

# Heaven Sent

Winter 2011

## New Golf Committee

The Pacific Northwest Angelman Syndrome Foundation Board of Directors is thrilled to announce a brand new Golf Tournament Committee to head up the Dave “Hendu” Henderson Midsummer Golf Classic. This event is the main source of revenue for the entire organization and the new committee will ensure a sustainable and effective system for putting on this yearly tournament. The 2011 PNWASF Golf Tournament Committee positions and volunteers are as follows:

Marketing, Sponsorship and Event Manager – Justin Platts

Financial Manager and Golf Coordinator – Sherri Rein

Volunteer Coordinator and Event Assistant – Corbin Thompson

Silent Auction Coordinators – Jon and Jennifer Hegge

Raffle Coordinator – Loni Henderson

The Dave Henderson Midsummer Golf Classic takes place on July 25, 2011 at Washington National Golf Course in Auburn, Washington. You can find more information at the PNWASF website under the “Current Activities” section.

If you would like to get involved by volunteering or by referring potential sponsors, donors or golfers please contact Justin Platts by e-mail at [justinplatts@gmail.com](mailto:justinplatts@gmail.com) or by phone at (253) 332-4189.

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## Nominations for PNWASF Board

The PNWASF Board of Directors is currently seeking nominations for board positions for PNWASF. Elections will take place at our annual retreat on March 5th, 2011. The board positions are for a three year term, March 2011- February 2014. 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 nomi-

## Adult Retreat and Business Meeting

### A Correction

The annual Adult Retreat and Business Meeting of the Pacific Northwest Angelman Syndrome Foundation will be held at the Quinault Beach Resort and Casino in Ocean Shores WA. The last newsletter stated it was the Quinault Lodge.

The meeting takes place March 4 - 6. It is the one time of year the board meets in person and members of the PNWASF are able to get together and swap stories and strategies on living with AS. Hope to see you there!



***All completed applications must be received at the ASF office no later than May 9, 2011.***

## ASF and PNWASF Providing Scholarships for 2011 Conference

The Angelman Syndrome Foundation will be offering a limited number of scholarships to ASF Biennial conference in Salt Lake City. Scholarship awards include conference registration and up to four (4) nights hotel accommodations at the Sheraton in Salt Lake City, UT. Scholarships will be awarded on a financial need basis. Scholarship funds are available up to \$1,000. Conference scholarships are not cash awards and no money or funds are exchanged. All completed applications must be received at the ASF office no later than May 9, 2011. Applications received after May 9, 2011, will not be considered.

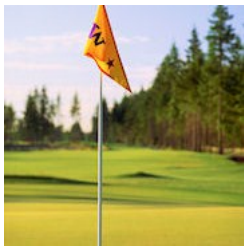
All information provided will be held strictly confidential. More info can be found at their website [www.angelman.org](http://www.angelman.org)

after the annual board meeting on the 5th of March. Keep an eye on your mailbox for the application form and our website if you are interested in attending.

The Pacific Northwest Angelman Syndrome Foundation will be offering scholarships to our members whose membership dues are up to date. The scholarship money may be used for air fare, room and board, conference fees, transportation and care provider fees. The amount of those scholarships and the application will be available



## Planning Has Begun For Golf Tournament Fund Raiser



It's hard to believe but it is time to start putting together the 2011 Dave "Hendu" Henderson Golf Tournament benefitting the Pacific Northwest Angelman Syndrome Foundation. Mark your calendars for Monday July 25th . Tee off is a shotgun start at 2 pm. We will again be playing at the beautiful Washington National, home of the Huskies.

We would love to have as many members as possible volunteer-

ing at the event but if you can't be there you can still help. We have packets available that you can give to your place of business. It explains the tournament, tells about AS and how we use the funds raised. Contact Sherri Rein at 253-638-6241 or email [rein-four@aol.com](mailto:rein-four@aol.com) if you would like a packet sent to you or have any questions.

