The mission of Prader-Willi Florida Association (PWFA) is to provide support through education, advocacy and research to the Prader-Willi community so individuals and their families may live to their greatest potential.

DR MILLER RESEARCH Participants NEEDED

Study ID: IRB201602266  Date Approved: 5/19/2017  Expiration Date: 2/24/2020

Children & Teens Needed for Nutrition Study

The Food Science and Human Nutrition Dept. at UF is conducting a study to determine the effects of fiber supplementation on general and gastrointestinal wellness. To participate you should be:

- An overweight child age 8-15 years old with occasional constipation
- Willing to consume snacks with and without fiber daily each for a 2-week period (total study length is 8 weeks)
- Willing to complete questionnaires about general and gastrointestinal wellness
- Gift card will be provided

If interested, please call and/or email

Study Phone: 352-263-9136
Email: ufnutrition@ifas.ufl.edu
June 2017

Dear Florida Families,

I hope this finds all of you well and enjoying your summer. It has been a busy one for me and I am hopeful it will slow down before school starts once again.

We held our On the Move walk and Spring Conference in April at Tropical Palms Resort. We heard from several knowledgeable speakers and we all learned at least one new thing we could take home and implement. Our walk a thon was attended by 13 families. We walked around the resort to spread awareness about Prader-Willi syndrome. While our crowd was small, our enthusiasm was mighty. We all enjoyed a day filled with fun and laughter. We closed our time together with a delicious dinner and of course our world famous raffle. This year we had a brand new TV in the raffle!!! Michelle Torbert won the TV...congratulations Michelle.

The board voted to welcome Catt Pudney as our newest member. We are excited, and appreciate her dedication and enthusiasm. The board also voted not to host a fall conference because of the National Conference being held in November. We will host the 2nd Annual Back in the Day Clobberfest to benefit PWFA on Saturday, October 28, 2017 in Clearwater. Mark your calendars to attend and support your Prader-Willi Florida Association. More information on the tournament and how to participate is in the newsletter.

If you need assistance to attend the National Conference (November 16-18, 2017) please contact me. Assistance will be granted on a first come, first serve basis. In order to be eligible for a grant you must be a Florida chapter member in good standing (dues are up to date), participate in at least one fundraising event in the past 2 years, and agree to volunteer your services, if needed, at the National Conference. Requests for assistance are confidential and you must prepay and PWFA will reimburse you the amount that we have agreed to cover.

On a sad note, I would like to extend our heartfelt sympathy to Miquel Sanchez and his family at the loss of his wife Maria. Both Miquel and Maria have served on the PWFA board for a long time. Maria will be missed and forever remembered in our hearts.

Finally, the DeLemos - Torbert families enjoyed the wedding of our children Libby DeLemos to Mr. David Torbert on March 4, 2017. A story was printed about their love story and PWS in the Gathered View. If you did not see it, I have enclosed a copy of the write up for you to enjoy. If Libby had never attended a PWFA conference she would not have met David. It is such a valuable experience for the entire family and I would encourage you to get involved so you can make a difference in the life of your child and your family. We are the greatest group of people who really love and care for one another...won't you consider getting involved and joining us?

Hope to see you all in October and then again at conference in November...until then...

I wish you love, joy, peace and above all HOPE!

Beverly

PWFA - President

Beverly DeLemos for more information 321-229-2986 or pwfa2015@gmail.com
National Prader-Willi Conference
Caribe Royale
8101 World Center Dr, Orlando, FL 32821

November 15-18, 2017

To register go to www.pwsausa.org.

Packed with Scientific Research, Informative Presentations
Day Program for PW Kids and Sibling's USA Chapter Leaders Meeting
Welcome reception
Adult Gala
Kids Gala

Prader-Willi Florida has Grants available for Participating, and Active Members of our Association.
Please contact Beverly DeLemos 321-229-2986 or pwfa2015@gmail.com
Volleyball Tournament in memory of George Hunt IV to benefit the Prader-Willi Syndrome Florida Association

**WHEN:** OCTOBER 28, 2017.
Sign in @ 8 a.m. First game starts @ 9 a.m.

**WHERE:** Volleyball Courts at Frenchy’s Rockaway Grill on Clearwater Beach

**PLEASE CONTACT** Terrann Mayo - 727-420-8090. or terrannmayo@gmail.com to Volunteer or Participate

The family has decided to donate the funds to PWFA, for our families support and research. An Awesome job was done to create and organize their first event they raised $ 5384 last year.

