

FLORIDA Gator-Willi News

Prader-Willi Florida Association

Volume 88 September 2017

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.

Clobberfest Hotel — Springhill Suites Clearwater Beach, Fl

309 Coronado Drive, Clearwater, FL 33767

Dates: October 27 - 29, 2017 \$129 per night - Code: PRADERWILL

DEADLINE: OCTOBER 4, 2017

727-218-1090



General Amenities

Free Breakfast, Mini fridge, Microwave oven King suites and double suites available with

Pull-out sofa bed

Valet Parking \$25.00 per day

We are emailing a link to register directly online.

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 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

WHAT: VOLLEYBALL TOURNAMENT. Come out and play! Or just to watch and take a look at our auction items and fun games. First, second and third place prizes will be awarded. Hope you can join us for a fun event!

HOW MUCH: Teams of 4 can enter with \$100 registration fee. Email clobberfestpwfa@gmail.com for additional information or a registration form.

*If you or anyone you know is interested in sponsoring the tournament or donating an item to the silent auction please use info above to contact Terrann Mayo, by call/text/email: (727)-420-8090 clobbefestpwfa@gmail.com

^{*} Prader-Willi is a genetic disorder caused by the inactivation or deletion of a portion of chromosome 15. Individuals with this syndrome suffer many challenges but the most notable symptom is constant instable hunger. Our goal is to raise money to go towards research for a cure to end their starvation! Still Hungry For A Cure! **PWFA** is a 501(c)(3) and all donations are tax deductible to the extent allowed by law.

Team Registration Form

Get a team TOGETHER

Team sign in/registration starts at 8am - First game starts at 9am

*If you have any questions or you or someone you know may be interested in sponsoring and/or donating an item to our silent auction please contact

Terrann Mayo by call/text/email: (727)-420-8090 clobberfestpwfa@gmail.com

PWFA is a 501(c)(3) and all donations are tax deductible to the extent allowed by law

	er names and shirt sizes: Shirts are included in registration fee. 2XL and 3XL are available but will cost \$3 extra and must be p (Can be written in next to player name.)
1	Men's (S) (N) (L) (XL)
	Ladies (S) (N) (L) (XL)
2	Men's (S) (M) (L) (XL) Ladies (S) (M) (L) (XL)
3	Men's (S) (M) (L) (XL) Ladies (S) (M) (L) (XL)
4	Men's (S) (M) (L) (XL) Ladies (S) (M) (L) (XL)
	Registration fee is \$100 per team. Make all checks payable to PWFA. Forms and checks can be
	mailed to Terrann Mayo, Mail (1654 Bayhill Dr Oldsmar, Fl 34677),
	Shirt orders must be in by September 25th
	at the latest so if you are running out of time the form can also be emailed to colbberfestpwfa@gmail.com.
	Number of additional shirts you would like, if any (\$25 Adult \$20 Children):
	Men's (S) (N) (XL) (2XL) (3XL)
	ladies (S) (M) (I) (XI) (2XI) (3XI)

SPONSORSHIP LEVELS

Volleyball Tournament in memory of George Hunt IV to benefit Prader-Willi Florida Association

Prader-Willi is a genetic disorder caused by the inactivation or deletion of a portion of chromosome 15. Individuals with this syndrome suffer many challenges but the most notable symptom is constant instable hunger. Our goal is to raise money to go towards research for a cure to end their starvation! Still Hungry For A Cure

Clobberfest Title Sponsor for \$1,000 includes: business logo on a prominent place on the t-shirt (example: front left breast or down the sleeve), 2 team admissions to the tournament, banner (must be provided by business) to be hung at the event, your business named on our Florida Website, and a recognition award. (Includes 4 shirts)

Net Sponsor for \$500 includes- 1 free entry into the tournament, business logo/ name on back of the shirt, banner (must be provided by busines) to be hung at the event, and recognition award. (Includes 2 shirts)

Base sponsor for \$200 includes- Business name on back of shirt and recognition award.

*If you would like to make a monetary or raffle item donation instead, please fill out form and send checks or items to the address listed on previous page as well as listing what you will be donating below. (If donating raffle item please include retail value below)

Silent Auction Donations

Item Description	:		
Value:			_
Special Instruction	ons (limits, expirati	on date, etc.):	
Item will be:	Mailed	Dropped off	Needs to be picked up
Friends of PWS o	donation: \$		
by call/text/emo	ail: (727)-420-8090 cla	obberfestpwfa@gmail.com, Ma	ail (1654 Bayhill Dr Oldsmar, Fl 34677),
*PW	FA is a 501(c)(3) and all d	lonations are tax deductible to the e	extent allowed by law *

Sponsorship Form

Event Name and Location: Big George Back In The Day Clobberfest for PWFA at Frenchy's Rockaway Grill on Clearwater Beach

Volunteer Event Coordinator: Terrann Mayo (727) 420-8090 clobberfestpwfa@gmail.com

Event Date: October 28, 2017

THANK YOU for your sponsorship and support of the Prader-Willi Association (PWFA).

Please complete this form, which enables us to acknowledge donors properly in all advertisements.

(Please email ad/logo to the volunteer event coordinator listed above)

То	oday's Date:			
Business Name:				_
Sponsor Contact:				-
Address:		State:	Zip:	
Telenhone:	Fmail:			

Email, Mail (1654 Bayhill Dr Oldsmar, Fl 34677), or give completed form to:

Terrann Mayo - clobberfestpwfa@gmail.com

All checks payable to PWFA





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 Siblings
USA Chapter Leaders Meeting
Welcome reception
Adult Gala
Kids Gala

Dr. MILLER Research Participants NEEDED

Study ID:IRB201602266 Date Approved: 5/16/2017 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





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	772-223-8717	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

-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 ddguiliano@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



Prader—Willi Florida Association PO Box 894 Newberry, Fl 32669

EMAIL:
PWFA2015@GMAIL.
COM

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, FI 34238

Tel: 800-926-4797

Tel: 941-312-0400

Www.pwsausa.org

International Prader Willi Syndrome IPWSO.org