

Nutritional Phases in Prader-Willi Syndrome

(Please Note: The information contained herein has yet to be published, should be considered confidential, and should not be disseminated to unauthorized persons).

Dr. Miller indicated that PWS has traditionally been described as having two nutritional phases. However, experience and a longitudinal study suggests that a more complex progression may expand the commonly accepted concept of only two nutritional stages. She proposed that there may be four main nutritional phases and subsequent sub-phases within these groups.

In the first phase, typically present at infancy, the PWS patient is hypotonic and not obese. Sub-phase 1A is characterized by difficulty feeding with or without a failure-to-thrive (FTT). Occasionally, FTT is present even with adequate calories for this age group. Sub-phase 1B occurs when the PW patient shows steady growth along a growth curve and growth appears to be normal.

The second main phase appears when weight starts to increase and crosses normal growth percentile lines. Typically, this will occur between 16 and 18 months of age. Sub-phase 2A occurs when weight increases without a significant increase in calories. During this phase an increased interest in food is usually not present. This suggests that early onset obesity is not a result of hyperphagia but has a different etiology. Sub-phase 2B is when PW patients increase daily calories and become overweight or obese. An increased interest in food can be observed as well as food seeking.

The third phase is a development of hyperphagia accompanied by lack of satiety and aggressive food seeking behaviors. This is the classical stage that most people associate with PWS but its onset is quite varied. It may appear as early as 3 years of age or as late as 15 years. Some PWS patients never experience this stage.

The fourth and final stage occurs when an individual, previously in phase 3, no longer has an insatiable appetite and can feel full. Significant improvements in appetite control may be observed. Experience suggests that this phase does not start until adulthood, anywhere from 21 - 50 years of age.

Professionals studying PWS are in the process of correlating these nutritional phases with data related to metabolic rates, DEXA body fat measurements, and levels of appetite-regulating hormones.

WEBSITE AT PWFA.ORG

President's Letter

Hello Florida Families,

I hope everyone made it through the Holidays and is looking forward to a Healthy and Prosperous New Year in 2011! We have several fun events going on this year and hope all of you will be able to join us or participate in some way.

March 26 and 27th is the 3rd Annual Casting for A Cause fishing tournament in Homestead Fl. Rorri and Gavin have come down to fish it every year and I hope we can have some more families participate too.

Instead of having our Spring meeting this year, we will be having a joint awareness and fundraiser event on May 7th in Jupiter. Details about Family Fun day are in the newsletter and we will continue to post more information on the web site as it progresses. May is National Prader Willi Awareness month and our chapter is joining with National for this 1st annual event. Every chapter will hold their own awareness/fundraiser sometime in May. We need everyone's help to make this a success. Even if you are unable to attend, we need your help in obtaining sponsors, selling raffle tickets and acquiring items for the silent auction. The sponsorship cover letter and form is on our Florida website and the donation form is in this newsletter. Please look at it and contact businesses in your area as well as family and friends for a donation. It will be a great day of fellowship with other families and I hope you will mark your calendars and make every attempt to come. The board will be meeting on the Friday evening before Family Fun Day.

I look forward to seeing you soon and if there is anything I can do for you or your families please do not hesitate to contact me.

Until next time,

Michelle

Reach me through my e-mail at: PWFA2007@aol.com OR 305-245-6484.

UPCOMING EVENTS

3rd Annual Casting for a Cause

Saturday & Sunday - March 26-27 2011

Fishing Tournament - Homestead, Florida

The proceeds benefit: PWFA & PWSA (USA).

Registration and tickets for both events



NEEDED SPONSORSHIPS

Information can contact me

Michelle Torbert at PWFA2007@aol.com or 305-245-6484

Captain's meeting is Thursday March, 24 @ Capri Rest.

Fishing Schedule

Offshore - Saturday, March 26th, 8am - 4pm—Sunday, March 27th, 8am - 3pm

Weigh Station Closes:

Saturday, March 26th at 5:30pm - Sunday, March 27th, at 4:00pm

Inshore/ Backcountry

Saturday, March 26th, 7am - 3pm - Everglades National Park Flamingo

Sunday, March 27th, 7am - 3pm - Everglades National Park Flamingo

Awards Celebration

Capri Restaurant - Sunday, March 27th

Cocktails 6:30pm

Dinner and Awards 7:00pm



Up Coming Conference will be:

SAVE the DATE — May 7, 2011



for the

"Family Fun Day to Cure Prader-Willi Syndrome"

is on May 7th from 11-3 at Ocean Cay Park
in Jupiter Florida.