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**School Times Newsletter and Website and Webinars**

Valuable information for our parents. Sign up for a FREE newsletter and resources.

**WEBSITE:** [http://conta.ccl2k04suo](http://conta.ccl2k04suo)

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The 9th Annual INSHORE AND OFFSHORE Casting for a Cause Fishing Tournament was held in Homestead on May 20, 201. It was a great success due to the dedication and hard word of Michelle Torbert. Please visit the website to see pictures of this amazing event.

castingforacause.com

Contact Michelle Torbert - 305-245-6484 PWFA2007@gmail.com
Prader Willi Spring Conference Tropical Palms
April 29, 2017

Spring Conference:
8:00-8:30 am Registration. Collected money from Spring Conference attendees for annual membership dues.
8:30-8:45 am Welcome and new families

PRESENTATIONS FOR SPRING PWFA CONFERENCE

8:45 am Speaker: Susan Triggiano-One Roof Special Needs Ministry. Providing tools given to your church that allows a person to take what others may think as a tragedy and turn it into Hope.

- Statewide Disability Resources: Special Olympics Florida: specialolympicsflorida.org
- VSA Florida (Statewide Organization on Arts and Disabilities): www.vsafl.org
- Special Needs Ministry: Different Dream Living: differentdream.com
- A Different Dream for My Child-Facebook: www.facebook.com/DifferentDream ; Ellen Stumbo: www.ellenstumbo.com ;
- Disability Matters: whydisabilitymatters.org ; Key Ministry: www.keyministry.org ;
- Find a church: www.keyministry.org/find-a-church ;
- Special Needs Ministry: Nathaniel’s Hope (Buddy Break etc): www.nathanielshope.org ;
- Rising Above Ministries: risingaboveministries.org ; Sandra Peoples: www.sandrapeoples.com ;
- Snappin’ Ministries: www.snappin.org ; Comfort in the Midst of Chaos: www.comfortinthemidstofchaos.com ;
- No Disabled Souls “God judges persons differently than humans do. Men and women look at the face; God looks into the heart.” 1 Sam 16:7 ; “We are God’s workmanship created in Christ Jesus.” Eph 2:10 ;

9:45 am - Break

10:00 am Speaker: Tammie Penta-OH NO!!!!!! Five-O Prader-Willi Syndrome and Law Enforcement. This course will provide introductory educating law enforcement on Prader-Willi syndrome. Have a positive relationship with your police department. How to educate your local police department. What to do when your child is arrested. What are civil remedies and how do they apply to your child. Compile a folder for the person with PWS. Include pamphlets on PWS along with a small personal bio on your child that describes triggers or things that work or don’t. Example: If you hear screaming please don’t call the police my child is having a meltdown. When partnering with police, determine what police agency services your home or business. Contact the community resource sergeant or officer of that area that will have a “sit down” talk about if they have a Crisis Intervention Team. Explain the issues law enforcement encounters with our population. Theft, allegations of abuse/neglect, running away, MELT DOWNs. Keep a Blue form for police providing all information for police and make a Red form for Medical Alerts. Alert/Educate your neighbors on PWS. If CPS or APS is called then contact Tammie immediately.
11:00-12:15 **Speakers: Jackie Mallow and Lizabeth Moser-Exploring Potentials and Possibilities through improved social interactions and positive behavioral choices.**

How perceptions are perceived very differently. Perceptions-Checking and Clarifying: Describe what you noticed/validate; Think of other ways it could have been interpreted- remove the “gray” and think of it more concretely; Clarify point of view/perception and acknowledge; discuss and adjust accordingly and come up with a plan.