Another way to help is to ask businesses or individuals to sponsor a

golf cart or better yet a hole We are also looking for raffle and silent auction items. You can find a donation letter in this newsletter to copy and pass out to businesses. You will be surprised how many businesses will donate if you just ask. We need everyone's support to make our fund raiser successful. Contact Justin Platts for more info, [justinplatts@gmail.com](mailto:justinplatts@gmail.com) or 253-332-4189

## Oregon and Washington Family Picnics

We are looking for two families to host the North End and South End picnics for this Spring or Summer. The picnic is a potluck with the PNWASF providing the entrée such as hamburgers, hot dogs or sandwiches.

The picnic can be held at a city park, water park or indoor pool. There have been bowling gatherings and a day at the petting zoo.

With the Wreggelsworths, a very popular venue. So, you see, it doesn't need to be just a picnic.

We need a family from Washington and a family from Oregon to each organize a picnic. An Oregon family would be especially appreciated. If you are interested please call Robin Marx at 541-485-8518 or email at [miroberkel99@yahoo.com](mailto:miroberkel99@yahoo.com)





## Angel of the Quarter: Alyssa Hegge

My name is Alyssa, I am 21 years old and I go to the transition center in Snohomish Washington. I like to walk with my Mom everywhere around our community. I like to do things with my friends. Last Christmas I took my friend Jeremy to a Christmas Party as you can see in the picture. I also like to go camping with my family. I'm going to get a job when I get out of school at my Mom's fitness club. It feels good to do a good job at what ever I do. Oh, also, I like to watch Tom and Jerry and Scooby do on TV.



Alyssa



Alyssa & Santa



Alyssa & Jeremy



# Angelman, Rett & Prader-Willi Syndromes Consortium

### What is the Angelman, Rett, and Prader-Willi Syndromes Consortium?

The Angelman, Rett, and Prader-Willi Syndromes Consortium is a team of doctors, nurses, research coordinators, and research labs throughout the U.S., working together to [improve the lives of people with Angelman, Rett, and Prader-Willi Syndromes](#) through research. Since Angelman, Rett, and Prader-Willi Syndromes are rare, there are low numbers of research volunteers and this adds a greater level of difficulty for researchers struggling to learn more about these disorders.

The purpose of this consortium is to provide a way for patients to join with doctors and researchers by participating in research studies. The greater the collaboration between doctors and patients, the more we can learn about these disorders. This important first step is necessary if we are ever to find newer treatments.

### Why is your participation important?

Every patient can play an important part in helping to find an effective treatment and cure for Angelman, Rett and Prader-Willi Syndromes. One very important way you can help is by joining the Patient Contact Registry, and possibly taking part in a clinical trial.

### Who Can Join the Contact Registry?

Anyone who is diagnosed with Angelman syndrome, Rett syndrome, or Prader-Willi syndrome can join the contact registry.

### How does the Contact Registry Work?

After you have read and agreed to the Authorization, the Registry form will appear on your screen. This form asks you for information such as your (or your

child's) name, address, birth date, place of birth, email address, or items relevant to your (or your child's) disorders.

Once you have entered and submitted this information online, the data will be stored in a secure, computerized database. No personal identifying information (such as your name, address, telephone number) will be given to anyone without your expressed approval.

**The Rare Diseases Clinical Research Network will make every effort to enroll all the patients we can, but we cannot make any guarantees that we will be able to enroll everyone in a particular study who wants to participate.**

Find the full article and more info at the ASF website. [www.angelman.org](http://www.angelman.org) and at <http://rarediseasesnetwork.epi.usf.edu/>

Every patient can play an important part in helping to find an effective treatment and cure for Angelman, Rett and Prader-Willi Syndromes.

**Pacific Northwest Angelman  
Syndrome Foundation**

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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 Robin at  
miroberke199@yahoo.com

Article Submission  
Deadlines  
Winter January 15  
Spring May 15  
Summer/Fall Sept. 15

**PNWASF Board of Directors**

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