

Summer/Fall 2010



PACIFIC NORTHWEST ANGELMAN SYNDROME FOUNDATION

Heaven Sent

The Dave “Hendu” Henderson Golf Classic

This year’s Dave “Hendu” Henderson Golf Classic was held on possibly the most gorgeous day of the year. We couldn’t have asked for a better day for golf. The course was the beautiful Washington National in Auburn WA, home of the Huskies.

This tournament is the PNWASF’s only fund raiser of the year so it is very important to our organization. We had a profit of about \$8500, a very good sum considering the downturn in donations for our silent auction. With these funds we will be able to send a few families to Salt Lake City for the ASF biennial conference, help fund Angelman Syndrome research and produce this newsletter. These are just a few things we are able to do thanks to you.

Thank you to all our golfers who stepped up to the plate purchasing all those raffle tickets, auction items and mulligans. Hmm, maybe we should consider allowing 3 mulligans per person next year.

We also would like to thank all our volunteers especially Scott Thompson who acted as MC. Also to Sherri Rein who will be stepping down as event coordinator. No worries though. Justin Platts, who has experience organizing events and is a brother of an Angel, will be filling Sherri’s shoes with a new organizational plan for the event.

Hopes are high for next year. More volunteers will be needed so we hope to see more members at the tournament and helping to gather raffle and silent auction items. Call or email the PNWASF if you are interested in helping. It is a ton of fun!



PNWASF Has New Webmaster

Have you been to our website lately? Well if you haven’t check it out, www.pnwasf.org. Thanks to our new webmaster, John Weisenfeld, everything is current and up to date.

We will be working on new features also with his help. One item is having this newsletter emailed for those who would prefer that method of delivery. It has the added benefit of keeping one more cost down for our group.

Another must see feature that John has set up is our

own Flickr account. Flickr is an online photo sharing website. The web address to access our account is <http://www.flickr.com/photos/pnwasf>. If you would like to post pictures there email them to gone31changes@photos.flickr.com. There are lots of pictures posted there right now from Camp Prime Time, Our Great Wolf Lodge weekend and other events.

Thanks again John. Without our great volunteers we wouldn’t be able to offer all we do.

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Our photo account is <http://www.flickr.com/photos/pnwasf>. If you would like to post pictures there email them to gone31changes@photos.flickr.com

Camp Prime Time

Camp prime Time was a real relaxing get together. We had 9 families join us at camp this year, the Platts, DeCamp's, McCarten's, Thomas's, Hegge's, Thompson's, Jorgenson's, Calahan's, Weisenfeld's, and the Ruddricks. The weather was mild in the 70's . A burn ban was in effect so campers had to cook their smores in the oven. Even though they were not cooked over the camp fire they still tasted great!!!

We got to see all the progress of the new addition being built onto the old lodge and it is a massive two stories with an elevator. The only part of the old lodge left is the kitchen and dining hall.

This year we had a lot of little campers Including a new family from Spokane with three little Angels full of energy. Everyone enjoyed the horseback riding and boat rides on Clear Lake. A couple of families tried their luck at fishing. "No luck". Oh well maybe next time. In all it was a nice get away for all who attended camp, most of all having all our meals cooked for us and hey, no dishes yay!!!!!!!!!!!!!! The next time we visit all the construction will be done and we will get to enjoy even more of what the camp will have to offer. See you in 2012.



Everyone enjoyed the horseback riding and boat rides on Clear Lake.



North End Picnic

This year the North End Picnic was held at the Wregglesworth's home on Saturday the 24th of July . Hot dogs, hamburgers and drinks were provided by PNWASF with potluck for side dishes and desserts. A big thank you again to Jim and Rhonda for sharing their home and petting zoo with our families. It is an ever popular place for our north end picnic.



