

# HEAVEN SENT

PACIFIC NORTHWEST ANGELMAN SYNDROME FOUNDATION



Loni Henderson & Crew



Good Food and Good Times  
At the Banquet

## Golf Tournament Results

It was **HOT,HOT, HOT** for this years Dave “Hendu” Henderson Golf Classic but it didn’t seem to phase our golfers. Everyone had a good time and enjoyed the facilities at the beautiful Washington Nat’l Golf Club. The net proceeds were a little disappointing this year, around \$3500, but the good news is that we heard quite a bit of positive feedback about the new location. We hope this will lead to a better turn out next year. PNWASF hosted more than 90 golfers rather than the full 144 with just a few hole sponsors.

We presented plaques to Dave Henderson for his generosity and support for the past tournaments, Loni Henderson for hours of volunteering in tournaments, Koreann Ashlie for her generous



donations to this year’s tournament and to Mike Brown who has MC’d the awards banquet every year. PNWASF would also like to thank our hole sponsors Keithly Electric, Hollinger Construction, Mortgage Master Service Corp, Rob Wunder & Assoc. and Koreann Ashlie

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## Nominations for PNWASF Board

The nominating committee is currently seeking nominations for board positions for PNWASF. Elections will take place at our annual retreat on March 9th, 2007. The board positions are for a three year term, March 2007-February 2010. 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.

## News From Camp Prime Time



Camp Primetime Volunteers

Camp Prime Time was held the first weekend in August this year and was great fun. 11 families attended and enjoyed the great weather and all the fun activities. We want to thank all the great volunteers that helped out and made our weekend so relaxing. We also want to thank Corbin Thompson for setting up and organizing our weekend. We had a wonderful time and look forward to returning in 2 years. More pictures are available on our website at [pnwasf.org](http://pnwasf.org).

Boat Ride on  
Clear Lake at



Camp Prime Time

*Spread the word about the tournament and the benefit PNWASF has been to your life*

## Planning for '07 Golf Tournament Underway

It seems like a long way off, but the planning has already started for next years golf tournament. PNWASF is excited to announce that Bob DeCamp has volunteered to head up this event along with Loni Henderson who will help get golfers and sponsors for our largest fund raising event of the year.

Our goal this year is to get a list of all the things that need to be done for this fund raising event and then start delegating more items. The more people that we can get involved and the more ideas we can generate the more chance we have to make this the successful fund raiser it has been in the past. .

Spread the word about the tournament and the benefit PNWASF has been to your life. Let people know how important it is to have a support group such as our Foundation. Let them know how we have increased awareness about AS by sending out thousands of pamphlets to doctors in our region. We also hosted the National ASF Conference years ago and currently support the conference with donations to help families attend. We maintain a current website and provide opportunities for regional families to exchange information, concerns and strategies related to life with AS families.

PNWASF would like to thank our volunteers for this years tournament, Jennifer Cyrus, The Platts Family, The Quintanilla Family, Sherri Rein and Gloria Derosa . Thanks to you all for your efforts!



## Angel of the Quarter Lindsay

Lindsay is our little Angel. She is 4-1/2 yrs old, 3-1/2 feet tall and full of mischief and love for almost everyone.

Lindsay was diagnosed just over 2 yrs ago in 2004, after 2yrs of constant testing to see why she didn't make many sounds, couldn't sit up, couldn't crawl and just didn't do any of the things other babies her age could/should do. When we finally got sent to Dr Bouldin of Children's Hospital. located here in the Everett area, he saw immediately that something was just not "right". After testing Lindsay for suspected seizures (unfounded at the time), Dr Bouldin ordered a full spectrum of blood tests. When we got the diagnosis, the immediate response was devastation, but afterwards it was relief because now we had a direction to go in.

Lindsay's favorite person in the whole world is her older sister Jaimi (age 5-1/2). She just squeals with delight when Jaimi enters the room and Jaimi is the one she looks for first when she gets home from school. Mama is her security blanket and she shadows her all day when she is not at school. She loves

to torment her Daddy too. She clearly adores him, but her favorite thing is to play hard to get when Daddy wants hugs and kisses. Then she just laughs and laughs when he comes to get her.

Lindsay's smile lights up the room and she can make even the grumpiest person smile. In fact, Lindsay faces sadness or grumpy as if it were her personal challenge and she works even harder to brighten and lighten the load for those souls. Very few people can resist her charms.

Lindsay is smart as a whip. She even amazes her teachers. Once we figured out that she couldn't "translate" left and right when facing you, we turned her around and taught her from her front point of view so that she had right on right and left on left. She picked up things much more quickly after that. And her retention was amazing. She only needs to be shown most things twice before she remembers them. I can't even do that with some things.

Lindsay's immediate family consists of Daddy (Jim) who works at Boeing; Mama (Cindy) who stays at home to care for the family; Jaimi ( 5-1/2) in Kindergarten and of course Lindsay (4-1/2) in Preschool.



Lindsay giving a hug to Johanna and her Mom

## Adult Retreat Coming Soon!

The annual adult retreat has been scheduled! It will be held March 9th-11th at the Shelburne Inn in Seaview, Washington. We have reserved 15 rooms which can be reserved on a first come-first served basis by Angelman families. The reservation policy has changed. To reserve your spot, please send a check in the amount of \$50 made payable to PNWASF to the Treasurer, Sherri Rein. The address to mail the check to is 12932 SE Kent Kangley Rd., #375 Kent, WA 98031. The \$50 will not be cashed until February 7th, 2007. After that date, reservations will be subject to availability by the resort.

