



Pacific Northwest Angelman Syndrome Foundation

Heaven Sent

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2008 Dave “Hendu” Henderson Midsummer Golf Classic

This year's golf tournament is going to be held on Monday July 28 with a shotgun start at 2:00PM. It will once again be held at the beautiful [Washington National Golf Club](#) home of the Washington Huskies. Entry fees include greens fees, cart and range balls. Awards ceremony, banquet dinner and great tee prizes. We are still looking for golfers, hole and cart sponsors as well as donations for our raffle and silent auction.

Our goal this year is to get a list of all the things that need to be done for this fund raising event and then start delegating more items. The more people that we can get involved and the more ideas we can generate the more chance we have to

make this the successful fund raiser it has been in the past. Spread the word about the tournament and the benefit PNWASF has been to your life. Let people know how important it is to have a support group such as our Foundation. Let them know how we have increased awareness about AS by sending out thousands of pamphlets to doctors in our region. We also hosted the National ASF Conference years ago and currently support the conference with donations to help families attend. We maintain a current website and provide opportunities for regional families to exchange information, concerns and strategies related to life with AS families.

If you have any question regarding sponsorship please contact Bob Decamp at 360-957-0232. For questions regarding registration, volunteering for or participating in the tournament contact Sherri Rein at 253-638-6241 or email at Reinfour@aol.com. You may also find links to our golf brochure and sponsor packet under the current events section of our website at www.pnwasf.org



18th Green at Washington National

Spread The Word
About The
Tournament And
The Benefit
PNWASF Has
Been To
Your Life.

Camp Prime Time

The PNWASF Family camp will be held at Camp Prime Time this year on August 8 though the 10th. The camp is located near Clear Lake on Road 744 in the Wenatchee National Forest east of White Pass in Washington.

Bring sleeping bags or blankets (each cabin has bunks), pillows, toiletries, towels, bug spray, sunscreen, medications, flashlights, and anything else you may need. Arrival time is

any time after 3pm on Friday and departure is 1pm Sunday afternoon. Space is available on a first-come, first-serve basis. If your family is interested in



Campfire at Camp Prime Time

attending please RSVP by July 7th by sending in your payment. The fee per family is only \$20 payable to PNWASF

12932 SE Kent-Kangley Rd #375 Kent, WA 98031 Scholarships are available to those families who need help with the fee.

For more information on the camp call Corbin Thompson at (253) 474-4865 or cell (253) 459-4725. Payment questions can be sent to Sherri Rein 253-638-6241



Camp Prime Time Provides:

- Lodge with a kitchen facility
- Sleeping cabins
- Accessible, clean bathing, and showering restrooms
- Electricity
- Telephone
- Hot water

A comfortable and accessible, yet rustic, environment

2008 Adult Retreat and Business Meeting

The Business meeting and Adult Retreat was held at the Hotel Elliot in Astoria this year. It was great getting together again, catching up on what everyone was doing and enjoying this great little town.

Three new directors were installed at the meeting. They are Elizabeth Beeghley from Portland Oregon, Cassie Brooks from Forest Grove Oregon and

Corbin Thompson from Tacoma Washington .

One of our co-presidents, John Cyrus was promoted to a new position in the company he works for and has been relocated to Florida. John resigned as President but Jennifer is staying on as president and maintaining the PNWASF website. Our Board of Directors is all volunteer so we want to thank

John for putting in his precious time along with

Jennifer and all of the other members of the board. We appreciate the time you give.

The next AS Biennial Conference will be held in Orlando FL in 2009. PNWASF will be offering 3 - \$3000 scholarships. There will be more info as the date gets closer.

Summer Family Picnics

This year's North End family picnic will be held at Willis Tucker Community Park in Snohomish on July 26th from noon till 4 pm. The address is 6705 Puget Park Drive, Snohomish WA. This is a new park and we have a shelter real close to the play park and bathrooms plus there are lots of good walking trails.

If your last name begins

with A-M bring a side dish, N-Z bring a dessert along with drinks for your family. The Foundation will be providing a burger and hot dog BBQ. For more info please call Jennifer Hegge at 206-782-5691

The South End picnic has yet to be decided but it may be in the Lane or Linn County area. If you have a suggestion please call Robin

Marx at 541-485-8518.



Park Shelter at Willis Tucker Community Park

CASS Scholarships Awarded

The 9th International Canadian Angelman Syndrome Society Conference will be held this year in Whistler BC on July 23 -26 at the beautiful Hilton Whistler Resort and Spa.

The Platts Family and the Dunn Family have both applied for and received \$2000 scholarships from the PNWASF to attend the conference.

