

# Heaven Sent



Spring 2011

## Pacific Northwest Angelman Syndrome Foundation

### The Dave “Hendu” Henderson Midsummer Golf Classic

On Monday, July 25, 2011 at 2pm the 15th annual Dave “Hendu” Henderson Midsummer Golf Classic at the great Washington National Golf Club in Auburn WA will begin with a shotgun start. Entry fees include greens fees, golf cart, range balls, great tee prizes, awards ceremony and a banquet dinner.

We are still looking for golfers, hole and cart sponsors as well as donations for our raffle and silent auction. Volunteers are also in demand at this event. We need people to take shift at the prize tees, people to help with the raffle and silent auction and to help set up.

Corbin Thompson is working on a special project for the tournament banquet. She is asking families to either email or send hard copies of photos of your Angel to be shown during the banquet in a slide show. 2 or 3 photos will be appropriate.

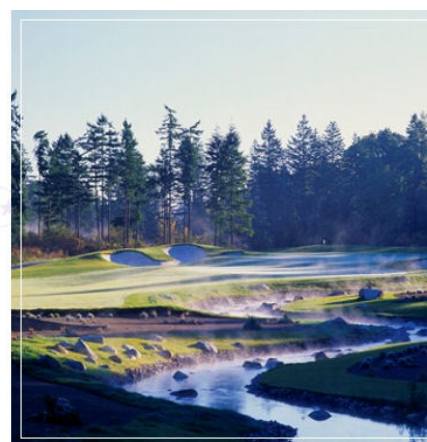
Digital pictures can be sent to [corbinthompson@hotmail.com](mailto:corbinthompson@hotmail.com) or hard copies can be sent to Corbin at 409 S. 52nd St Tacoma, WA 98408. Make sure to write your name and address on the back of each picture you send.

Justin Platts is our new Events Manager for the golf tournament. If you have any questions, would like to donate, volunteer or play you can reach Justin at (253) 332-4189 or by email

[justinplatts@gmail.com](mailto:justinplatts@gmail.com).

Thank you for your support to the Pacific Northwest Angelman Syndrome Foundation. Please mail your contribution to the above address.

Checks should be made payable to PNWASF. Your contribution will have a direct impact on improving the future of local AS children and their families.



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### Website Update

We have noticed the photos on our website, [www.pnwasf.org](http://www.pnwasf.org), are looking dated. Some of these little kids are teenagers or adults now.

Would you consider sending in new photos to update or photo gallery. We want to keep the old

ones just want to add some new. It's lovely to see how much our kids change.

Email photos to [pnwasf@pnwasf.org](mailto:pnwasf@pnwasf.org)

Please send updated information on your Angel including first

name, age and AS diagnosis if known (such as deletion positive, UBE3A, clinical, etc.)

We can't wait to see all the new photos and how they've all changed. It will be nice to see new faces too!

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## 2011 Adult Retreat and Business Meeting: Two New Board Members Welcomed

The PNWASF's annual retreat was held at the Quinault Beach Resort and Casino in Ocean Shores WA this year on March 4th - 6th. As usual a great time was had by all.

Important decisions were made on Saturday at the business meeting. Two new directors were elected to the board. Justin Platts, who is the brother of Angel Bridgett, was elected and is also our new event manager for the Dave "Hendu" Henderson Midsummer Golf Classic, our one and only fund raiser.

Rhonda Kirtland from Portland was voted in and will be filling in for the spot vacated by Janelle Thompson who resigned after moving to California earlier this year. Gloria Derosa was also re-elected as director.

Members approved up to \$7500 for scholarships (up to \$2500 per family) for the ASF

Biennial Conference in Utah. Letters went out in March (you did not get one if you already received a scholarship in a prior year).

Members also approved \$1000 donation to ASF for lanyards for the conference which feature our logo. Approved \$500 to ASF for research and \$500 to donate to a participant in the ASF walk-a-thon.

Camp Taloali was not available to us this year so Robin will be looking into other camps for the summer including Camp Kiwanda near Mt. Hood OR. Cost of camp is a big factor this year.

Thank you Daryl for the photos!



*Jennifer, Jon and Corbin  
in deep discussion*

## Summer Picnics & Family Camp

The **North End** picnic will be held August 13th at the Stewart Heights Pool, 402 east 56th Tacoma WA 98404

We reserved a poolside meeting room and have access to the pool area from 12 to 5pm. PNWASF is providing cold sandwich's and soft drinks, Please bring a side dish or a dessert to share with the group. Bring swim suits, towels and sunscreen. Extended family members are welcome to join as well as care providers.

Contact Corbin Thompson at corbinthompson@hotmail.com or 253-459-4725 to RSVP.

The **South End** picnic will be held June 25th at Silver Falls State Park From 12 to 5pm. The North Falls Lodge has been reserved for our group and is available to us before and after the stated times.

Access to the day use area has a \$5 fee per vehicle.. Main dish provided by the Foundation. Please bring a side dish for potluck meal. Contact Rhonda at rskirtland@hotmail.com for RSVP or questions

Please Join Us! It's great to get together with other Angelman families.

Some sad news. **Summer Camp** will not be held this summer. Camp Taloali was not available for rental this year. After checking other camps the costs were just too prohibitive.

We are so lucky to be able to have a place like Camp Prime Time we are able to use every other year without cost. They are very generous people.

We will continue to look for a camp that will be perfect for us in Oregon for the years we cannot use Camp Prime Time.

