

## 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  
PNWASF website PNWASF.org



PNWASF wishes to thank Mike Brown and the Blue Sky Charities for donating \$750 to our organization. Blue Sky Charities held their annual Turkey Bowl on November 26th, and PNWASF was lucky enough to be one of their beneficiaries of the fund-raising proceeds. Thank you to all who participated in this event.

### 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/Editor  
(253) 638-6241  
Jennifer Cyrus (541) 924-9875  
Jon Hegge (206) 782-5691  
Chris Watts (503) 581-3530  
Gloria DeRosa (360) 876-8342



# Heaven Sent

Pacific Northwest Angelman Syndrome Foundation Newsletter



Volume 14

Winter 2005

### Inside this issue:

Christmas Toy Giveaway	1
Oregon Conference	1
Nominations for Board Positions	1
Newsletter Editor Wanted	1
Golf Tournament Fund-raiser	2
Oregon Family Picnic/ Coldwell Banker Bain	2
Adult Annual Retreat	3
Angel of the Quarter	3
Blue Sky Charities Donation	4



## PNWASF Christmas Toy Giveaway



On December 17th, PNWASF parents were able to shop for gifts for each of their children, free of charge. This unique giveaway was sponsored by Starbucks, in care of Starlight Foundation of Washington State.



Corbin Thompson coordinated this event, with the help of Jennifer Hegge, Jenelle Thompson and Judy Pimelt. Thank you so much!

We also want to thank Steve McGraw of the Starlight Foundation for coordinating this, and to all Washington State Starbucks for making our Angels' Christmas Season a little brighter. Merry Christmas and Happy New Year to everyone!

### PNWASF Participates in Oregon Conference

In October, PNWASF participated in the Division for Early Childhood Conference at the Hilton in Portland, Oregon. An exhibitor booth was set up and manned by PNWASF volunteers, who passed out information about AS, as well as our Organization. The volunteers were very happy to learn that most of the attendees of the conference had heard about AS. A couple years ago this would not have been the case. The word is getting out!

We want to thank our volunteers for taking the time to help with this event. They were Jennifer Cyrus, John Cyrus, Akiko Erwin, Irwin Heckman, Robin Marx, Chris Watts, as well as his mom. The hard work of our volunteers is paying off! People are learning about AS.

*Our prayers and best wishes for speedy recoveries go out to Tyler Thompson, Walt Tossey and Dave Platts, who have all had recent hospital stays. We hope you all get well soon!*



### Nominations for PNWASF Board Positions



The nominating committee is currently seeking nominations for three board positions for PNWASF. Elections will take place at our annual retreat on February 25, 2006 (see retreat information on page 3 of this newsletter). The board positions are for a three year term (March, 2006 - February, 2009). PNWASF relies on its board members for many of the day to day decision making, as well as for fundraising activities. If you would like more information on these positions or would like to be nominated, please contact David Platts at (253) 639-1643.

### Wanted: Newsletter Editor

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. We are also looking for articles about your Angel, including Angels of the Quarter. Please submit these to Reinfour@aol.com. Any help would be greatly appreciated.

## Planning Begins for Golf Tournament Fundraiser!



It's hard to believe, but planning is already underway for the Tenth Annual Dave "Hendu" Henderson Golf Classic. We are having some exciting changes occur at this event. The board unanimously voted to change the location of the tournament to Washington National Golf Course in Auburn, Washington. This is a fabulous golf course, and is known for many of its great tournaments. They have a wonderful country barbeque planned for after the event, which will be held on Monday, July 24th.

Many PNWASF members have asked how they can help make this event more successful, so we thought we'd give you a couple ideas.

One of the ways to help is to ask businesses to sponsor a hole. We will have packets available in early January that you can give to your place of business. It explains the tournament, tells about AS, and how we use the funds raised. We can also make a presentation to the business if needed. Please contact Dave Platts at (253) 639-1643 or e-mail [daveplatts@responseloans.com](mailto:daveplatts@responseloans.com) if you would like a packet sent to you or have any questions on hole sponsors.

Another way to help is to get a business or individual to sponsor a golf cart. This is a low cost way to support our Organization. The cost is \$25 per cart, and we make up the signs and post them on each golf cart. We are also looking for raffle items, which in the past have included gift certificates to restaurants, hotels and stores, golf items, etc. Businesses or individuals can donate items or money to purchase items. We have a pre-made letter to request either of these items from businesses or individuals. You will be surprised at how many businesses will donate if you just ask. If you would like a letter mailed or e-mailed to you, please contact Sherri Rein at (253) 638-6241 or e-mail [Reinfour@aol.com](mailto:Reinfour@aol.com).

And finally, of course we need golfers - 144 golfers to be exact. Our cost this year will be \$500 for a foursome, if paid by June 15th (\$600 after June 15th) or \$150 for individual golfers. We have brochures available that can be mailed to you to hand out to any potential golfers.

