



State Office
4075 West 226 Street
Fairview Park, Ohio 44126
web site: www.pwsaohio.org
e-mail: pwsaohio@aol.com

HIGHLIGHTS

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Officers:

President
Jennifer Bolander
Vice President
Laura Orozco
Treasurer
Jack Shiley
Secretary
Sonya Coulter

Mission Statement

Prader-Willi Syndrome Association of Ohio is a chapter of PWSA (USA) and is a non-profit, tax-exempt organization dedicated to providing understanding and awareness of Prader-Willi syndrome, to supporting

Prader-Willi Voice

Upcoming Events

PWSA of Ohio Awareness Day

Cleveland Metropolitan Zoo
Saturday, May 22, 2010, 10am to
5pm

Advance **discount tickets and free
lunch reservations due no later than May 12**
See page 3 for details and registration form



Jazzy's Walk, a walkathon to raise funds for PWSA of Ohio and PWSA(USA)

Saturday May 29, 2010, 10am, Deweese Parkway in
Dayton

Join members and friends in walking for PWSA of Ohio.
If you cannot attend the walk, get sponsorships and the
organization will have someone walk in your place.

The proceeds from this event will be split between PWSA(USA) and
PWSA of Ohio.

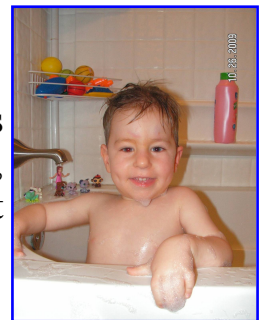
See page 5 for details and pages 6 and 7 for registration and sponsorship
forms.

John's Journey

Slim and Chubby's in Strongsville

Saturday, June 19, 5 to 8 pm, **\$25.00/person** (Includes
food, domestic bottle & draft beer, well liquor, wine,
coffee and soft drinks) 100% of proceeds benefit
PWSA of Ohio

**Door Prizes, Sideboards, Chinese Raffle,
Silent Auction**



**For details and tickets contact:
Sonya Coulter (216) 401-1027 or
Maureen Erwine (216) 287-4784**

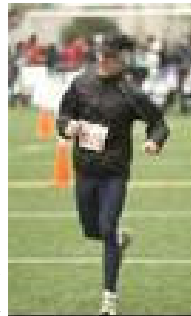
2010 Mark Your Calendar 2010

May 22, Saturday PWSA of Ohio Awareness Day Cleveland Metropolitan Zoo	May 29, Saturday, 10 AM Jazzy's Walk to Benefit PWS DeWeese Park, Dayton
June 7-11, Monday to Friday Recreation Unlimited Summer Camp Ashley	June 19, Saturday John's Journey Slim and Chubby's Bar and Grill, Strongsville
July 17, Saturday, PWSA of Ohio Board Meeting, location to be announced	
October 2, Saturday PWSA of Ohio Board Meeting Annual Membership Meeting Location to be announced	October 15 to 17, Friday to Sunday PWSA of Ohio Fall Weekend Camp Recreation Unlimited, Ashley
December 4, Saturday, PWSA of Ohio Christmas Party, Tartan Fields Golf Club, Delaware	

Chuck Runs Boston for PWSA of Ohio Report

The race has been run, but the fundraiser continues. This fundraiser will officially close on July 19. You still have time help reach the goal of \$5,000. To date the project has raised \$2264.40.

Chuck St. John, the uncle of Sophie Bolander (6 years old, with PWS), ran well. Out of a field of 25,000 runners, he finished in 8,255th place, with a time of 3 hours, 34 minutes and 4 seconds. He placed 6477th out of all the men who ran. That is very impressive! He had a "I Love Someone with Prader-Willi Syndrome" decal pinned to his shirt for the race.