Angel of the Quarter: Evan Kirtland

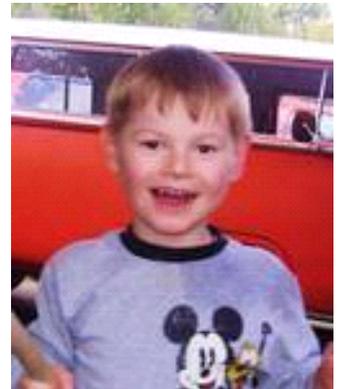
Evan is our only child and before he was an “Angel” he was a “Heart Baby”. At 20 weeks in utero he was diagnosed with Hypoplastic Left Heart Syndrome (HLHS). A rare heart defect that is always fatal if not corrected shortly after birth. We understood it would take a total of three open-heart surgeries to redirect the blood flow entirely through the right side of the heart. When he was born we were told hours after delivery that his heart had suffered so much damage from my preeclampsia condition and the difficult birth that the life saving heart surgery would not be an option. The doctors gave Evan and us a couple of days with each other. Miraculously Evan’s heart recovered enough that the doctors thought a chance at survival was better than none at all. They went forward with the first surgery at day four of his life.

Evan never fed from a bottle or nursed and had severe reflux problems. He ultimately had a gastrointestinal tube inserted to keep him hydrated and nourished in preparation for his second open-heart surgery at six months of age. He was such a happy baby considering all he had been through. We thought we were blessed to have such a good natured child.

Developmental delays were normal for “Heart Babies” so we didn’t think much about the developmental milestones he was missing. After a couple of years of multiple therapies Evan just wasn’t making the progress he should have. Evan’s grandmother saw the actor Colin Ferrell on a morning show talking about his son with Angelman Syndrome. It sounded similar to Evan and his behaviors. After reading all the characteristics we felt strongly that this was what we were dealing with. Our behavioral pediatrician told us that he definitely didn’t have AS and that he was delayed due to the cardiac condition. We just couldn’t get past the similarities between him and the signs associated with AS. We waited for months to see a neurologist to find out why he was having what we thought were seizures. She referred us to a geneticist who agreed with our suspicions of AS. The first round of testing came back negative. We all thought we should try the second round of testing. We knew if that came back negative he would be diagnosed as clinical AS. So we prepared for the news.

After the New Year this last January 2010 five years after his birth we finally got the answer, positive UBE3a mutation. It was devastating news but satisfying to finally know why our little angel understood us but couldn’t speak to us. Since January we have sub-

merged ourselves into the Angelman family. It has been like being rescued from a deserted island! We have had some of the most amazing encounters with other parents and professionals. Evan is now starting Kindergarten in a partial inclusive classroom in Hillsboro, OR. We are waiting to receive his Augmentative Communication Device which we are very excited about. He is starting Horse Riding Therapy this fall thanks to his experience at Camp Primetime this summer. Evan will have the last of the three heart surgeries in the summer of 2011. For now we are thankful for our Angel on Earth who passes on the most contagious thing of all...a smile.



Save The Date: Adult Retreat and ASF Biennial Conference

There are two big events coming up next year, 2011, to mark on your calendars.

Friday March 4th through Sunday March 6th will be the annual Adult Retreat and Business Meeting. This year it will be located in Ocean Shores WA at the beautiful Lake Quinault Lodge. If you are interested in voting for or becoming part of our board of directors this is the meeting for you to attend. The only scheduled event of the weekend is the meeting with dinner to follow. All other activities are yours to decide though it is always lots of fun to get together with old and new friends within the PNWASF that are also attending.

The ASF Biennial Conference and Scientific Symposium will be held

July 26 - 30, 2011 at the Sheraton in Salt Lake City. The Angelman Syndrome Foundation will be offering a limited number of scholarships to aid families who may not otherwise be able to attend. 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

**PACIFIC NORTHWEST
ANGELMAN SYNDROME
FOUNDATION**

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We're on the web!
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*Be Not Afraid of Growing Slowly,
Be Afraid Only of Standing Still*

Chinese Proverb

Newsletter Info

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
miroberkel99@yahoo.com

Article Submission Deadlines
Winter January 15
Spring May 15
Summer/Fall September 15

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Officers and Board of Directors

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Janelle Thompson: Vice President
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