therefore be taken with this medication – if in doubt consult your [physician]."

Canyon Verde

An Innovative Activity Center for Adults with Special Needs

Site visit overview by Lisa Graziano, PWCF Executive Director

For families living in the South Bay who are looking for opportunities for learning, growth, and social interaction for your loved one with PWS there is a wonderful day program called Canyon Verde tucked quietly away in Redondo Beach.

As soon as I entered Canyon Verde's campus I was impressed by the welcoming, engaging and encouraging environment they've created for their clients. The grounds are bright and cheery and well maintained. The programs are staffed with smiling, energetic and supportive professionals, most of whom have a great many years of experience working in various aspects of the special needs world.

The majority of clients attending Canyon Verde are diagnosed with mild to moderate intellectual disabilities. They currently serve one man who has PWS whom I had the pleasure to meet in their Music Room. I toured the Art Room, the library nook, and the expansive computer room where clients have access to state-of-the-art hardware and software. As I walked across the quad to take a look at the area where the clients' artwork is categorized, priced, and sold to the general public, I stepped between rows of clients who were enjoying – yes, enjoying! – their daily exercise and calisthenics session which were being led by staff who were enthusiastically demonstrating and exercising alongside their clients.

Canyon Verde's daily program includes functional academics, social skills, music, and pre-vocational activities including self-advocacy, communication skills, maintenance, horticulture, community immersion, arts & crafts, telephone skills, physical fitness, hygiene, functional reading and mathematics, safety and first aid, computer skills, and work and volunteer experience. Their beautiful "square foot" raised gardens provide opportunities for clients to learn a variety of gardening skills while enjoying the fruits of their labor during lunch. Additional skills and units of learning are offered based on the assessment of each individual's needs and their choices.

This program won't serve the needs of every adult with PWS, but for those of whom the fit is a good one, Canyon Verde offers a unique and truly nurturing experience.

Support PWCF Without Spending Any Extra Money!

Register your Ralph's Reward Card online in the Community Contribution Program and PWCF receives a donation every time you shop!

Go to www.ralphs.com

1. In the Search box enter Click "Community Contributions"
2. In the middle of the page, under "Participant" click on "enroll"
3. Follow the directions to establish your online account or sign-in to your existing account
4. Designate Prader-Willi California Foundation – Organization #93694. Now, whenever you use your Rewards Card, a portion of your purchases will be donated to PWCF!

Sign up for eScrip to Support PWCF 3 ways!

Sign-up and register your reward cards, credit cards and debit cards then whenever you shop at participating merchants a portion of your purchase amount will be given to PWCF

Visit www.escrip.com

- Click on "about the program" along the top then click on "sign-up"
- Search for Prader-Willi California Foundation or enter group ID# 500042750
- Once our name appears you can select it and then continue your enrollment
- Once your cards are registered a portion of purchases made at participating merchants will automatically be donated to PWCF

Shop at the eScrip online mall

- Once you set up your eScrip account you can shop lots of merchants including Amazon right from your personal eScrip page. Or install the AutoEarn program to make sure participating online merchants are redirected to your eScrip page and that a portion of your purchase is donated to PWCF
- Or shop through this link: https://secure.escrip.com/jsp/group/onlinemall/groupmallredir.jsp?gid=500042750

Participate in the eScrip Dining by Rewards Network

- Once you enroll in the eScrip program and register your cards, a portion of purchases made at participating restart aunts will automatically be donated to PWCF!

Note: Safeway/Vons limit their contributions to K-12 schools therefore PWCF is not eligible to receive donations for purchases made at their stores; however purchases at all other participating merchants are eligible.

Raising Awareness

March 9 in Vallejo: Ivette Ramos set up a PWS Awareness Booth at the **Vallejo Youth Expo and Parent Summit**. Ivette and her lovely helpers distributed scores of PWS brochures and glow-in-the-dark wristbands she'd requested from the PWCF Office.

Ivette Ramos Raises Awareness

March 23 in San Francisco: **Patti McRae** and **Austin and Lesley deLone** worked PWCF's and RDSHP shared Awareness Booth at the **Support for Families Information Fair**. In addition to their PWS literature and wristband giveaways, they showed PWCF's *Walk With Us* DVD. Fifty to sixty families received information on PWS, including one service-oriented group who is newly working with someone with PWS and who shall, as a result of this event, receive formal PWS training and support!