This year's conference theme is entitled "Making Connections". It is a special opportunity to renew old friendships, meet new friends, and benefit from the presentations of a truly remarkable slate of speakers chosen carefully by the directors of

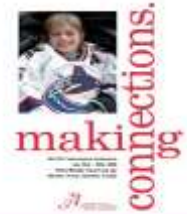
CASS for their expertise, experience, and insight. The day will consist of split-day conference experiences that give everyone in attendance the opportunity to learn, yet also to have fun and relax. So, once again **at this conference, speakers' sessions will end, for the most part, at 1:00 pm.** After that – you and your families will have the Afternoons open to socialize with other AS families. We AS parents learn a GREAT deal from each

Other and that's important too. This will all happen at a great family-friendly relaxation-oriented

venue.

For further information check the CASS 2008 Conference website at <http://www.angelmancanada.org/index.html> or Charles McNiel, Conference Coordinator at (514)636-4603 or via email to Charles@AngelmanCanada.org

Congratulations Platts and Dunn Families!



A "Long Shot" Pays Off

Grandmother's Alzheimer's leads scientist to a major breakthrough in Angelman Syndrome

By Elizabeth McBreen from Spectrum Magazine

As a research scientist, Edwin Weeber, Ph.D., never thought he would be in a position to receive fan mail. Weeber, who is currently an Associate Professor at the University of Southern Florida (USF), has spent his graduate and post-graduate career conducting research on Angelman syndrome (AS). After 10 years of research and testing, he has discovered how to reverse the deficits of the disorder in mice.

Weeber started out as a graduate student studying microbiology at Baylor College of Medicine in Texas. Because his grandmother was suffering from Alzheimer's at the time, he was drawn to research of the brain, specifically learning and cognitive ability. Weeber began working with David Sweatt, Ph.D., who was conducting cognitive studies in his lab. While working in Sweatt's lab, Weeber became particularly interested in the hippocampus, a part of the brain that plays a role in memory. Down the hall from Sweatt's lab, another researcher was studying AS in mice models.

"Angelman syndrome is a maternal imprinted disorder and there are no expressions of it in some parts of the brain – one of these is the hippocampus. So instead of studying random things in the hippocampus, I decided

to study Angelman syndrome," says Weeber.

The deletion or mutation of the mother's gene causes AS," says Weeber. Interested in the biomedical aspects of the disorder, he began studying enzymes and proteins in the brain that work with this gene. Weeber would make his groundbreaking discovery while working in his own lab at Vanderbilt University.

As he worked with his mice models from Baylor, Weeber discovered that he could reverse the effects of AS by regulating a particular enzyme, CaMKII. CaMKII is "an enzyme that is essential for learning and memory, as well as normal motor learning. We found that one of the biological abnormalities in AS mice was reduced CaMKII activity. It was known that reduced CaMKII activity results in neurological deficits. Thus, we concluded that regulating CaMKII in the mice may reverse their neurological deficits," says Weeber. When Weeber tested his theory by crossing mice with AS and mice with a mutation that caused them to retain their CaMKII activity, the resulting offspring had no AS symptoms. The seizure activity, mental retardation and problems with motor coordination all disappeared in the mice models. These results caused

Weeber to conclude that the deletion or mutation of the maternal part of the UBE3A gene caused reduced CaMKII activity, resulting in AS. Weeber says that when the activity of CaMKII enzyme is regulated, the deletion of the maternal part of the UBE3A gene is corrected. He adds that this enzyme is not produced until after the mice are born. This may also be the case in humans.

Weeber says that this conclusion is an important when it comes to the treatment of AS. "This suggests that AS is not developmental in nature, but rather biochemical. In other words, the brain appears to be wired correctly, but the change in CaMKII activity prevents the proper communication between the neurons in the areas of the brain where maternal UBE3A imprinting occurs." While Weeber's discovery has many positive implications for AS patients, it could also be good news for people with autism. He says that while AS patients and autistic people look very different, there are genetic similarities. "Future research may in fact find a relationship between changes in UBE3A and autism," says Weeber. Other disorders having to do with cognitive function may also benefit from his research.



Edwin Weeber,
Ph.D.

Read the full article about Dr. Weeber's research at [Spectrum publications.com/](http://Spectrumpublications.com/) A Long Shot Pays Off

Pacific Northwest
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Foundation

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We're On The Web!

www.pnwASF.org

Although families are encouraged to share their experiences, it is the Policy of the PWASF not to support or endorse any particular treatment, therapy or medication.

*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 January 15
Spring May 15
Summer/Fall
September 15

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