If you would like to add to this effort, you can still do so by donating in either of two ways:

1. Go to www.firstgiving.com/pwsaohio, and donate securely online directly from that page via credit card
2. Donate by check: Write your check payable to "PWSA OF OHIO" and write "Chuck runs Boston" in the memo line. Donations received in this way will be added to the "Amount Raised" total on the FirstGiving page. Mail your check to PWSA of Ohio, 4075 W 226, Fairview Park, OH 44126

PWS Clinic Accepting New Patients

COPEDS (Central Ohio Pediatric Endocrinology and Diabetes Services)

William B. Zipf, MD	55 Dillmont Dr Suite 100
Rolando A. Lozano, MD	Columbus Ohio 43235
Patty S. Graves, CNP	website: www.COPEDS.com
Call to schedule an appointment 614-839-3040	

PWSA of Ohio is a chapter in good standing with PWSA(USA) as well as an Affiliate Member of The ARC of Ohio and a Member of the Ohio Association of Non Profit Organizations

Newsletter

Tom & Sandy Giusti
 E-mail: juicete@aol.com

Webmaster
 Kathy Pack

Trustees:

Sandy Giusti
 Brent and Natalie McGrady
 Darla Minamyre
 Rob and Diane Seely

All board meetings are open to the general membership.

Please RSVP to State Office, if you plan to attend. See the newsletter calendar for the dates and locations.

Is your membership information up-to-date?

Please complete a membership form each year to maintain an **active membership status**.

Notice: Membership in PWSA(USA) does not give a person/family membership in PWSA of Ohio and membership in PWSA of Ohio does not give a person/family membership in PWSA(USA). Each organization must be joined separately.

Your contribution is not in exchange for any products or services and is, therefore, tax-deductible.

Acknowledgements

Sincere thanks for contributions and help received as of May 9, 2010

Donors

General

\$100 David Robins, Creative Foundations

\$ 50 Susan Cornett, Creative Foundations
Mark and Nancy Griffiths

\$ 30 Ray and Claudia Todd

In honor of Angie Giusti

\$700 Tom and Sandy Giusti

Benefit Dinner

\$500

Alan and Wanda Jones

\$300

Pat Justus

\$200

Matt and Jennifer Barnes

Tom and Pat Byrd

Benefit Dinner continued

\$200

Jim and Joan Cameron

Frank and Joan Chester

Rita Ficheria and Marilyn Murray

David and Ellen Haid

Jerry and Sally Jordan

Ron and Carol Kuck

Dr. Bernie and Susan Master

Dean and Darla Minamyer

Chuck and Marilyn Riep

Ron and Barbara Rowland

Ralph and Joan Talmage

Phil and Judi Waid

Dan and Ruthanne Waters

Dr. Bill and Belinda Zipf

Benefit dinner continued

\$100

Dick Cameron

Frank and Yvette Dantonio

Bill DeMora

John and Phyllis Fargo

Joe and Marilyn Gigliotto

John and Kay Hoppers

Granger and Kristen McKinney

Dr. Grant and Cordie Morrow

Don and Carol Nay

Johnny Reichley

Fred and Carol Rieser

Alec and Kathleen Wightman

\$50

John and Suan Youngkin

\$25

Ron and Lisa Roberts

Volunteers

Festival, April 17

Mary Anderson

Tina Giusti

Tom and Sandy Giusti

Amy Howdyshell

Chris Link

Rolando Lozano, MD, COPEDES PWS Clinic

Peggy Martin, Family Advocate Ohio Dept. DD

Devoney Mills

Darla Minamyer

Abby Niekamp

Rachel Stahl

Bethany Tuente

Katie Wellman

Kevin and Antoinette Yuhas

Benefit Dinners, April 23 and 24

Mary Anderson

Jen Bolander

Chris Link

Rita Ficheria

Thomas Giusti

Tina Giusti

Tom and Sandy Giusti

Patty Graves

Kevin McGuire

Marilyn Murray

Laura Orozco

Sharon Sabo

Pat Shiley

It is through the generosity of our donors and volunteers that we are able to do so much for those with Prader-Willi Syndrome and their families.

Want Articles and Pictures of Our Families And Children and Adults with PWS

This newsletter is for and about people in Ohio affected by PWS. If you have a picture, article, achievement, cute story, etc. about your person with PWS or a favorite low calorie recipe, please send it so it can be included in the newsletter. Send any and all by email to juicete@aol.com or by US mail to Sandy Giusti, 1763 Hickory Hill Drive, Columbus, Ohio 43228

Condolences

PWSA of Ohio extends condolences to the family of Joe DeVictor. Joe and his wife, Pat, have been members of PWSA of Ohio since their son, Alex was born with PWS two years ago. Joe died suddenly and unexpectedly in April.



May is Prader-Willi Syndrome Awareness Month! Join us for PWS Awareness Day at the



3900 Wildlife Way Cleveland OH 44109 (216) 661-6500

Saturday, May 22, 2010

10 a.m. – 5 p.m.

