



Heaven Sent



Washington National

PNWASF Golf Tournament Huge Success!

Dave “Hendu” Henderson Mid-summer Golf Classic Fund-raiser is Deemed a Huge Success!

This year’s golf tournament ended up being the most successful since the tournament started 11 years ago. We had a full course, with 144 golfers, 8 hole sponsors and 76 golf cart sponsors. The event raised over \$17,000 for PNWASF!

Our sincerest appreciation and thank you goes out to Dave Henderson and Loni Henderson, as without them, this event would not take place. Thank you also to Mike Brown for another outstanding year as MC of the raffle and silent auction.

We want to thank our hole sponsors, Dynamic Computing Services, Keithly Electric Com-

pany, Jornada Roofing, Inc., Marianne Baty Pittard and Jeffrey Pittard, Oki Golf, Legacy Propane Tacoma LLC, J H Kelly Construction, and Heartland Mortgage.

We also want to thank those who sponsored golf carts or donated raffle/silent auction items during the tournament: Sound Telecom, Henry Tucker, Uncle Dave’s Café, Rein Family in honor of Tyler Thompson’s graduation, Summit Mortgage, Chris Brooks Construction, CKI Inc., The Garrett Cyrus Family, Ivar’s and Kidd Valley Restaurants, Shelburne Inn, Tacoma Rainiers, Sid and Jean Cackette, JM Corp & Son, We’re Outta Here Travel, Freddie’s Club of Fife, Target, Champs, Frito-Lay, Red Robin, Fred Meyer, Starbucks, Czarnik Construction, Glacier Lanes, The Lindsay Robertson Family, Jones Chiropractic Inc. PS, Miller Brewing

Company, Heartland Mortgage, S&M Decking, Bonefish Grill, Outback Steakhouse, John L. Scott (Maple Valley Office), Berthy Carson (John L. Scott realtor), The Bridgitte Platts Family, The Chase Henderson Family, Redbird Sports and the Angela DeRosa/Luna Family.

Of course the event would not be successful without our wonderful volunteers, so huge thank you’s go to Loni Henderson, Bob DeCamp, David Platts, Cindy Robertson, Jennifer Cyrus, Sherri Rein, Gloria DeRosa, Amber Gamber, Janis Harsila and Geri Quintanilla. We look forward to another successful event next year!

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Chase and Garret driving the golf cart



ASF MINI CONFERENCE/ADVOCATING FOR YOUR CHILD NO MATTER THEIR AGE!

Join us as we talk about:

- **Resources and where to begin**
- **Ways to join in the process of making those resources happen**
- **Becoming involved and creating solutions for your child**

The ASF is pleased to announce its fourth regional workshop on Saturday, October 20, 2007 at the Grace R. Moore Library in Tacoma, WA. This exciting workshop will feature Jackie Golden, ASF Resource Specialist, Parkville, MD, presenting: Advocating For Your Child No Matter Their Age! "But no one told me about that!" How many times have we heard these words from parents and family members of children and adults with Angelman Syndrome? It used to be that the information was hard to get, hard to find and hard to negotiate.

With the introduction of the internet, parent support and advocacy groups such as the ASF and the addition of a Resource Specialist to the ASF team you are no longer isolated and on your own. No one in your state will simply come up to you and say "Here are resources for your child!" The key to finding out about resources, information and new ideas is to become informed, become an ad-

vocate and talk to other parents that have walked in your shoes.

Join us as we talk about:

- Resources and where to begin
- Ways to join in the process of making those resources happen
- Becoming involved and creating solutions for your child

The Angelman Syndrome Foundation is proud to present this one-day workshop for your benefit. Utilize the knowledge and expertise of our esteemed invited workshop clinicians to offer a better and brighter future for your child and your family.

ASF one-day workshops will be offered in different geographic locations throughout the United States. All workshops will be offered on a limited time and geographic basis, so you are highly encouraged to register and attend as soon as possible. The ASF workshop program is part of a series of pilot projects approved by the ASF Board of Directors in July, 2006. Evaluation of the use and effec-

tiveness of the workshops is on an on-going basis and future need and scheduling of workshops will be determined by attendance at the workshops. Don't delay in helping your child and your family reach their greatest potential. Registration is now open for this workshop. Cost of the workshop is \$25/ASF member, \$30/non-member.

