

## HEAVEN SENT

PACIFIC NORTHWEST ANGELMAN SYNDROME FOUNDATION  
12932 SE. KENT-KANGLEY RD. #375  
KENT, WA. 98031

### Newsletter Information

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

Sherri Rein  
26230 131st Pl SE  
Kent, WA 98030  
Or e-mail items to Sherri Rein at  
Reinfour@aol.com

*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.*

### Article Submission Deadlines

Winter December 15  
Spring April 15  
Summer/Fall August 15

PNWASF phone number

1-866-330-9256

### MY ANGEL

Angels come in many forms  
They do not choose the way they're born.  
Feelings circling them are torn.

I'm sure if they could talk they'd say  
They are happy to be made this way.  
For what their job on earth is for  
Is making the ones around them more.

To give them knowledge beautiful and rare,  
And help them understand why they care!

Our Angels are our special gift  
To give our lives a cheerful lift.  
We would not have them any other way  
The reason is they've changed our days.

Through thin and thick  
Through happiness and times of sick,  
We will be there for you  
I know my Angel, so will you.

We'll travel along a great many miles  
There will never be a lack of smiles.  
This is why we are together  
To make our lives a whole lot better.

Love Mum XXX

Paula de Been a totally devoted mum of

### Current Board Members of PNWASF

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Gloria DeRosa (360) 876-8342

PNWASF is currently seeking an editor for this newsletter. If you would be interested in learning more about this opportunity, please contact Sherri Rein at (253) 638-6241 or e-mail Reinfour@aol.com. We are also looking for articles about your Angel, including Angels of the Quarter. Please submit these to Reinfour@aol.com. Any help would be greatly appreciated.



# Heaven Sent

Pacific Northwest Angelman Syndrome Foundation Newsletter



Volume 13

Summer/Fall 2005

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### Southend Picnic is Here!

A south end barbeque will be held in Seaside, Oregon on Saturday, September 17 for all Angelman families and friends. It starts at 2:00 p.m. and will be held at Broadway Park, 1140 Broadway, right next to the Sunset Empire Swimming Pool. Families should bring their own drinks and a side dish or dessert to share. Hamburgers and hotdogs will be provided by PNWASF, and pies are being donated by the Pig n Pancake Restaurants.

The community swimming pool, right next to the park, has open swim from 5-8 p.m. that evening. The cost is \$2.50 per person. Any families that are interested in taking part in the open swim need to let Jennifer Cyrus so that she can make arrangements with the pool to have enough life guards on duty. If you have any questions regarding the barbeque, swimming, or to RSVP please contact Jennifer Cyrus at (541) 924-9875 or jjcyrus@earthlink.net. It is going to be a great time! We hope to see lots of families there, especially since our Oregon membership has increased substantially in the past year.

### Summer Fun For Angelman Families



Angel Tyler Thompson, age 17

There were two family events which took place this summer. The first was the Northend picnic held at Jim and Rhonda Wreggelsworth's house and the second was the annual weekend camping trip, which this year was held at Camp Easter Seals. Both events had a great turnout. It was wonderful to see some of our new families attend both events. Thank you to Jim and Rhonda for hosting the picnic, and to Corbin Thompson for arranging the weekend camp.



Angel Erich, age 11



### Coldwell Banker Bain and Agent Koreann Ashlie give back to the PNWASF through its Community Partnership Program

Coldwell Banker Bain has formed a unique partnership with PNWASF in an effort to help raise money for our organization.

Each time a PNWASF member, or friend or relative of a member, buys or sells real estate with Coldwell Banker Bain through sales agent Koreann Ashlie, she and Coldwell Banker Bain will donate an amount equal to 10% of the commission from the transaction to PNWASF.

For more information on the PNWASF Partnership with CBBain, please call Koreann Ashlie at (425) 241-3893 or visit her website at [www.koreannashlie.com](http://www.koreannashlie.com).



## Dave “Hendu” Henderson Midsummer Golf Classic Fundraiser A Huge Success

The weather was perfect for our annual golf fundraiser held July 28th at Avalon Golf Course in Burlington, Washington. We had approximately 100 golfers turn out for this event, which raised over \$6,400! Michael Powers provided everyone entertainment with his amazing music talents during the event. Mike Brown of KOMO Radio MC'd our raffle event. Our sincere appreciation goes out to Dave Henderson, as without him, this event would not take place.

We want to thank our hole sponsors, Davis Wright Tremaine, LLP and Superior Marine Service, Inc.

We also want to thank those who sponsored golf carts during this event: We're Outta Here Travel LLC, Branom Instrument Co., Sound Telecom, Chris Brook Construction, S&M Decking, Big Dog Paint Company, Czarnik Construction, Wal Mart, Jenell Thompson, Rob Wunder & Associates, DeRosa/Luna family for their angel daughter, Angela, Sid and Jean Cackette for their angel granddaughter Kim, Michelle Darrington, Tossey family for their angel daughter, Marla, Platts family for their angel daughter, Bridgitte, and Cyrus family for their angel son, Garrett.