Directions to the zoo and further information about Zoo facilities available at

www.clemetzoo.com

To purchase Zoo tickets in advance at a discounted price, and to reserve your free lunch, please detach and fill out form below and mail, WITH PAYMENT (cash or check) to:

PWSA of Ohio Central Office
4075 W 226 St., Fairview Park, OH 44126

PLEASE MAKE CHECKS PAYABLE TO "PWSA OF OHIO"

Ticket Prices: Adults (12 yrs old and up): \$8.00
Children (2-11 yrs old): \$5.00
(Ages 2 and under are free)

Have lunch on us! A healthy lunch will be provided courtesy of PWSA of Ohio, but *you must reserve your spot with the form below!!!*

WE HOPE TO SEE YOU ALL ON MAY 22ND! AWARENESS T-SHIRTS WILL BE AVAILABLE FOR PURCHASE!

----- cut here -----

NAME _____

I would like to purchase tickets:

Adult tickets: _____ x \$8.00 = \$ _____

Childrens' tickets: _____ x \$5.00 = \$ _____ TOTAL for TICKETS: _____

I would like to reserve lunches: Adult lunches: _____ Childrens' lunches: _____

[Please note, the lunch served will be the same, and suitable, for both adults and children; however for planning purposes the chapter needs to know how many of each will be needed.]

THIS FORM IS DUE *NO LATER* THAN **MAY 12**

Jazzy's Walk

The proceeds from this event will be split between PWSA(USA) and PWSA of Ohio. "Jazzy's Walk" is a wonderful opportunity to increase both awareness of PWS and support for our children and families who live with its challenges on a daily basis.

There are three ways by which you can participate in "Jazzy's Walk":



Join in the Walk: This is not a competitive event, and the route itself is of the moderate length of 3 miles. We will have a table with water, protein bars and a certified instructor to make sure we stretch before and after the walk.

Consider being a "Super Sponsor Plus:" If you can't join us on May 29, you can still help with the fundraising effort by being an "Event Sponsor", and asking for sponsorship dollars from family and friends. We will have one walk in your place. Simply use the enclosed Sponsor Form (See page 7), and write "**Event Sponsor**" in the **Walker Information**" section and mail all funds raised to Julie A. Sutton, 823 N. Upland Ave, Dayton, Ohio 45402. Please make all checks payable to **PWSA of Ohio**.

Consider being a "Super Sponsor"! You can be a **Super Sponsor** by simply sending in your own sponsorship contribution. Use the Sponsor form (See page 7), write "**Event Sponsor**" in the **Walker Information**" section, and mail your donations to Julie A. Sutton, 823 N. Upland Ave, Dayton, Ohio 45402 by **June 7, 2010**. Thank You!

Registration form and Sponsor form on pages 6 and 7 respectively.

Thank you in advance for your help. If you have any questions, please contact Julie Sutton at (937) 268-3293 or cell (937) 620-2217.



YOU CAN MAKE A DIFFERENCE!!!

Recipe corner:

Whole Grain Healthy Banana Bread From the kitchen of Sonya Coulter, Mom to John, 3½ years old



Don't let the healthy name fool you, this banana bread is moist and full of flavor. Whole grains, high fiber and low fat and sugar are just added benefits.

¾ cup SLENDA®	2 cups whole wheat flour
¾ cup flax seed meal	1 tsp. baking soda
5 ripe bananas, mashed	½ tsp. salt
¼ cup skim milk	
¼ cup low-fat sour cream	
2 tsp. egg whites	

Preheat oven to 350°. Grease a 9x5 inch loaf pan.

In a medium bowl, mix together the SLENDA, flax meal, bananas, milk, sour cream and egg whites until well blended. Combine the flour, baking soda and salt; stir into banana mixture until moistened. Spoon into prepared pan.

Bake for 1 hour and 10 minutes or until a toothpick inserted into the crown of the loaf comes out clean.

Yield: 10 servings

Nutritional information per serving:
calories 217, total fat 1.4 g., cholesterol 2 mg.

Sonya says, "Good low-fat recipe....John loves it ...and it's filling, too!"

