

ANGELMAN

Pacific NW Angelman Syndrome Foundation



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Are your annual dues paid???

<http://www.pnwasf.org/html/documents/MEMBERSHIPFORM.pdf>

ASF Biennial Conference Recorded Sessions

Did you know that all the recorded sessions from the Conference are available for purchase? You can purchase all or ala carte from \$10 to \$149. See link below to order online.

<http://www.intelliquestmedia.com/store/search.php?a=E&c=201515>

ASF Biennial AS Conference

The 2015 Angelman Syndrome Foundation (ASF) Biennial Conference was held July 15-17, 2015 in Illinois. PNWASF supported our members and their families by offering a scholarship to assist with the cost of attending the AS Conference. This year's recipients were Sheila McCartan and Tom Schooley. Please read the following review from their experience.

In July, we had the great opportunity to attend the bi-annual Angelman Syndrome Foundation Conference in Schaumburg, Illinois thanks to the generous financial support of the PNWASF. This conference was our first and it not only exceeded our expectations, but it provided new energy, ideas, and purpose for parenting our son, Arthur. These national conferences are open to families and many people bring their entire family and even care givers. We chose to leave Arthur at home so both of us were able to attend sessions and focus on learning and networking.

Like most conferences, there were general sessions for all attendees and a large menu of breakout sessions to choose from. The presenters of the general sessions were national experts at the forefront of AS research and work. Topics ranged from progress in gene therapy to current research on communication, epilepsy, and AS into adulthood. All of the general sessions were eye opening and inspirational. Learning about the many aspects of research being conducted gave us hope for the future, not only for Arthur, but all individuals with AS.

We each chose different breakout sessions which really maximized our time. The sessions varied from very personal sessions like "Just for Fathers", to broader topics like "Genetics 101", and "Using Augmentative and Adaptive Communication". Each session provided a wealth of information and ideas. The presenters were all professionals in their field and many were parents of individuals with AS.

The most inspiring sessions were those on communication. Erin Sheldon's presentations on communication covered the practical aspects such as what individuals with AS may actually see, and enlightening perspectives on what communication means and just how difficult it is to learn how to convey our thoughts to others. We came away empowered to try new things and to not give up. When the PNWASF announced that Ms. Sheldon would present AAC in a very hands-on workshop, the Family Literacy Camp, in Stayton, Oregon we knew we had to go. We now have word boards all over the house and are modeling all the time. Arthur often enough surprises us by pointing at appropriate symbols proving that this system can work. The combination of these two wonderful opportunities, the conference and workshop, could not have come at a better time and provided some very much needed direction and help.

Throughout the 3-day conference, we took time to talk with other families. We met people from other countries including Argentina, Japan, Canada, Mexico, and Norway. Getting to know these families opened our eyes to the global scope of AS. These families, just like we here in the US, have the same challenges. It was interesting to hear about the services and support others have. One thing that really struck us was the unique situation we have in the NW with our very own PNWASF. So many people said they had no contact with other AS families; the national conference was really it for them. We feel so fortunate to have such a great local network that provides fantastic opportunities for us. So thank you PNWASF for giving us this great opportunity and for all you do to support families in the Pacific North West.

Camp Taloali –Angelman Family Literacy Camp

The colors of the rainbow and Augmentative Alternative Communication (AAC) spread across Camp Taloali in Stayton, Oregon this last August. The PNWASF's Angelman Family Literacy Camp was organized by board member Noel Zeedyk. The camp consisted three day's of literacy workshops that hosted all ages of individuals with Angelman syndrome (AS), their families and caregivers. The workshops were lead by Erin Sheldon PhD, a worldwide speaker and publisher in the art of literacy and communication for our children with Angelman syndrome. She is also a fellow parent of a child with AS. She presented a variety of topics to assist with the integration of emergent literacy techniques and the use of modeling using AAC of all types. Personalized books were made for each individual to take home and specially catered one-on-one sessions were available to the campers as well.

Dr. Sam Sennott who manages the Universal Design Laboratory (uLab) at Portland State University presented during the workshops his newest interactive project called the Inclusive Shared Storybook Reading Project. He is also know for co-developing the highly successful AAC application, Proloquo2Go. Four students accompanied him from the Portland State University Special Education Program. The students interacted and modeled with our Angel campers using AAC during the weekend. You could find Erin, Sam and his students working side by side with our Angels all weekend.

There were private cabins that the campers, their family and caregivers lodged in as well as RV and tent spaces. A camp cook kept everyone fed three times a day. Over the weekend the campers enjoyed a musical number with sing-a-long songs, trips to the swimming pool and a variety of craft projects. This camp proved that literacy and communication is for everyone!



Camp Taloali Sibling Rivalry!