Location:

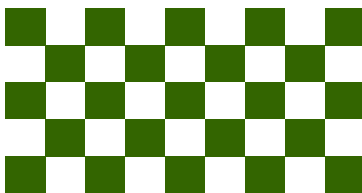
Grace R. Moore Library
215 South 56th Street
Tacoma, WA 98408
253-591-5666

Time: 10:30 a.m. - 5:00 p.m.

Please visit the ASF website to download the registration form PDF at www.angelman.org Click on mini workshops October 20 2007

Contact Sheila Wenger at swenger@angelman.org for more info.
1-800-432-6435

The PNWASF will be providing a pizza lunch for our members who attend.



Angel of the Quarter

Written by Danielle Covey

My brother Anthony is definitely an angel. He is 5 years old and the love of my family's life. He is an angel to us all the time. There are many things he is not capable of doing yet, but he makes up for it in the love he always gives us. He just graduated kindergarten, and will be in first grade next year at Monte Cristo Elementary in Granite Falls. Everyone knows Anthony at his school. You can only hear him coming a mile away!! He uses a walker

at school, and races down the hallways. He always has a smile and loves to socialize. We have 2 dogs and 2 cats and he loves to give them all big sloppy wet kisses! I am very proud of my brother and love to show him off. If we can't find Anthony, we always now to look in the bathroom....he is playing in the sink getting everything wet!!!! My brother is very busy and loves to take things apart. If I'm having a bad day,

all I have to do is look at Anthony and he gives me the biggest smile.... this will make anyone feel better. I learn more from him than he ever will from me. He is my hero. I love Anthony and feel very lucky to be in his family!!!

Danielle
Anthony Covey's big sister and #1 fan

Top to bottom: Anthony With his Dad, Dario; Mom, Denise and his "Sissy" Danielle



2007 Family Camping Weekend

A new camp was found this year for the South camping weekend. A big **Thank You** to the Cyrus family for all the arrangements they made to make the camp fun for everyone. Camp Talaoli is located just 16 miles east of Salem right off of Hwy 22. Once you drive down the long driveway it's hard to believe you're right off the highway with all the beautiful big trees and the Santiam river running in the back of the property.

The camp has 8 cabins, all heated with 4 bunk beds in each and cupboards to store your gear. There was also a couple of spaces to park a trailer or RV. A nice large main hall with picnic tables, a nice commercial kitchen and a huge fireplace for those rainy nights. Of course, the most popular activity at camp was the indoor swimming pool. Nobody wanted to leave. That is until it was time to eat! Jennifer Cyrus' parents,

Gary and Joyce, did an exceptional job as camp cooks. Meals were planned out perfect right down to the somores around the campfire. Rain did try to threaten us one night but the campfire kept the chill away. Next year camp will be back at Camp Prime Time but we hope to use Camp Talaoli again in 2009 when Family Camp Weekend is back down south.



Kenny showing everyone his magazine



Sitting around the campfire





*Historical Old
Courthouse &
Arch*



*The Pool at the Hyatt
Union Station St.
Louis*



*Raging Rivers Water
Park along the
Mississippi*



*Kelly and Erich at the
Hyatt Regency Union
Station*

ASF Biennial Conference 2007

The 10th Biennial Angelman Syndrome Foundation Conference was held in St. Louis Missouri on July 25 - 28. The general conference was preceded by the Scientific Symposium. Day one of the symposium featured 8 researchers from the US, Israel, Germany and Japan all of whom discussed "Mechanisms of Genetic Imprinting in the Angelman/Prader-Willi region. of the 15th chromosome". Day 2 was attended by researchers from Canada, the United Kingdom, The Netherlands and the US.

The General conference was filled with speakers conducting seminars on subjects such as Genetics 101, sleep issues, male puberty and gynecology. There were seminars on how to advocate for your

child in education and medical insurance. Assistive technology and physical fitness such as adaptive cycling and aquatics were very popular. As we all know siblings are a very important factor in the life of our Angels and there were some seminars which spoke to their concerns as well. There were so many subjects it was hard to choose what to sit in on. The Just for Sibs, Just for Dads and Just for Moms workshops were our family's favorite though.

