

HEAVEN SENT

PACIFIC NORTHWEST ANGELMAN SYNDROME FOUNDATION
12932 SE KENT-KANGLEY RD. #375
KENT, WA. 98031

Newsletter Information

Please submit articles, pictures, prose or angel tips for the newsletter to:

Sherri Rein
26230 131st Pl SE
Kent, WA 98030
Or e-mail items to Sherri Rein at
Reinfour@aol.com

Although families are encouraged to share their experiences, it is the policy of the PNWASF not to support or endorse any particular treatment, therapy or medication.

Article Submission Deadlines

Winter December 15
Spring April 15
Summer/Fall August 15

PNWASF phone number

1-866-330-9256

“Whenever I speak to a mother or father with a recently diagnosed child...I tell them, ‘Whatever problem you have to meet, others not only understand, but they have found a solution; and whatever road you have to travel, others have traveled before you, so there is no need to travel alone.’ The breaking of that awful feeling of isolation is the greatest gift one Angelman family can give to another, a gift that has been given freely, hundreds of times.”

Audrey Angelman, July, 1997

Current Board Members of PNWASF

Dave Platts,
President (253) 639-1643
Lory Tossey,
Vice President (360) 794-4901
Jen Salvione,
Secretary (206) 533-8563
Sherri Rein,
Treasurer (253) 638-6241
Jennifer Cyrus (541) 924-9875
Jon Hegge (206) 782-5691
Chris Watts (503) 581-3530
Gloria DeRosa (360) 876-8342

PNWASF is currently seeking an editor for this newsletter. If you would be interested in learning more about this opportunity, please contact Sherri Rein at (253) 638-6241 or e-mail Reinfour@aol.com. I'm even willing to share the position! We are also looking for articles about your Angel, including Angel of the Quarter. Please submit these to Reinfour@aol.com. Please help!!



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Pacific Northwest Angelman Syndrome Foundation Newsletter



Volume 12

Spring 2005

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EASTER SEALS CAMP



A fun-filled camp experience for all AS families will be held August 19th – 21st at the Easter Seals Camp in Vaughn, Washington. The address is 17809 S. Vaughn Rd., KPN, Vaughn, WA 98394. Angels, siblings, parents, caregivers and friends are all welcome to camp, swim (there is an indoor pool), hike, boat, fish, and play games. Arrival time is anytime after 3:00 p.m. on Friday and departure time is by 1:00 p.m. on Sunday.

A \$25 nonrefundable deposit is all you will need to pay to attend the whole weekend. Scholarships are available for families who are unable to pay the deposit. Cabins are provided for each family (be sure to bring your own sleeping bags, pillows and blankets). All meals are provided.

Space is available on a first-come, first-serve basis. Send your \$25 nonrefundable deposit (make checks payable to PNWASF) to Corbin Thompson, 409 South 52nd Street, Tacoma, WA 98408. Reservations must be made by July 28th. We will need to know how many individuals are in your family, as well as which meals you plan on eating with the group. This year we are having to hire our own cook and purchase food, so we need an exact count for each meal. The meals available are Friday (dinner) from 5:30 - 7:00 p.m., breakfast, lunch and dinner on Saturday, and breakfast and lunch on Sunday. If you have any questions or need additional information, please contact Corbin at (253) 474-4865.

Directory Update

Enclosed is the current PNWASF directory. If your name is not on it and you would like to be, please fill out the enclosed membership form and return to PNWASF as soon as possible. Also, if you have any changes or updates, please let us know. You can mail the form to PNWASF, 12932 SE Kent Kangley Rd., #375, Kent, WA 98031 or e-mail to Sherri Rein at Reinfour@aol.com. On page 2 of this newsletter is a list of members who have supported PNWASF by becoming a voting member. If your name is not listed, and you would like to support PNWASF, please enclose the appropriate dues. Thank you for your support!



List of contributors January 1- June 17, 2005

Thank you to the following contributors:

Membership dues:

Sherri and Jim Bainard
Dot Brenchley
John and Jennifer Cyrus
Gloria DeRosa and Chris Luna
David and Janis Harsila
Jennifer and Jon Hegge
Dave Henderson
Robert and Cindi Howard
Daryl and Pauline Johnson
Jim and Sherri Rein
Kim and Gary Sheldon
Paul and Sandy Silveria
Keith and Corbin Thompson
Lory and Walt Tossey
Rhonda and Jim Wreggelsworth

Donations in memory of Rich Stolmeier:

Larry and Marilyn Adams
Anonymous
Jerry, Bridget and Curt Armstrong
David Brook MD & Barbara Gamrath
Vicki and Jesse Browning
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Chris and Kathy Clogston
Cochran
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Dr. Craig McAllister, MD and Stacey Castleberry
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Seattle Mariners
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Darrel and Gail Vitulli
Constance and Lee Wagoner
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Donations in memory of Gordon Thompson:

Erling and Harriett Williamson
Charles and Eleanor Miller

Other:

Dot Brenchley
John and Jennifer Cyrus
Gloria DeRosa and Chris Luna
David and Janis Harsila
Jennifer and Jon Hegge
Dave Henderson (Continued next column)

(Continued from previous column)

Robert and Cindi Howard
Daryl and Pauline Johnson
Jim and Sherri Rein
Kim and Gary Sheldon
Paul and Sandy Silveria
Lory and Walt Tossey
Rhonda and Jim Wreggelsworth

Golf Cart Sponsors:

Branom Instrument Co.
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We're Outta Here Travel LLC

ADULT RETREAT

The annual adult retreat was held March 4 – 6 at Quinault Beach Resort and Casino in Ocean Shores, Washington. We had 14 families attend this weekend event. The rooms were awesome, all with ocean views. Our business meeting was held on Saturday. We will post the minutes of this meeting shortly on our website, if you would like to see what was accomplished. Thanks to everyone who attended! It was a relaxing weekend for all to enjoy!