The sibling campers of the Camp Taloali— Angelman Family Literacy Camp were not left out on this adventure. Some special older siblings including Board Member, Kimberly Adam, organized fun events while their siblings and parents attended the workshops. There was some serious competition amongst this group! Special craft projects and fun activities helped build a bond with this special group and created memories to last a lifetime.



Dave "Hendu" Henderson Mid-Summer Golf Classic

It was a beautiful day for this year's golf classic held at [Washington National Golf Club](#) this last July. Dave "Hendu" Henderson and family again helped the PNWASF with this event by raising awareness and the funds used for the activities, workshops and scholarships we offer for our members. Dave "Hendu" Henderson is a former Major League Baseball player who played for the Seattle Mariners from 1981 to 1986, Boston Red Sox from 1986 to 1987, San Francisco Giants in 1987, Oakland Athletics from 1988 to 1993 and Kansas City Royals in 1994. He helped his teams reach the World Series four times during his career, winning in 1989 with Oakland sweeping the San Francisco Giants.

The format was a four person scramble, shotgun start with many other events like an awards banquet, tee prizes, challenge "Hendu" to a driving contest, and mulligans. There were many desirable items that were auctioned off during the banquet and a few lucky attendees took home a raffle basket. We had a few Angels who attended the event and helped cheer on the golfers! Thank you to Tim and Jeanne Adam and to all the volunteers that helped make this fundraising event a success. Your dedication is appreciated!



Volunteers Needed for Fundraising Committee

Do you know someone who would be interested in volunteering their time to join the PNWASF Fundraising Committee? Please contact the Fundraising Committee Coordinator Robin Marx at rm Marx10@gmail.com if you are interested or would like additional details.



Summer in the Pacific North West

This summer the South Washington Picnic and Family Swim Day was held again in August at the Stewart Heights Pool. Many families came out and enjoyed the warmer days of summer while eating lunch provided by PNWASF by the poolside. Thanks go out again to Corbin for organizing this event!

The 2016 ASF Walk has been announced for the Washington location on May 21st. It will be held again at Jefferson Park in Seattle. See Facebook event link for details.

<https://www.facebook.com/events/1031681480204921/>



2016 Adult Retreat and Business Meeting

PNWASF is now taking reservations for two nights lodging for the 2016 Adult Retreat located at the Shelburne Inn in Seaview, WA. The dates are March 4th—6th with a total cost of \$90 for the weekend. The foundation's business meeting will be held on Saturday morning and is open for all members that want to attend.

Come join your fellow members in an adult only environment! Please mail your deposit and membership dues to our secretary, Robin Marx, at 91029 South Miller Street, Coburg, OR 97408. Checks payable to PNWASF (link to membership form is located on the first page). Space is limited so don't delay!

<http://www.theshelburneinn.com/>



Foundation for Angelman Syndrome Therapeutics (FAST) - 2015 Global Summit on Angelman Syndrome

Couldn't make the trip to Chicago, IL this year to attend? You can view the scientific panels and presentations online.

Click the link below.

<https://www.youtube.com/user/cureangelman>

Community Grants Program

Would you like to plan a workshop, start a fundraiser, develop an advocacy project or create informational materials? Whatever your idea, a community grant may be just what you need to make it happen! The PNWASF Board of Directors knows that parents, siblings, doctors, teachers and others all have great ideas for how to make a difference within the AS Community. The Board wants to fund the best of these ideas!

At this time, grant applications will be limited to a maximum of \$1,500. However, the Board will review all applications in order to provide feedback. This will allow an application to be resubmitted at a later date. We ask that you submit an application that will support multiple families or the community at large. Applications that address great needs and provide large impact will be the ones most likely to receive support. If you have a large scale idea (requiring more than \$1,500), we suggest identifying additional sources of funding.

You can apply online by clicking the Community Grants link on www.pnwasf.org

https://docs.google.com/forms/d/1qSoWkvLfcuIMWiCN14cM_QimBJY2YAGLu-DtcnAEsBM/viewform



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Fred Meyer Rewards Card & Amazon Smile

You can now register your existing or new rewards card with Fred Meyer's Charity Program. You can help raise funds when you shop this holiday season by registering your card with PNWASF's id# **93849**. Go to www.fredmeyer.com, click the Rewards tab to locate the Community Rewards in the drop down, link your card using the above id#.

You can also support PNWASF by registering the foundation with Smile.Amazon.com and they will make a donation from your purchases <https://smile.amazon.com/>

Board Members

President: Justin Platts **Vice President:** Jeannie Adam **Treasurer:** Sherri Rein
Secretary: Robin Marx
Board Chairs: Geri Quintanilla, Gloria DeRosa, Kim Adam, Noel Zeedyk, Penny Ahart Rhonda Kirtland, & Sarah Webb

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.

PNWASF

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