Are you planning to hold a garage sale? Participating in a community event? Raise awareness of PWS in your community simply by displaying and giving away PWS brochures and wristbands. To help you spread awareness, PWCF will provide you with PWS brochures and our very cool PWS glow-in-the-dark wristbands. Donate a portion of your proceeds back to PWCF to help support the next awareness-raising opportunity!

MEMBERSHIP ACTIVITY

January-March 2013

We are fortunate and grateful that the majority of families renew their membership each year. In the interest of space, therefore, we list only new Individual and Family Members. All new and renewing Extended Family, Family Friends, and Professional Members are listed.

New Extended Family Members
Judy Barry

Renewed Extended Family Members
Karen & Russell Benedikt
Marlene & Tom Burke
Paul Graziano
Pat Grey
Kathy & Ralph Paige
Mark Savit
Judith Steinhart
Carol Williams

Renewed Professional Members
Tony Kueter – People's Care Inc.
Mysti Medina – Medina Home Care
Valerie Nix – North Star Services
Joe Tontodonato – ARC of San Diego
Paul Wurst – Options in Supported Living LLC

We Get Mail

Dear PWCF: On behalf of the Children's Hospital of Orange County Foundation's Stewardship Committee, I would like to express my sincere appreciation and thank you for supporting Dr. Susan Clark and the Endocrinology department. We take pride in knowing that you believe in our mission to provide excellent medical care to the children in Orange County. We are grateful for your philanthropy and for your donation. *Sincerely, Delphina*

Dear PWCF: …Thank you, thank you, thank you!! We love the toys [for our PWS Clinic waiting room]. The doctor kits are adorable. All the toys will be enjoyed by our patients. You did a great job picking them out. We really appreciate you getting them for us. *Jamie Fisher, M.S., Genetic Medicine Central California*

Wyatt Special Education Advocacy Training: A Summary

by Katherine Crawford, Family Support Coordinator

It's an intimidating prospect to go to an IEP meeting as a parent. Have you ever felt alone sitting on one side of the table, staring at a row of adversaries on the other side? Have you been frustrated by gridlock in the face of trying out a new idea for your child? If so, you're in good company. According to the US census, the past decade has seen about 6.5 million kids served by Individualized Education Plans every year.

The real challenge is that intensive interventions can be extremely costly, budgets are tighter than ever, and school culture and bureaucracy can run headfirst into parental instincts and emotions. In light of this, it's no surprise that conflict can erupt in spite of the best intentions of the law, the school, and parents. Fortunately there is much that can be done to bridge this gap, and this is where the Wyatt Special Education Advocacy Training comes in.

PWSA-USA unveiled a new Train-the-Trainer project to spread advocacy knowledge to parents throughout the U.S. They invited people throughout the country to apply for this training and selected eleven applicants to fly out to Sarasota. These people included two members of the Prader-Willi California Foundation (Roger Goatcher from Northern California, and me from Southern California). Roger and I took part in an intensive multi-day training to prepare us for sharing what we learned with families. We heard from Pat Howey from Wrightslaw, as well as PWSA-USA education consultants Mary K. Ziccardi, Michelle Holbrook, and Dr. BJ Goff, author of the book *Supporting Adults with Prader-Willi Syndrome in Residential Settings.* From these talks, I've drawn my favorite rules of thumb for the parent advocate.

The first rule of thumb to keep in mind is that it is completely normal to feel anxious about an upcoming IEP meeting. It does get easier with practice, and advocating for your child is a skill worth getting good at! The second rule is to keep a cool head no matter what emotions you're feeling on the inside. Maintain focus on your goal of advocating for your child, and don't lose sight of the bigger picture even when you are advocating for smaller things. The third rule is to come prepared. If nothing else, make a page summary of your child's strength areas, challenge areas, and methods you've used or suggest be used to overcome those challenges. The school may be the expert in teaching, but *you* are the expert in your child. The IEP meeting is the perfect opportunity for both sides to come together to share knowledge.

The final rule of thumb: listen. There is no partnership without communication, and no communication without listening. If you know *why* the school is suggesting a change that you disagree with, you have the ability to intervene intelligently.

"Special Ed" came about after the Individuals with Disabilities Education Act (IDEA), enacted in 1975. "The purpose of this law was to ensure all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living, and to ensure that the rights of children with disabilities and parents of such children are protected."

As I write this, PWCF is in the process of planning a series of IEP workshops. We'll keep you up-to-date on the project as it progresses.

