

Heaven Sent

The Pacific Northwest Angelman Syndrome Foundation



Jon & Jennifer Hegge and Erin Platts



PNWASF Business Meeting and Parent Retreat

The annual business meeting and Parent retreat was held once again at the beautiful Shelburne Inn in Long Beach Washington. It was a real treat having the whole bed and breakfast just for our group. It was almost like having the meeting over at **someone's house.**

New officers and directors were voted in at the meeting. Jon Hegge will be our new leader, Robin Marx as secretary and the newest board member Jenelle Thompson as vice president, the first sibling of an Angel ever to serve on the board. A new director, Erin Platts, has also added. These are all volunteer positions so it is wonderful to see the dedication of our group.

John Weisenfeld has graciously volunteered to be the new webmaster for our website, www.pnwASF.org. John has up-



dated the site with new features. There is now a link to our calendar of events and a link to our Flickr site so you can send photos of all the fun and important events the PNWASF participates in. We really needed someone for this important task. Thank you John!

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The Dave "Hendu" Henderson Midsummer Golf Classic

The Pacific Northwest Angelman Syndrome Foundation has one fund raiser a year, The **Dave "Hendu" Henderson Midsummer Golf Classic.**

The purpose of this tournament is to create awareness of Angelman Syndrome (AS) and help fund the continued efforts of PNWASF. The funds raised go to our families for conference scholarships, retreats, informational booths on Angelman Syndrome at conferences and research money given to the national Angelman Syndrome Foundation.

This year's golf tournament is going to be held on Monday July 26th with a shot gun start at

2:00PM. It will once again be held at the beautiful Washington National Golf Club home of the University of Washington Huskies Golf Team.

Donations for the raffle and silent auction are needed as soon as possible. Please help by asking local businesses for donations. Volunteers are also very much needed. It really is a lot of fun so please consider helping out.

For questions regarding registration, participating in or donating to the tournament contact Sherri Rein at 253-638-6241 or email reinfour@aol.com

Family Retreat: Great Wolf Lodge



Erich Opens Another Chest With His Wand



Story Time

The Great Wolf Lodge was a real "splash"!! We had 14 families attend and each one said they had a wonderful time." Gloria DeRosa Luna said "it was the best family vacation they ever had" Those who attended were DeRosa/ Luna's, Thompson's, Decamps, Rein's, Johnson's, Jorgenson's, Quintenilla's, Garrick's, Lamper's (who drove 9 hours from Idaho), McCarten's, Platt's, Wisenfeld's, Marx, and the Wregglesworth's. We had a whopping 64 people enjoying themselves for the weekend. This was the best turnout in the history of our foundation's family events.

The Lodge had everything you could need or want. From a Starbucks to an 84 degree, 340,000 gallon water park that included 6 slides and 3 pools. Also an animatronics story time and a very fun wizard and wand quest

game throughout the hotel where your wand activates all sorts of statues, pictures, treasure chests and animatronics animals. In all I would like to say it was a Great Wolf weekend.



The Wregglesworth's



Eugene & Tyler Enjoy The Hot Tub

Camp Prime Time

Our family camp this year will be held at Camp Prime Time August 20th-22nd. The camp will have 13 cabins open. One is being used for a temporary playroom while the lodge is under construction. The Prime Time facilities provide:

Lodge with a kitchen facility

Sleeping cabins

Accessible, clean bathing, and showering restrooms

Electricity

Telephone

Hot water

A comfortable and accessible, yet rustic, environment.

If you plan on attending you will need to send a check for \$20.00 nonrefundable to Corbin Thompson, 409 south 52nd street Tacoma WA 98408 Make checks out to Camp Prime Time. Camp is first come first serve, so as your checks are received You will be notified and confirmed your cabin. Checks are to be mailed before July 20th. Hope we have a great turnout, camp is always a blast. Questions? call Corbin at (253) 474-4865

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PNWASF is looking for an Oregon family to volunteer to organize a South End Picnic

Summer Picnics

Washington's North End Picnic is going to be at the Wregglesworth's home Saturday July 24th starting at 1pm. This is a potluck so bring your favorite dish to share. Hotdogs, hamburgers and drinks will be provided. I would like to give Jim and Rhonda a big thank you again for sharing their home and petting zoo with our families.

PNWASF is looking for an Oregon family to volunteer to organize a South End Picnic. The picnic can be held at a park or at your home. If you would prefer not to cook burgers and hotdogs we can also

supply deli sandwiches or another item that doesn't need to be cooked.