What we know-the hypothalamus: Functions include: controls appetite, body temperature regulation, water balance, influences blood pressure; is part of the Limbic System. Limbic system: emotions, memory, motivation.

Complexities of Supports: Know what the individual average body temperature is and their blood pressure. Behavioral Social Awareness Sequential processing deficit (if and then), Impulsivity (action before thought), Rigid Thought Process (stuck thinking), Version of truth (miss representation), Sensory Issues (overload), Social Awareness (poor insight), Medical Challenges (hunger, sleep).

Best Practices: Communication is key, routines and consistency, rules and guidelines, diet and exercise, behavior management plan, crisis plan, discuss and put it in writing. Precipitating Factors that are triggers to meltdowns: environment, health, cognitive function, relationships, peers, family, staff, weather, change, medications, work, loss/death, moves, seasons, money, spiritual, sleep patterns, perceptions, social events, hunger, psychological, psychiatric, unknown, community and holidays. It’s all in the approach.

Signs of Anxiety- pacing, facial discoloration, self-talk, wringing of hands, facial movements, odor, isolation, breathing changes, body language. Response to anxiety: active listening, validation of the underlying emotions, verbal support, redirect/shift focus in a non-threatening manner. Signs of agitation: yelling, swearing, verbal/physically threatening, minor property damage. Ways to respond to agitation: validation, direct/redirect, avoid power struggles, “I can hear you when you speak in a calm manner”, avoid over communication, remain calm, silent support.

Signs of Tension Reduction- Crying, breathing settles, speech becomes clearer, responds to simple communication: Ways to respond: Allow opportunity for individual to release personal emotions in an appropriate manner. Validate/reinforce positive choices, refrain from reviewing situation, openness in body language and communication, “I’m ok” “Your ok” reassurance. Closure Provided-Individual may apologize for negative behaviors, individual communicates in a positive manner, and individual may take time to self. Ways to respond: Openly talk about things.

12:15pm LUNCH YIP/YAP eat lunch with us

1:15 – 2:00pm General Meeting – Celebrated the marriage of Libby and David Torbert. Introduction of Officers and Board Members. Discussion of Walk a thon information. Discussion of Fundraising Efforts. Upcoming Events: Back in the Day Clobberfest-Clearwater Beach on October 28th, 2017. Membership – make sure you pay for your membership. Provides family support and advocacy for educational issues, funds research promoted by PWSAUSA and so much more. Explained policy on meeting the requirements to be granted a grant to attend the National Conference in November.

2:00 – 2:10pm Break

2:15-3:00 Break-out sessions with Tammie Penta and Jackie Mallow and Lizabeth Moser

3:00-3:20pm Break

3:20pm Meet for On the Move Walk around park.

3:30-4:30 Walk around the park for PWS-snacks and water outside clubhouse after the walk

4:45pm Raffle!!!

5:45pm Dinner in the clubhouse

After dinner families have the option to go to the pool, visit Old Towne for the car show, go to Fun Spot or just hang out and visit.
ATTENTION LAW ENFORCEMENT
PRADER-WILLI SYNDROME CLIENT

NAME AND DATE OF BIRTH

PRADER-WILLI SYNDROME IS A DEVELOPMENTAL DISABILITY

• IT CAUSES COGNITIVE AND BEHAVIORAL ISSUES THAT CANNOT BE CONTROLLED BY THE CLIENT. THEY HAVE AN INSATIATIABLE APPETITE AND WILL SEEK FOOD.