The *PWCF News* is the newsletter of the Prader-Willi California Foundation (PWCF) and is sent to all its members. The opinions expressed in the *PWCF News* represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the Officers and Board of Directors of the Prader-Willi California Foundation. For contributions to this newsletter, questions or comments, please write: Attention Editor, *PWCF News*, 514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, CA 90277 – or phone – 310-372-5053 ~ 800-400-9994 (within CA), or email us at PWCF1@aol.com

We Remember

Yvette Tarica

May 26, 1962 - March 10, 2013

Yvette Sarah Tarica, beloved daughter of Henry and Renee, loving sister of Lianne (David), Jeanine (Mark), and aunt of Josh, Justin, Zachary and Sophia, passed away on Sunday March 10.

It appears that complications of gastroparesis took her life. She fought hard to stay with the family she loved so dearly. As was her thoughtful nature, Yvette asked her parents to make sure they thank her doctors for working so hard to save her life and thank the nurses for being so kind. She did this all while being intubated, without ability to speak, writing her thoughts and wishes on paper. This was Yvette. Always the kind and gentle soul, she touched many. Yvette Tarica will be loved forever and missed by all who had the good fortune to know her.

Funeral services were attended by hundreds at Mount Sinai Memorial Park Simi Valley on Wednesday March 13. Donations in memory of Yvette continue to be received by the PWCF.

To all family and friends of the Prader-Willi California Foundation, we would like to thank you for your words of comfort and support during this very difficult time of grieving the loss of our daughter Yvette.
With much love, Henry and Renee Tarica

We Remember

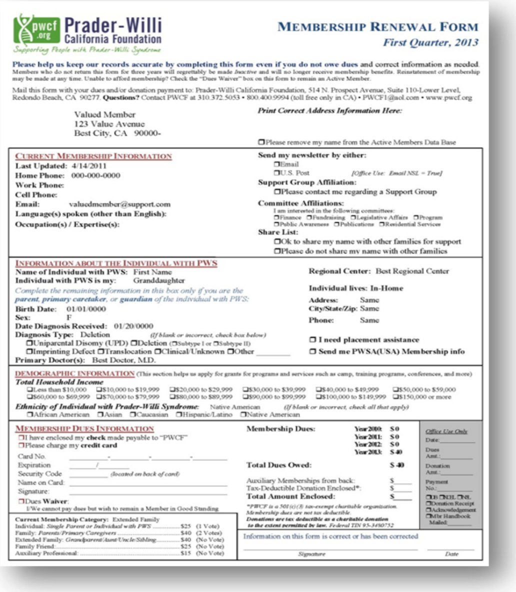
Kim Reguera

June 18, 1968 - August 24, 2012

Written by Shirley Allen, Case Manager, PRIDE Industries

Kim worked at PRIDE Industries in Auburn for almost 15 years. She demonstrated many skills that enabled her to do many of the jobs on the work floor. She had excellent fine motor skills, a great memory for detail, and listened to directions and followed them to a "T." Kim liked working, staying busy and making money. She liked having a boyfriend like her peers did. He was the one thing that made her lose focus and wander away from her work. Not so different from any other young adult!

Kim was funny and had a great sense of humor. She enjoyed teasing her co-workers and staff. She liked asking silly questions. Her greatest skill was her imagination. Kim's laughter was contagious and she would always say things that would make you laugh and just shake your head! She loved the movie Shrek, the color green, dressing up as Princess Fiona, and loved music, dancing, and eating out. In her free time Kim participated in Special Olympics.



Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

MEMBERSHIP RENEWAL FORM
First Quarter, 2013

Please help us keep our records accurate by completing this form even if you do not owe dues and correct information as needed. Members who do not return this form for three years will regrettably be made *Inactive* and will no longer receive membership benefits. Reinstatement of membership may be made at any time. Unable to afford membership? Check the "Dues Waiver" box on this form to remain an Active Member.