This is a Florida and National joint fundraiser and awareness.

Make plans for your Family to attend.

We will provide information on hotels, registrations at a later date.

SEE IN KIND DONATIONS FORM - page 5

SILENT AUCTION ITEMS

We are looking for donations for the silent auction for Family Fun Day. This is not a raffle so we are looking for, theme gift baskets, gift certificates to nation or state wide restaurants, sports paraphernalia, higher end donations like vacation or weekend getaways, tickets to sporting events, etc... If you purchase smaller gift cards etc. we will group them together with baskets, just send to Michelle Torbert or Michelle Wallace so they can group. We need these items as soon as possible so we can organize the auction. If you can put together a themed Gift basket and will bring to Conference, please send Michelle Wallace a picture of basket and a complete list of contents. If you have any questions please contact:

Michelle Wallace at wallaceml@bellsouth.net or call 561.644.3386

Large Bounce House - Petting Zoo - Balloon Maker

DJ - Pony Rides - Carnival Games - Face Painter

Chick-fil-A - Drinks - Snow Cones - Popcorn



GREAT SOURCE OF INFO



<http://www.teachmorelovemore.org/SpecialNeeds.asp>

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

IN-KIND DONATION FORM

Thank you for your donation and support of PWFA (USA). Please complete this form, which enables us to acknowledge donors and comply with IRS regulations regarding disclosure of item values.

Family Fun Day to Cure Prader-Willi Syndrome

Silent auction, DJ, food, pony rides, petting zoo, bounce houses, face painter, games and lots more fun for the family!

Event Date: May 7, 2011 from 11:00-3:00

Ocean Cay Park, Jupiter, FL

Please complete one form for each in-kind donation.

Donor _____

Company _____

Address _____

City/State/Zip _____

Phone _____ Email _____

Description of item _____

Value of Donated Item _____

Restrictions or Conditions, if any _____

Donor's Signature _____ Date _____

For more information, please contact event coordinator

Michelle Wallace at wallacemL@bellsouth.net or 561-644-3386

Proceeds will benefit Prader-Willi Florida Association.

All donations are tax deductible to the extent permitted by law. PWFA tax ID #85-8012645527C-9

Please return this completed form with your donation. Please make a copy for your records.

Michelle Wallace

Family Fun Day to Cure PWS

641 Inlet road, North Palm Beach, FL 33408

www.pwfa.org



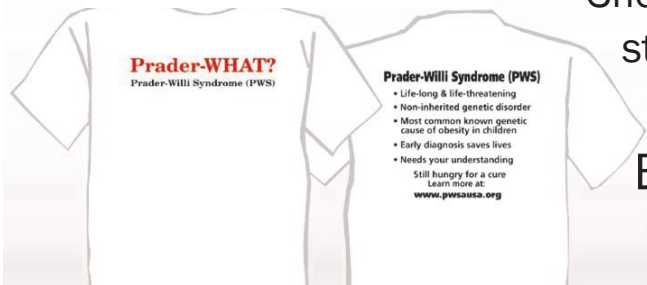
Contact Jennifer Cheshire

For balance of inventory and colors n sizes.

772-324-8031

Jennifer_Cheshire@comcast.net

She would love to clear out this inventory to start her next fundraiser for Prader-Willi



Buy for Youself, friends, family, gifts.

Do you need help or guidance for you PW Child.

If they are an Adult or even if they live independently and you need help:

Contact Debbie and John Stallings

772-287-2587 or cashflowjs@bellsouth.net

They have meetings with ARC about your concerns / complaints

IEP (individual educational plan) Concerns contact **Mary Pringle**

239-872-4778 - Pringleclan@msn.com

All other questions and age groups contact your local

District Leader or Michelle Torbert - See pages 2 and 6

PWSA National Crisis Counselor - 1-800-926-4797

Non-medical crisis assistance is available Monday –Friday 10AM-5PM EST

PWFA Fall Conference 2010

Date: October 16, 2010

Location: Regal Sun Resort, Orlando

Program Opening:

Michelle Torbert started the general meeting by introducing the new board members. She advised that the Sanchez's had stepped down from the Vice-President office of PWFA and the new VP's are Tom and Debra Crowley. She welcomed new families to the conference.