• THIS CLIENT HAS A ___IQ AND FUNCTIONS AS A ___ YEAR OLD

• **(NAME)** WILL BE VERBALLY AGGRESSIVE BUT WILL NOT INJURE SELF OR OTHERS. KEEPING THEM IN A SAFE LOCATION WHILE THEY WORK THROUGH THEIR MELTDOWN WILL HELP AS WILL NOT ASKING THEM ANY QUESTIONS DURING THIS TIME, AS THAT PROLONGS THE TANTRUM. (or you can put the opposite, ie: aggressive and what to do)

• PWS CLIENTS MUST HAVE FOOD LOCKED FROM THEM AT ALL TIMES. IF THEY GET INTO FOOD UNSUPERVISED, IT IS LIFE THREATENING

  • THIS PWS CLIENT WILL LIE ABOUT (food or whatever)

  • STAFF HAS PWS INFORMATION AVAILABLE IF THERE ARE FURTHER QUESTIONS

More information available at PWSA.USA.org Tel: 800-926-4797 or Crisis assistance
"On the MOVE" Walk a Thon

There were only 14 families out of our mailing list of over 300 that participated in our annual fundraiser. We raised $11,245. All of the funds raised assist families with informative speakers at conferences, organize and pay for special projects, provide for the needs of our families and PW clientele and assist with research. We also offer grants to our state and national meetings. Imagine what we could do if half of you participated. The family with highest earnings will receive a free conference, hotel, and meals. (The VALERA family won in 2016, and AGAIN in 2017! GREAT JOB!)

Maria Del Carmen Sanchez passes away in May 2017

The Sanchez family has been actively involved with our state and national association for many years.

We will surely miss her smiling face, dedication, and involvement with our board.

The DeLemos family recently, with the passing of Doug DeLemos’ mother, elected to have memorials donated to PWFA in memory of her. We can accept “in honor gifts” or “memory gifts” for our chapter. We would send a note to the family that a gift was given in their loved ones honor or memory. We will also send your family a list of families that honored your loved one.

PWFA, PO Box 894, Newberry, FL 32669
SIBLINGS OF SISTERS WITH PWS FIND SUPPORT ... AND LOVE

It was approximately 2007 when Beverly and Doug DeLemos attended their first PWS conference in Florida. Though their daughter Abby was diagnosed at age 3, they had never taken the step to attend a conference until she was 16. They came with their 18-year-old daughter Holly and their 12-year-old daughter Libby. As the years progressed, they faithfully attended both the spring and fall Florida conferences and Libby began to volunteer in the childcare program. She met the four Torbert boys (Thomas, Eric, David and Alex), sons of Michelle and Tommy Torbert, and older brothers to Leslie, with PWS. All the siblings became friends and would socialize during the conference weekends.

When Libby and David were in high school, they began a long-distance dating relationship – Libby lived in Orlando and David lived in Homestead, about a four-hour drive apart. They saw each other as they could over holidays and long weekends. This relationship continued as they both entered college. It was great that they didn’t have to explain their sisters to their significant other and they found humor in saying, oh, yeah, my sister does that, too! The love for their sisters increased their bond to each other and they both shared a love for this very special population. The Torbert boys volunteered with the YAP andSibling Programs at the PWSA (USA) National Conferences on four to five occasions and Libby did as well for two to three of those events. They enjoyed the support and camaraderie of the other siblings they met.

In the fall of 2015, David and Libby became engaged and were married March 4, 2017. Abby served as maid of honor and Leslie was a bridesmaid. Two of the bridesmaids, Terann and Lynn Mayo, also have a younger sister with the syndrome and they met through the Florida PWS conferences to form their very special friendship with Libby. All of the groomsmen grew up with Leslie, participated in the annual Casting for a Cause Fishing Tournament, and helped out at conference events as well. Interacting with the PWS population developed a strong sense of compassion and empathy in these young men.

Two years ago, after Michelle had been president of the Florida chapter for eight years and was ready to step down, she was able to convince Beverly to step up to that role – keeping things all in the family!