As usual ASF scheduled some great activities for the kids. Thursday was a day to explore at the St. Louis Science Center where there was a special exhibit of life size animatronics dinosaurs. Friday was an optional

event to Raging Rivers Water Park along the Mississippi River in Grafton IL.

Saturday was a day trip to the beautiful St. Louis Zoo. It was very enjoyable seeing people we had met at previous conferences and meeting new people.

The next conference has yet to be scheduled but it will be on the east coast in 2009. The Canadian conference is being held in 2008 at Whistler, BC which may be an option to attend since it is relatively close .

Remember, PNWASF as well as ASF do have scholarships for those who would like to attend but feel they may not have the funds. It is well worth your and your family's while to attend.

2007 Angelman Syndrome Conference, Saint Louis A Sibling's Perspective: By Kelly Marx

This summer my family and I traveled to Saint Louis for the Angelman conference. During the conference, one of my parents went to seminars and the other went on the children's activities with us. On the first day, we went to the Saint Louis science center and on the second day, we went to

the Saint Louis Zoo. There was also a Just for Siblings seminar that I attended. During the seminar we talked about what it was like to have a sibling with Angelman Syndrome and we participated in activities to get to know each other better. It was nice to see all of my friends again

from the last conference. Also, having all the other Angels there made me feel very comfortable because I didn't have to worry about what my brother was doing. Overall, it was a very fulfilling experience and I enjoyed it.



North & South Picnics: Fun For All

NORTHEND

The North End picnic was held at Golden Gardens Park in Seattle, Washington on Sunday, July 8 from Noon to 4:00 PNWASF provided hot dogs and hamburgers, drinks, plates, silverware, and condiments. Thank you so much to Jennifer Hegge for organizing this event.



Golden Garden's Park in Seattle

SOUTHEND

The South End Summer Picnic/BBQ was held Saturday August 11th @ 3 p.m. at Shute Park Aquatic and Recreation Center 953 SE Maple St. in Hillsboro, Or. We met at the pool for swimming between 3:30 and 4:30 in the reserved indoor heated pool with a fountain. It was very nice having the whole pool to ourselves.

Next we moved over to the picnic shelter in the park. There was a live open mike for rock and roll bands happening that day which added some extra entertainment.

It was a beautiful day for a BBQ and John Cyrus did a great job grilling up the burgers and hot

dogs for everyone.

After lunch the adults got together and talked about family, AS issues and what everyone had done over the summer. The PNWASF would like to thank Cassie Hall for organizing the event and shopping for all the food the PNWASF provided.

Also a big Thank You! To Pig & Pancake for covering the costs for renting the pool and the shelter. The generosity of our volunteers and supporters is what makes this such a great organization.



The Irwin's enjoy their lunch at the South End Picnic



The heated pool at Shute Park South End Picnic



Kaleb needs more pasta!

Save The Date: 2008 Adult Retreat

The 2008 PNWASF annual business meeting and adult/parent retreat is scheduled for the weekend of March 7—9.

This year the retreat will be at the beautiful Elliot Hotel in downtown As-

toria Oregon. The cost per couple will be \$50 which needs to be paid to PNWASF

C/O Sherrie Rein
12932 Kent-Kangley Rd.
#375
Kent, WA 98031
Hope to see you there!



What to do in Astoria

- Visit the Astoria Column
- Visit the Columbia Maritime Museum
- Eat! Many great restaurants and Bars
- Visit Fort Clatsop which is the end of the Lewis and Clark Trail

**Pacific Northwest Angelman
Syndrome Foundation**

*12932 Kent-Kangley Rd. #375
Kent, WA 98031*

Newsletter Information
Please submit articles, pic-
tures, prose or angel tips
for the newsletter to:

WE'RE ON THE WEB
WWW.PNWASF.ORG

Robin Marx
91029 S. Miller St.
Coburg, OR 97408
Or email to Robin @
miroberkel99@yahoo.com

**Article Submission Dead-
lines**

Winter January 15
Spring May 15
Summer/Fall September 15

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