## Want Ads: Stuff You May Want or Need

I have a free Britax car seat –the model is the Regent which fits kids between 22-80 lbs and under 53 inches tall. It's in really good shape. The cover comes off for washing . it would be really good for an angel who is bigger /needs more support than a conventional car seat provides. You can look at it online and goes for 269.00 new. You can give me a call if you are interested in picking it up in Port Orchard or I may be able to meet you ½ way - 360 876-8342- ask for Gloria . A new friend gave it to me as it does not work for her special needs

son because it does not have a pommel – it would be nice if whoever takes it could send her a thank you note.

If you have items you would like to give away or something you need that one of our members may have no use for any longer, go ahead and post it here. Just send your listing to the address on the back of this newsletter.



## ASF Conference Scholarships/ Canadian Angelman Syndrome Society

The Pacific Northwest Angelman Syndrome Foundation has awarded scholarships of up to \$2500 to three member families to attend the ASF Biennial Conference and Scientific Symposium in Salt Lake City Utah.

This years recipients are:

Rhonda and Craig Kirtland

Dawn Sells

Steven and Rebekah Ek

A biennial conference is like no other. The wealth of information is immense, so much to learn especially from other parents and caregivers. Make time to relax and chat with others living with Angelman Syndrome whether it's by the pool, in the lobby or during a meal. You will all find this to be a very rich experience.



### Join us in Calgary!

Mark your 2012 calendars, CASS invites everyone to beautiful Calgary, Alberta, to share in 4 days of education, information, fun and western hospitality. Conference attendees will hear presentations from many distinguished speakers.

11th CASS International Conference July 25 – 28, 2012 <http://www.angelmancanada.org/>

## ASF Biennial Conference, Salt Lake City, UT

The ASF Biennial Conference and Scientific Symposium are the premier Angelman Syndrome meetings, bringing together world-class leaders in AS and UBE3A research, as well as the leading experts in “all things Angelman”. In addition to scientific research advancements, attendees will experience first-hand the opportunity to meet and discuss the topics and issues that are most relevant to you—whether it is obtaining financial resources for your individual and your family, educational information, hands-on technology experience, the most current information on seizures and treatment, the invaluable experience of face-to-face connections with others who know and understand Angelman syndrome and live it every day—it is all available to you in one stop. To register for the 2011 ASF Scientific Symposium & Biennial Conference, Please visit

<http://www.angelman.org/>

A discounted group rate of \$129 is available at the Sheraton in SLC. The Sheraton is the hub of the conference. Click here to make your reservation today!

If you are planning your vacation in Salt Lake, the Sheraton has extended the rate three days before and after the conference. We will see you in Salt Lake City!

### When

Tuesday, 26 Jul 2011 10:20 AM - Saturday, 30 Jul 2011 11:20 AM - (GMT-07:00) Mountain Time

### Where

Sheraton Salt Lake City  
150 West 500 South  
Salt Lake City, Utah 84101

### Event Contact

Sheila Wenger

[swenger@angelman.org](mailto:swenger@angelman.org)

800-432-6435

*Bringing together world-class leaders in AS and UBE3A research, as well as the leading experts in “all things Angelman”*

## Save the Date: Great Wolf Lodge

We have another opportunity for a family overnight at Great Wolf Lodge. This year would be a little different though than last. We would reserve 20 rooms, and it is for one night only. The date would be Sept 2nd, which is the Friday of Labor Day weekend.



*Fort Mackenzie at Great Wolf Lodge Waterpark*

The cost would be \$50 per family of 4 for the room and water park only. Meals would be the responsibility of each family. We would limit the number of rooms per family to one and occupancy at 4. Additional rooms would be able to be reserved by calling the lodge directly. Even

though you will be required to check out of your room at 11 am on Saturday, you can still use the park for the full day. At this time, we just want to know how many families would be interested since it is only for one night and it is a holiday weekend. Please e-mail me back with your names of those attending and phone number if you think your family would be interested in participating.

Corbin's email: [corbinthompson@hotmail.com](mailto:corbinthompson@hotmail.com)

## Pacific Northwest Angelman Syndrome Foundation

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#375  
Kent, WA 98031

Phone: 866-330-9256  
E-mail: [pnwasf@pnwasf.org](mailto:pnwasf@pnwasf.org)

**We're On  
The Web**

**[www.pnwasf.org](http://www.pnwasf.org)**

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

*Be Not Afraid of Growing Slowly,  
Be Afraid Only of Standing Still*

### Newsletter Information

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

**Robin Marx**  
**91029 S. Miller St.**  
**Coburg, OR 97408 or**  
**email to Robin at**  
**[miroberkel99@yahoo.com](mailto:miroberkel99@yahoo.com)**

#### Article Submission

##### Deadlines

**Winter: Jan 15**

**Spring: May 15**

**Summer/Fall: Sept. 15**

### Board of Directors

Jon Hegge/ President  
Everett, WA  
2011-2013

Sherri Rein/ Treasurer  
Kent, WA  
2010-2012

Robin Marx/Secretary  
Coburg, OR  
2009-2011

Gloria DeRosa/ Director  
Port Orchard, WA  
2011-2013

Corbin Thompson/Director  
Tacoma, WA  
2010-2012

Erin Platts/Director  
Covington, WA  
2010-2012

Rhonda Kirtland/Director  
Portland, OR  
2011-2013

Justin Platts/Director  
Tacoma, WA  
2011-2013