Finally, we would like to thank those who made donations of cash or prizes for our raffle and giveaway bags: Dave Henderson, Koreann Ashlie of Coldwell Banker, Uncle Dave's Café in Port Orchard, WA, Allenmore Golf Course, Sherri and Jim Rein, Lory Tossey, Quinault Beach Resort & Casino, Shelburne Inn, Wildwaves Enchanted Village, Tacoma Rainiers Baseball Club, Ivar's/Kidd Valley, and Freddie's Club of Fife.

Of course this event would not be successful without our wonderful volunteers, so huge thank you's go to Dave Platts, Justin Platts, Erin Platts, Lory Tossey, Sherri Rein, Geri Quintanilla, Koreann Ashlie, Jon Hegge, and Gloria DeRosa. We look forward to an even better fundraiser next year!

### PNWASF members sound off on ASF Conference

It was hard for me to leave my family behind, but I chose to go alone. It was one of the best things I have ever done. The experience for me was very emotional; the first night I desperately wanted to come home. I think I cried through the entire JUST FOR MOMS class, it was like each one of them had felt just like I have felt at some point in the last 3.5 years and even though that was comforting, it was also overwhelming. I also realize that seeing some of the older Angels was difficult for me at first. However, I soon met 2 women from the East Coast and in no time at all felt like I had known them my entire life. I learned so much from the speakers and was blown away by Tim Freeman, the behavioral psychologist from Seattle. I think for me the biggest thing I took away with me was the fact that I do not feel alone anymore and even though I have support, I have come to realize there is nothing like another Angel family. ~Cassie Hall-Brooks, mom to Angel Kaleb

My very first experience at the Angelman Syndrome Conference was very worthwhile for me. I had written my Senior Thesis paper on Angelman Syndrome, and it was great to meet some of the medical and scientific people that I had quoted in my paper. I developed a greater understanding about what AS was about at the conference. I attended the Scientific Symposium and met with doctors and professionals in the field who gave me invaluable information for my current Master's thesis. The various workshops and programs were always informative and very interesting. The information I gathered was helpful for understanding and being able to help my niece. Meeting the Angels and their families was a wonderful experience for me. I thank the conference committees and volunteers who have worked so hard to make this conference so excellent and professional. I thoroughly enjoyed the lunches and dinners provided during the conference, too. It was a very relaxing but intensive conference. Thank you again. ~~ Akiko Erwin, Aunt to Angel Jade

My husband, who attended the conference with me wrote: *I enjoyed the experience of meeting all the people I possibly could in a week - volunteers (they were great to work with - I was one too!), presenters (awesome intelligence, professional accomplishments and dedication to a cause), and even employees of the hotel, cafes and Starbucks. No one can ever say enough about the caring and dedication of the parents and the siblings of the AS children and adults. The main and break-out sessions that I attended all were well-organized, on time, and professionally presented. And the information that was shared was very valuable for my further understanding of AS and its causes, methods of discovery and identification, treatment, rehab, family support, and health care needs. One of my special enjoyments was the interaction I had with some of the AS individuals directly and their responsiveness and demonstrated friendliness towards me personally. I was very emotionally touched by their happy and engaging mannerisms and smiling faces. ~Irwin Heckman*

## Angel of the Quarter



Jolena and I celebrated the arrival of little Johanna Rose on April 18, 2004. The first month was rough, as little Johanna was admitted to 2 hospitals for feeding issues and failure to thrive—the latter being complications of rotavirus. Once we were all finally home, we struggled to find a formula which seemed to minimize Johanna's reflux. Breastfeeding just wasn't working. She gained weight, but slowly and the GERD made it seem like “2 steps forward, 1 step back.”

I don't remember the exact day that we realized that we had the happiest baby there ever was. Such a blessing she is, all giggles and a high pain tolerance (!?), and does she like her bath times!

When Johanna turned a year old she was still under weight (although above average in length). She was barely sitting up and not even crawling, so we started asking ourselves those questions about “delay”, and “is there something wrong?”

A round of visits with our pediatrician and a pediatric neurologist ensued. I'll always remember the day our pediatrician reported that the neurologist had a suspicion of “happy puppet” or Angelman Syndrome, which he pronounced variously like Angelman or a germanic Engelmann. We were referred to a genetic counselor.

After that appointment I dove into the internet and searched on AS. It was amazing how many of the AS traits I found fitting our little girl, from reflux to strabismus, from flapping arms to happy demeanor.

Our first trip to the genetic counselor put us on a roller coaster since we were told that Johanna “didn't look like” she had AS. They suspected fragile X or something else; so they took some blood for a genetic screen and sent us home.

It was a few weeks later on Tuesday, June 28<sup>th</sup> when we got the final diagnosis that Johanna had “abnormal methylation status of maternal and paternal contribution to the PWS / AS critical region (15q11-q13). This is consistent with the diagnosis of Angelman Syndrome.”

What a relief to finally know! We realize that having a diagnosis so early is a gift which not all others receive. Now we are looking forward to meeting other AS families. Thank you PNWASF!

Signed,  
John, Jolena and Johanna Weisenfeld.



### List of cash contributors June 18 - September 5, 2005

#### Thank you to the following contributors:

##### Membership dues:

Cassie Hall and Chris Brooks  
Nuhad D. Dinno, MD  
Mike and Robin Marx  
Mike Ordal  
John & Jolena Weisenfeld

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