Speaker: Jennifer Miller, Department of Pediatrics, Endocrinology, UF, Nutritional Phases in PWS - see Page 1

Speaker: Maria Sanchez, parent and board member. Spoke briefly on adolescent support groups in the Miami area. She provided information on available resources and indicated she had further information if anyone was interested in support of PWS families. She also spoke about the failure of the School Restraint Bill to pass the 2010 Florida Legislature.

Speaker: Evan Farrar, Executive Director, National PWSA. He expressed his personal mission statement as the new Director of PWSA to include an improved quality of life of PWS individuals, support for families, and the increased need for information regarding PWS awareness. He spoke briefly about the upcoming National Conference to be held in Orlando in November 2011. He ended his presentation announcing they are looking to hire someone to fill his previous position as Crisis Intervention Counselor, PWSA.

Speaker: Barb McManus, PWSA. Spoke about the necessity for volunteers and coordinators to assist in the 2011 PWSA National Conference. She indicated various avenues of fundraising and obtaining donations for this event.

Speaker: Mary Pringle, PWS parent. Spoke about the Family Care Council and Partners in Policy Making.

Speaker: Dr. Greg Cherpes, Children's Institute of Pittsburgh. He gave a power-point presentation regarding psychotropic medications and their use in PWS. This presentation was a detailed analysis of various uses of these medications, the successes that have been observed and the ineffectiveness in some cases. He underscored the importance of dosage requirements for patients with PWS as their metabolism differs from that of the general population. Power-point presentation is available for anyone wishing to obtain a copy.

Business Meeting

Break-out sessions with Dr. Miller and Dr. Cherpes speaking on their respective topics and presentations. Q and A sessions followed.

Meeting ended with the presentation of volunteer certificates followed by the ever popular raffle fundraiser

PWSA (USA) National Conference - Orlando - 11/11/2011 to 11/13/2011

Volunteers needed to plan the

**Welcome reception for the National Conference as well as the Gala,
if there is anyone who would like to help with this to please contact asap:**

Michelle Torbert PWFA2007@aol.com OR 305-245-6484

SAVE THIS DATE for this national face-to-face conference for families, care providers, medical professionals, therapists and more, covering an array of relevant topics about PWS in workshop, support groups and classroom formats.

Time for socializing and having fun is part of this don't miss event.

The theme for the YAP (Youth & Adult) Program is "Survivor: Orlando", based on the popular television show.

The Buena Vista Palace Hotel is located on Walt Disney World property across the street from the Downtown Disney Marketplace. The hotel is located on 27 beautifully landscaped acres just 20 minutes from the Orlando International Airport. For a photo tour of the hotel, please make your reservations under the group rate, 866-397-6516 or www.buonavistapalace.com.

The Scientific and Providers Conferences will be held on November 11th, followed by two days of stimulating speakers and informative sessions for our families that includes exciting, fun-filled YIP and YAP Programs.

(800) 926-4797 - (941) 312-0400 - www.pwsausa.org - PWSA (USA Conference 2011)



**We would like to Honor and ask those to remember the
long time supporters and father's of some of our
PW adults**

Ray Sharp

David Basker

DONATION JARS

Please collect the funds from your donation jars and if not effective please move, to another location.

Send to Desiree Guiliano -1580 NW 97th Ave.-Coral Springs, FL 33071
954-753-5165-ddguiliano@gmail.com or print from website PWFA.org





Advertise on our Prader Willi Website

For a nominal fee of \$40.00 a year we will promote your company,

This will include your Prader Willi Florida Membership.

This will help us cover the cost expense of maintaining the webpage.

Contact: debpeaton@tampabay.rr.com or 813-240-9267

More Skip a Lunch Donors

- | | |
|----------------------|---|
| 1. Lynn Ferpes | 4. Brandon and Amara Blust |
| 2. Alicia Ward | 5. Arthur & Deborah Mundell for Christian |
| 3. B.M. Stockert CPS | 6. Debra A Piescik, Inc, - AllState Insurance Co. |



Denise Sarko's "The Cherished Bride" had a fundraiser raising \$500 for PWFA

Florida Medicaid Diaper Request Form

To be completed by Physician for children over age 3

Patient's Name: _____ Patient's DOB: _____

Patient's Medicaid ID Number: _____

Diapers for _____ are of a medical necessity Y N (please circle one)

Patient's diagnosis (that causes incontinence): _____

Diagnosis Code: _____

Patient's Waist size: _____

Patient's Hip size: _____

Patient's Weight: _____

Type and size of product needed: _____

Quantity: Up to 200 units monthly

Number of refills on script _____