Benefit Dinners Again a Success

On the evenings of April 23 and 24, thirty three diners enjoyed a five course Italian meal at the home of Tom and Sandy Giusti in Columbus. The dinner was cooked and served by Sandy and friends of PWSA of Ohio. As you can see by the pictures, fun was had by both the diners and the kitchen volunteers. Besides those who came to the dinner many others contributed to the event. Over \$5000 was received for PWSA of Ohio through the generosity of these donors.



**JAZZY'S WALK FOR PRADER-WILLI SYNDROME AWARENESS
 SPONSOR FORM
 STILL WATER RIVER RECREATIONAL TRAIL
 DEWEESE PARKWAY, RIDGE AVENUE, DAYTON OHIO, 45414
 Saturday, May 29th, 2010
 Check-in 9:00 a.m. Walk begins at 10:00 a.m.**

Sponsors are an important part of reaching our goal of building awareness and raising funds! Ask relatives, friends, neighbors and co-workers to sponsor you by making a tax-deductible donation to PWSA of Ohio. Please make checks payable to PWSA of Ohio. Thank you for your participation and support!

ALL SPONSOR FORMS AND MONIES ARE TO BE TURNED IN DURING THE CHECK-IN TIME AT THE WALK. FUNDS RAISED FROM THIS EVENT WILL BE USED FOR THE BENEFIT OF PWSA OF OHIO AND PWSA(USA).

PLEASE PRINT ALL INFORMATION

Walker Information

Name: _____ Team Name _____
 Address _____ City _____
 State _____ Zip _____
 Phone _____ e-mail _____

SPONSOR INFORMATION

Sponsor's name	Sponsor's address	Donation amount	check#
1.	_____	_____	_____
2.	_____	_____	_____
3.	_____	_____	_____
4.	_____	_____	_____
5.	_____	_____	_____
6.	_____	_____	_____
7.	_____	_____	_____
8.	_____	_____	_____
9.	_____	_____	_____
10.	_____	_____	_____
11.	_____	_____	_____
12.	_____	_____	_____

PLEASE MAKE CHECKS PAYABLE TO: PWSA OF OHIO
*PWSA of Ohio is a qualified Internal Revenue Code Section 501(c)(3)charitable organization.
 Donations are tax-deductible.*

THANK YOU FOR YOUR SUPPORT!

This form may be copied

For more information about Prader-Willi Syndrome, please contact:

**PWSA of Ohio: 440-716-0552 or www.pwsaohio.org
 PWSA(USA) Office, 1-800-926-4797 or www.pwsausa.org**

JAZZY'S WALK

"Come Walk With Us"

JAZZY'S WALK, MAY 29, 2010
 Registration Form
 Still Water River Recreational Trail, DeWeese Parkway
 Ridge Avenue, Dayton, Ohio 45414

Time: Pre-registered check-in, and on-site registration begin at 9:00 a.m.; Walk start time 10:00 a.m.

Please complete registration form below and bring to event and/or mail to: Julie A. Sutton, 823 N. Upland Ave, Dayton, Ohio 45402

REGISTRATION FORM: If registering a team (3 people or more), please register ALL team members on ONE FORM. Team registration payment must be included with this form. In address area below, ONLY TEAM CAPTAIN'S INFORMATION IS REQUESTED.

Names of all walkers	Age, if minor	Team name
1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____
4. _____	_____	_____
5. _____	_____	_____
6. _____	_____	_____
7. _____	_____	_____
8. _____	_____	_____
9. _____	_____	_____
10. _____	_____	_____

Team Captain _____
 Address _____ City _____ State _____ Zip _____
 Phone: _____ Cell: _____ E-mail: _____

REGISTRATION FEES: please indicate type of registration
 ___ TEAM REGISTRATION: \$25 per team (\$30 for on-site registration)
 \$ _____
 ___ INDIVIDUAL WALKER: \$10 (\$15 for on-site registration)
 \$ _____
 ___ CHILDREN WALKER: \$5 (\$7 for on-site registration)
 \$ _____
 ___ PERSON WITH PWS: FREE: please fill out and mail form for attendance purposes only
 \$ _____ N/A _____

TOTAL ENCLOSED for registration fees \$ _____

ALL CHECKS MUST BE MADE PAYABLE TO: PWSA OF OHIO

FUNDS RAISED FROM THIS EVENT WILL BENEFIT BOTH PWSA OF OHIO AND PWSA(USA).
 Contributions are tax deductible.