As you can see, there are many items that make up our annual golf tournament. We need everyone's support to make this event successful. Please help in any way you are able. For additional information, please contact Dave or Sherri at the above phone numbers or e-mail addresses.



### Coldwell Banker Bain and Agent Koreann Ashlie give back to the PNWASF through its Community Partnership Program

Coldwell Banker Bain has formed a unique partnership with PNWASF in an effort to help raise money for our organization.

Each time a PNWASF member, or friend or relative of a member, buys or sells real estate with Coldwell Banker Bain through sales agent Koreann Ashlie, she and Coldwell Banker Bain will donate an amount equal to 10% of the commission from the transaction to PNWASF.

For more information on the PNWASF Partnership with CBBain, please call Koreann Ashlie at (425) 241-3893 or visit her website at [www.koreannashlie.com](http://www.koreannashlie.com).



## Oregon Family Picnic

Our southend summer picnic was held in September at Broadway Park in Seaside, Oregon. Although there was a small turnout (four families attended the event), those who were there had a great time. Thank you to Jennifer Cyrus for coordinating this event. Jennifer has been very busy trying to get more awareness in Oregon and more involvement from our PNWASF Oregon families.

## Angel of the Quarter



Our Angel of the quarter is five year old Garrett Cyrus. He lives in Albany, Oregon with his family consisting of his dad John, mom Jennifer, big brother Evan, and little brother Camden. He is in morning Kindergarten class at Fir Grove Primary his neighborhood school, which he attends accompanied by his one-on-one assistant Liz.

Garrett is deletion positive and was diagnosed in February of 2003 at the age of 2 ½. He began receiving therapy services both through early intervention and the local children's therapy center, Mighty Oaks when he was one. He also attends a class Friday nights at Oregon State University through their disability movement program. IMPACT is a program where each child has a college student volunteer that helps them to participate in group activities with other disabled students of similar ages in the gym and then they all go swimming in the pool.



Some of Garrett's favorite things are spending time playing with his brothers, riding the bus to school, playing in the water (whether it is in the sink, bathtub, swimming pool, it doesn't matter), playing with his toys which involve lots of music, lights, and the putting in and dumping out of balls, going shopping or anywhere there are lots of people, riding his adapted tricycle, and swinging at the park. He also enjoys camping in our new trailer that includes bunk beds, one of which has been adapted by his grandpa to be an enclosed bed. Lastly but definitely not least Garrett loves trains. He enjoys watching his Thomas the Tank Engine movies but his favorite thing is going to daddy's work (the railroad yard) and watching the real thing or watching movies about Steam engines.

## Adult Annual Retreat Coming Soon!

The annual adult retreat has been scheduled! It will be held February 24th - 26th at Shilo Inn Oceanfront in Seaside, Oregon. We have 20 rooms available to us, which can be reserved by Angelman families on a first come-first served basis. There are two room types this year. The first type has one Queen Bed facing the city of Seaside, with a microwave and mini refrigerator. This room will be available to all families at no charge (although a donation of \$75 is requested). To reserve this type of room, please call Sherri Rein at (253) 638-6241 or e-mail your request to [Reinfour@aol.com](mailto:Reinfour@aol.com).

The second room type is an Oceanfront room on the 2nd floor with two queen beds, kitchen, fireplace and private deck overlooking the beach. These are available to families who are willing to pay an upgrade charge of \$43.60 per night, plus a donation of \$75. To reserve this upgraded room, you MUST pay in advance. Please call Sherri Rein at (253) 638-6241 or e-mail your request to [Reinfour@aol.com](mailto:Reinfour@aol.com), and then mail your payment of \$162.20, made payable to PNWASF, 12932 SE Kent Kangley Rd., #375, Kent, WA 98031. We must receive payment by January 24th to reserve this room type. Your check will not be cashed until February 10th, 2006.

Reservations for either room type must be made by January 24, 2006. After that date, reservations will be subject to availability by the hotel. A donation in the amount of \$75 is suggested from each family attending the retreat. PNWASF has reserved a meeting room for Saturday, starting at 4:30 p.m. for our annual membership meeting. Dinner for this meeting will be provided for all attendees at no cost. All other meals are the responsibility of each family. We have also set up a meeting room for Friday night. Be sure to ask for the location of this room when you check in. We will meet up at 6:00 p.m. and make dinner plans for that evening.

If you have not been to this event before, it is usually attended by 12 to 16 families (adults only), and it is a great time to get to know each other or renew old friendships. Feel free to bring current pictures of your family to share. Other than the membership meeting on Saturday, there are no specific activities planned.

Check in time is 4:00 p.m. on Friday, February 24th. If you want to get more information on the hotel, their website is [www.shiloinns.com](http://www.shiloinns.com). The address is 30 North Prom, Seaside, OR 97138. You can get directions on their website or call the resort at 1-800-222-2244. For driving directions on their website, click on locations, choose Oregon, and then choose Seaside Oceanfront. Then click on maps/driving directions on the left hand side. Hope to see you there!