When your state chapter holds an event, or with the National Convention coming up in November, please consider attending – not only for the support you will receive, the support your child with PWS will receive, but also for the support and acceptance your other children will receive by meeting and forming friendships with other siblings. Who knows, maybe there will be another love story to tell...
Officers for 2015—2018

President  Beverly DeLemos  321-229-2986  PWFA2015@gmail.com
Vice Pres.  Kathleen Hunt  727-434-1929  kagetely@aol.com
Secretary  Traci Bonali  727-424-3133  tracibonali@gmail.com
Treasurer  Deborah Hall-Peaton  813-294-2981  debpeaton@gmail.com

Board of Directors for 2015—2018

Michelle Torbert  305-245-6484  PWFA2007@gmail.com
Deborah & John Stallings  772-882-4817  debbiestallings694@comcast.net
Angelia Yacavone  561-433-1321  aby822@aol.com
Marion Goodman  727-525-0595  m33703@aol.com
Christy Kirkpatrick  407-397-9597  chloechan@msn.com
Mary Pringle  239-872-4778  Pringleclan@MSN.com
Maureen Fiske  561-741-1087  mofiske@comcast.net
Miguel Sanchez  954-430-3492  snch397@aol.com
Desiree Guiliano  954-753-5165  ddguiliano@gmail.com
Doug DeLemos  321-229-2984  dougdelemos@gmail.com
Catt Pudney  415-794-1644  pudcatt@gmail.com
Jason John  904-304-4553  JasonJ904@comcast.net
Jennifer Cheshire  772-324-8031  Jennifer_Cheshire@comcast.net
Claire & Ricardo Bocanegra  239-839-8774  clari@portofinodental.org

WANT TO SERVE AS A DIRECTOR OR OFFICER PLEASE CONTACT Beverly DeLemos
- District Leaders -

Denise Sarko 352-209-5805 djscameo@cfl.rr.com.

Circuit 1 - Escambia, Okaloosa, Santa Rosa, Walton - area code 850

Circuit 2 - Franklin, Gadsden, Jefferson, Leon, Liberty, Wakulla - area code 850

Circuit 3 - Madison, Hamilton, Columbia, Suwannee, Lafayette, Taylor, Dixie - area code 352

Circuit 5 - Citrus, Hernando, Lake, Marion, Sumter - area code 352

Circuit 8 - Baker, Union, Bradford, Gilchrist, Alachua, Levy - area code 352

Circuit 14 - Bay, Calhoun, Gulf, Holmes, Jackson, Washington - area code 850

Christy Kirkpatrick 407-397-9597 chloechan@msn.com

Circuit 4 - Clay, Duval, Nassau - area code 904

Circuit 7 - St. John’s, Putnam, Flagler, Volusia - area code 386

Christy Kirkpatrick 407-397-9597 chloechan@msn.com

Circuit 9 - Orange, Osceola - area code 407

Circuit 18 - Seminole, Brevard - area code 407

Claire Bocanegra 239-561-5370 portofinosmiles@gmail.com

Circuit 20 - Charlotte, Collier, Glades, Hendry, Lee - area code 239

Angelia Yacovone 561-433-1321 aby822@aol.com

Circuit 15 - Palm Beach - area code 561

Desiree Guiliano 954-753-5165 ddguilliano@gmail.com

Circuit 17 - Broward - area code 954

Maria & Miguel Sanchez 954-430-3492 sm940@bellsouth.net

Circuit 11 - Dade - area code 305

Circuit 16 - Monroe - area code 305

Jennifer Cheshire 772-324-8031 Jennifer_Cheshire@comcast.net

Circuit 19 - Indian River, Martin, Okeechobee, St Lucie - area code 772

Kathleen Hunt 727-434-1929 KathuntPWS@aol.com

Circuit 10 - Hardee, Highlands, Polk - area code 863

Circuit 6 - Pasco, Pinellas - area code 727

Circuit 12 - DeSoto, Manatee, Sarasota - area code 813

Circuit 13 - Hillsborough - area code 813
In case anyone needs an additional copy of the Medical Alert booklet you can click on the link from National and print one out. If you want it in booklet form you can order them from National. Everyone should have a copy in each of your cars, your purse, etc. That way if an emergency ever happens you have something to show the doctors or hospitals. 

http://www.pwsausa.org/support/medalert.htm

Prader-Willi Syndrome Association (USA)
8588 Potter Park Drive, Suite 500
Sarasota, Fl 34238
Tel: 800-926-4797
Tel: 941-312-0400
Www.pwsausa.org

International Prader Willi Syndrome
IPWSO.org