Mail this form with your dues and/or donation payment to: Prader-Willi California Foundation, 514 N. Prospect Avenue, Suite 110-Lower Level, Redondo Beach, CA 90277. **Questions?** Contact PWCF at 310.372.5053 • 800.400.9994 (toll free only in CA) • PWCF1@aol.com • www.pwcf.org

Valued Member
123 Value Avenue
Best City, CA 90000-

Print Correct Address Information Here:

☐Please remove my name from the Active Members Data Base

CURRENT MEMBERSHIP INFORMATION

Last Updated: 4/14/2011
Home Phone: 000-000-0000
Work Phone:
Cell Phone:
Email: valuedmember@support.com
Language(s) spoken (other than English):
Occupation(s) / Expertise(s):

Send my newsletter by either:
☐Email
☐U.S. Post *[Office Use: Email NSL = True]*
Support Group Affiliation:
☐Please contact me regarding a Support Group
Committee Affiliations:
I am interested in the following committees:
☐Finance ☐Fundraising ☐Legislative Affairs ☐Program
☐Public Awareness ☐Publications ☐Residential Services
Share List:
☐Ok to share my name with other families for support
☐Please do not share my name with other families

INFORMATION ABOUT THE INDIVIDUAL WITH PWS

Name of Individual with PWS: First Name
Individual with PWS is my: Granddaughter
Complete the remaining information in this box only if you are the ***parent, primary caretaker****, or* ***guardian*** *of the individual with PWS:*
Birth Date: 01/01/0000
Sex: F
Date Diagnosis Received: 01/20/0000
Diagnosis Type: Deletion *(If blank or incorrect, check box below)*
☐Uniparental Disomy (UPD) ☐Deletion (☐Subtype I or ☐Subtype II)
☐Imprinting Defect ☐Translocation ☐Clinical/Unknown ☐Other ________
Primary Doctor(s): Best Doctor, M.D.

Regional Center: Best Regional Center
Individual lives: In-Home
Address: Same
City/State/Zip: Same
Phone: Same
☐ **I need placement assistance**
☐ **Send me PWSA(USA) Membership info**

DEMOGRAPHIC INFORMATION (This section helps us apply for grants for programs and services such as camp, training programs, conferences, and more)

Total Household Income
☐Less than $10,000 ☐$10,000 to $19,999 ☐$20,000 to $29,999 ☐$30,000 to $39,999 ☐$40,000 to $49,999 ☐$50,000 to $59,000
☐$60,000 to $69,999 ☐$70,000 to $79,999 ☐$80,000 to $89,999 ☐$90,000 to $99,999 ☐$100,000 to $149,999 ☐$150,000 or more
Ethnicity of Individual with Prader-Willi Syndrome: Native American *(If blank or incorrect, check all that apply)*
☐African American ☐Asian ☐Caucasian ☐Hispanic/Latino ☐Native American

MEMBERSHIP DUES INFORMATION

☐I have enclosed my **check** made payable to "PWCF"
☐Please charge my **credit card**
Card No. ________-________-________-________
Expiration ______/______
Security Code ________ *(located on back of card)*
Name on Card: ______________________
Signature: ______________________
☐Dues **Waiver**:
I/We cannot pay dues but wish to remain a Member in Good Standing

Current Membership Category: Extended Family

Individual: *Single Parent or Individual with PWS*	$25	(1 Vote)
Family: *Parents/Primary Caregivers*	$40	(2 Votes)
Extended Family: *Grandparent/Aunt/Uncle/Sibling*	$40	(No Vote)
Family Friend:	$25	(No Vote)
Auxiliary Professional:	$15	(No Vote)

Membership Dues:
Year 2010: $ 0
Year 2011: $ 0
Year 2012: $ 0
Year 2013: $ 40
Total Dues Owed: $ 40
Auxiliary Memberships from back: $_____
Tax-Deductible Donation Enclosed*: $_____
Total Amount Enclosed: $_____
**PWCF is a 501(c)(3) tax-exempt charitable organization. Membership dues are not tax deductible.*
Donations are tax deductible as a charitable donation to the extent permitted by law. *Federal TIN 95-3480752*

Office Use Only
Date:________
Dues Amt.:________
Donation Amt.:________
Payment No.:________
☐DB ☐NDL ☐NL
☐Donation Receipt
☐Acknowledgement
☐Mbr Handbook Mailed:________

Information on this form is correct or has been corrected
________________ *Signature* ________ *Date*

Renew Your Membership

Membership Renewal Forms are on their way to your mailbox.

Renew your membership by completing your form and returning it to the PWCF Office. If you owe membership dues, pay by check or credit card. If you don't owe dues, please return your form so we keep our Database current.

Membership dues are not tax deductible, but PWCF is a 501(c)(3) charitable organization so your donation is tax deductible to the extent permitted by law.

Your support through membership dues and donations keep the PWCF strong so that we can provide vitally needed supports and services to families and professionals who serve persons with PWS.

Renew your PWCF membership today!

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Prader-Willi California Foundation proudly maintains an affiliation with the national Prader-Willi Syndrome Association (USA).