If you have not been to this event before, it is

usually attended by 10 to 12 adults (adults only), and it's 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 4pm pm Friday, March 9th. For more information on the resort go to their website, [www.theshelburneinn.com](http://www.theshelburneinn.com) or by calling 1-800-466-1896

Questions on the retreat can be directed to Penny Wilson at 360-782-4049. If you have any questions on the deposit, or would like to request a scholarship, contact Sherri Rein at 253-638-6241.

*The Annual Adult Retreat will be held March 9th - 11th 2007 at the Shelburne Inn in Seaview, Washington*

## SOUTH END PICNIC

The south end picnic was held on Saturday, August 26 in Seaside, OR. While attendance was limited the weather was perfect and everyone had a great time. The Hall's and Cyrus' along with some extended family and Garrett's speech therapist from Oregon and the Lampers' all the way from Idaho had wonderful conversation and a great barbeque lunch at the beautiful Oregon Coast.

It came as no surprise to anyone that the Angels figured out how to turn the picnic shelter into their own water park. Caleb and Garrett played in the water while Joe pushed a stroller all over the park. Plans for next years south end picnic are already underway. Please send any suggestions for dates, locations, or events to Jennifer Cyrus via e-mail at [jjcyrus@comcast.net](mailto:jjcyrus@comcast.net)



Garrett & Caleb Creating Their Own Water Park

## 2007 ASF Biennial Conference

Mark your calendars for the ASF 10th Biennial Conference to be held July 25-28 2007 at the Hyatt Regency St. Louis. Plans are already underway for this exciting event you won't want to miss. Visit the ASF website at [angelman.org](http://angelman.org) to view details of the conference. PNWASF will be offering scholarships for families in financial need who would otherwise be unable to attend this conference. See enclosed application. ASF is also offering scholarships for registration and hotel costs up to \$1,000. This application is also enclosed or can be downloaded from their website. Both PNWASF and ASF did not use all their scholarship money for the 2005 conference, so if you are eligible, please apply. You can apply to both and have the full conference paid for, except meals and spending money.

Anyone who has attended any of these conferences will tell you the information is invaluable. Meeting so many Angels and their families is awesome. You will walk away with many friendships and valuable information on AS.

If you have any questions about the PNWASF scholarship, please contact Sherri Rein at 253-638-6241 or e-mail [Reinfour@aol.com](mailto:Reinfour@aol.com). Questions about the ASF scholarship should be directed to Eileen Braun at 800-432-6435 or email [ebraun@angelman.org](mailto:ebraun@angelman.org).

If you are even thinking about attending the conference and/or planning on applying for either scholarship, you might want to reserve your room now as rooms are filling up fast due to a rivalry baseball game between the St. Louis Cardinals and Chicago Cubs occurring the same time as the AS conference. Arrival dates before July 24th are already sold out. You can make reservations online (go to the ASF website at [angelman.org](http://angelman.org) and click on the link under 2007 Biennial Conference Hotel Information ) or call the hotel directly at 314-231-1234 and mention that you are with the Angelman Syndrome group. Cancellations can be made up to 1 day prior to your arrival and no deposits are required.

## Everything We Ever Needed to Know We Learned From an Angel

There is no such thing as "Angel-Proofing" your house.

An Angels voice is louder then 200 adults in a crowded restaurant.

Balls make marks on ceilings.

You should not throw a ball when a ceiling fan is on.

When you hear the toilet flush and an angel laugh, it is already too late

A king sized water bed holds enough water to fill a 200 square foot house 4 inches deep.

Legos will pass through an Angel's digestive track.

When dialed randomly over a period of time numbers on a phone dial will combine in such a way that a three hour phone call to Scandinavia will appear on your phone bill.

VCRs do not eject peanut butter and jelly sandwiches.  
Quiet does NOT mean DO NOT WORRY!

Baby powder is impossible to get out of shag carpeting.

Toothpaste and Desitin have qualities very similar to those of finger-paint.

Objects on someone else's plate are closer then they appear.

Never leave the sprinkler or hose in such a way that your angel can turn the water on, unless you need a shower!

Small mittens also fit nicely in the VCR.

Laughter is often the best medicine.

And the most important thing our Angels have taught us is...

That just because a person can not speak does not mean they have nothing to say!

Contributed By: Janice Daley, Charles de Broin, Julie Hyman and Jeanne Imperati

**Angelman Syndrome From A to Z**

*Everything you ever wanted to know about Angelman Syndrome... and then some!*

**Compiled By Alice Evans and Julie Hyman**



**PNWASF**

***PACIFIC NORTHWEST ANGELMAN  
SYNDROME FOUNDATION***

Primary Business Address  
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**Email: PNWASF@PNWASF.ORG**



**We're on the Web**  
**[www.pnwasf.org](http://www.pnwasf.org)**

**Newsletter Information**

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

Robin Marx

91029 S. Miller St.

Coburg, OR 97408

Or e-mail items to Robin at

[miroberkel99@yahoo.com](mailto:miroberkel99@yahoo.com)

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

**Article Submission Deadlines**

Winter January 15

Spring April 15

Summer/Fall August 15

**Current Board Members**

**David Platts: Director/ President**

**Lory Tossey:**  
**Director/Vice President**

**Jon Hegge:**  
**Director/Vice President**

**Sherri Rein:**  
**Director/Treasurer**  
Home: 253-638-6241

**Jennifer Cyrus: Director/  
Secretary**

**Chris Watts: Director**

**Gloria DeRosa: Director**

**Jen Salvione: Director**