The picnics are a nice inexpensive opportunity for our families to get together and enjoy each other's company and exchange ideas. If you are interested in organizing this event call Robin Marx at 541-485-8518 or email her at miroberkel99@yahoo.com

Angel of the Quarter: Ashley Howard

Our angel turned 21 in 2009, her name is Ashley. Oh, we were so happy when she was born. We already had our little boy who was 18 months old when Ashley came into the world. Our first thoughts were wow we have two great kids who are close in age and will spend a lot of time together. Well this dream was shattered when Ashley **wasn't playing like babys do and didn't want anything** to do with her brother. So our journey began. What is wrong with our beautiful blond hair, blue eyed smiling little girl who wont even try to walk or talk? **She won't sleep** thrthrough out the night and she gags all the time, the list goes on and on. When Ashley was about **seven (she had already been in children's therapy** center doing physical and speech therapy from the age of 19 months and in school in special ED classes) we heard about this special diagnoses called ANGELMAN SYNDROME.

We frantically searched the internet and found a place in Florida that had some information along with a story of a girl who had Angelman Syndrome. **"OH MY GOD!"** Is all I could say when we received the information in the mail along with the picture and story of this young girl who had Angelman syndrome. I said this is our Ashley, she **looks just like this girl. Well our neurologist hadn't heard of Angelman's.** We gave him all the information we had and he looked up and found what he could. We did the blood test and she is not missing the 15th chromosome.

Well life went on and we did the best we could. We took her everywhere. Our best times were camping and going out in our boat. She loves the sand and the water, she even went on the inner tube behind the boat. She went river rafting and even floated with her dad through the rapids out of the boat! Life does not end with a diagnosis. We have a great circle of friends who have always accepted her for who she is.

Our life has been trying at times. She gives us challenges. She is a tough, strong willed girl and smart. She walks and has since she was 3 years old. She had scoliosis surgery when she was 15, I am not sure I could have gone through all that pain. At 16 she became unbearable to live with as she reverted back to what she had done when she was younger, keeping us up all night doing the messy things we all hate to clean up. She became very stubborn, she refused to do anything for me (she would do things for her dad), **she wouldn't sleep in her bed anymore,** she wanted to sleep in the hall by our bedroom door, she refused to get on the bus, or use the bathroom. The list goes on and on. My husband and son and I **had to make our biggest decision of our's and Ashley's life.** It was time to look for a place for Ashley to move to, a group home.

I looked into a few homes and did not like what a saw, but I kept calling looking for an all female home with young adults. This was not easy. Well I finally found the home we wanted to move her into. There was even a bed available so on my way home I called my husband and said I found the perfect home for Ashley. We made the call the next

day and the bed had been taken right after I left. I was crushed. But I did not give up, I called the owner back and told her I wanted to be put on a waiting list, this was in April 2007. I did not hear from her until June with news she had purchased another home and it was going to be ready by August.

August 1st came and we took Ashley there. It was the worst day of our lives, my **husband's and mine,** but poor Ashley was **devastated as of course she didn't understand what was going on. We couldn't see her for two weeks but we called all the time.** We needed to get her used to her new home. Ashley turned 18 on August 16th and that was the first time we saw her in her new home. We felt awful and had to keep telling ourselves it was best for Ashley. This was three years ago last August and it has been the best decision we could have made. Ashley adjusted to her new home and she has 6 other young women and a full time care giver during the week and another care giver on the week ends. She is volunteering, instead of working for pay, putting together survival kits.

Ashley and her roommates and the owner of the house went on a vacation last summer. They rented a house for a few days at the ocean. They had a great time. They went to see the Lion King play and Ashley loved it. They go to movies, shopping, they **have birthday party's for each other. They attended Ashley's graduation from her transition program** this past June, while her dad and I were out of town.

The best part is Ashley will come visit us at our home, she enjoys having a meal with us or watching a movie. Then after three hours or so she is ready to go back to her house. She is happy when she gets back to her home and is happy to see us leave and happy when we pick her up. Her new friends love her too. The owner of the house is a godsend. We are so lucky to have found her and to have Ashley live in one of her homes. We never thought our daughter would adjust to her new home and friends but she surprised us. She grew up.

Our blue eyed, blond hair, smiling, little girl has a good life with her friends in her home. They really care for her. She has her family who loves her to death and would do anything for her. We are so happy that she is having a real life on her own in her way.

We as parents want our children to grow up and be independent, be on their own and to be happy. We feel that we have accomplished this for Ashley and I hope you will try and do the same for your special angel some day.

The Howard family Cindi, Bob, Drew and Ashley (our angel.)



Ashley



The Pacific Northwest Angelman Syndrome Foundation

Business Address
12932 Kent-Kangley Rd. #375
Kent, WA 98031

Phone: 866-330-9256
Email: pnwasf@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

WE'RE ON THE WEB!
WWW.PNWASF.ORG

Be Not Afraid of Growing Slowly,
Be Afraid Only of Standing Still
Chinese Proverb

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

Article Submission

Deadlines

Winter: Jan 15

Spring: May 15

Summer/Fall: Sept. 15

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PNWASF Board of Directors