Infant & Early Childhood Conference

We wish to thank the following people for volunteering at our booth during the Infant & Early Childhood Conference in Bellevue, Washington: Lory Tossey, Carolyn Smith and Dave Platts.

MEDICAL TRI-FOLD

One of our members, Jennifer Cyrus, has taken on the enormous task of producing and distributing a medical tri-fold about AS to the medical community in Oregon, Alaska, and Washington. The goal of this tri-fold is to help educate physicians about AS, and hopefully diagnose children at an early age, when therapies are so important. Thank you, Jennifer, for your awesome work on this project.



ASF Conference



The Ninth Biennial ASF Conference is almost here. This year it will be held in Anaheim, California, June 29 to July 2. At PNWASF's annual meeting in March, the membership voted to grant scholarships up to \$7,500 to families in need who would not otherwise be able to attend the conference. An application was mailed to all families on our mailing list. There were only three families who applied, so we were able to give a scholarship of \$2,500 to each of these three families.

The three families who were awarded the scholarships are: Hegge family, Ordal family and DeRosa/Luna family. We hope each family will share with us some of the valuable information they receive from attending this conference. In addition to the three families above, there are many other families from our region who will also be attending.

New Board Members

We would like to welcome two new board members to PNWASF. They are Jennifer Cyrus from Albany, Oregon and Gloria DeRosa from Port Orchard, Washington. These two join the team of President, Dave Platts, Vice President, Lory Tossey, Secretary Jen Salvione, Treasurer, Sherri Rein, and Board Members Jon Hegge and Chris



Watts. This is a great group of individuals who volunteer many hours of their time to PNWASF. Thank you to all for your hard work and dedication.

Don't forget to visit our website at PNWASF.org to view current activities. We also would love to post any pictures you have of your Angel. Send them to PNWASF@pnwasf.org.

Angel of the Quarter

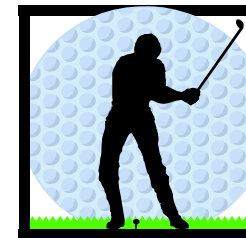
By Teresa Jorgenson



Our Angel of the Quarter is Noah Jorgenson. Noah is 5 years old now and started pre-school last Fall. I was so nervous about sending him, but he really enjoyed the year, especially the school's therapy pool and music time. Noah is fairly musical and especially loves a strong rock beat. Being the son of a classical musician, though, he's heard his share of scales and classical music and enjoys that as well. Noah's list of favorite things include being kissed by the dog, fireworks (especially the loud ones), carbs of all kinds, his siblings, swings, and of course, water. Noah has his own cheering section with his siblings. They love to see the new things he does, always want to see what he brings home from school and the log of what he did that day. Noah loves his siblings a lot and is pretty much all

boy, so his brothers can always get him to laugh. The siblings all know that the day Noah walks, we will have a big ice cream cake and celebration. Right now, Noah is hard at work trying to walk with therapy both at school and at Cascade Children's Therapy. He "bear walks" and cruises and all his therapists seem confident he will someday walk. He's pretty good at making his needs known. Reflux is gone now that we know his food allergies. Noah's chiropractor daddy keeps him very well adjusted and we're all happy to have a chiropractor in the family with all the extra lifting we do now that Noah is such a very big boy!

Dave "Hendu" Henderson Midsummer Golf Classic Fundraiser



It's that time of year again! Our annual fundraiser is fast approaching. We will be holding the Dave "Hendu" Henderson Midsummer Golf Classic Fundraiser on July 28th at the Avalon Golf Course in Burlington, WA. Dave Henderson has been a tremendous support to our Organization, and graciously volunteers his time and energy for this event. Of course, to make this event successful, we need everyone's help. So, enclosed you will find two items relating to the golf tournament. The first is our golfer brochure. If you, or someone you know, is a golfer, please show them this

brochure. Check with your work place, and see if you can sign up a foursome. We have spots for 144 golfers! Foursomes that signup by July 1 receive the early-sign up bonus of \$400.

The second item is a letter that can be given to family, friends and businesses who may not be able to attend the tournament, but would be willing to donate a raffle item or to sponsor a golf cart. You can make as many copies of the letter as you need. The cost to sponsor a golf cart is only \$25. Golf carts can be sponsored by businesses, individuals, or families. Raffle prizes can be anything from restaurant certificates, store gift cards, passes to events (such as Wildwaves or Pacific Science Center), hotel certificates, to golf or sports items. The donation items can be mailed to the address on the letter, or if the item is too big to mail, please call Sherri at (253) 638-6241 to arrange for pickup.

We are also in need of business sponsors for this event. If you know of a business who might be interested in sponsoring a hole, please contact Jon Hegge at (206) 782-5691. We can send them a sponsorship packet.

if you need more information about any of the above, please contact David Platts at (253) 639-1643 or Sherri Rein at (253) 638-6241.