

Angel Spotlight

Poppy Annelies Newell

Miss Poppy has been the life of the party since her birth three years ago! She came racing into this world and has yet to slow down. Poppy lives in Stayton, Oregon with her parents, two older sisters that she completely adores (13 year old Brialyn and 8 year old Ainsley), and a menagerie of pets (she loves to torment). She has been an avid lover of water, smiling, eating everything (especially things not edible), socializing, and giving loves since the day she entered this world. Her smile quickly lights up a room and draws everyone to her. She easily makes friends and fans of those she meets. Her favorite activities include swinging in her hammock, riding horses, crawling through tunnels, and snuggling. Just after her third birthday, she added walking independently to her resume of talents. She continues to amaze and teach us every day!



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Are your annual dues paid???

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

Community Grants Program

The Pacific Northwest Angelman Syndrome Foundation Board of Directors is thrilled to announce the PNWASF Community Grants Program. We know that we cannot support every area of need throughout Washington, Oregon and Alaska ourselves. However, we know that we can work with you to enable successful events and programs throughout the region. The creation of the Community Grants program came about starting with the simple idea of giving the community the tools necessary to make a difference.

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!

The first batch of grants will be reviewed by members of the Board of Directors in March 2015. 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.

We cannot wait to see what ideas you come up with! We know that you're eager to make a difference for our Angels and their families. We invite you to take the first step towards that today. You can now apply online by clicking the Community Grants link on www.pnwasf.org

Sincerely,
Justin Platts

President, Board of Directors



Washington Picnic 2014

The annual Washington picnic was held again this year at the Stewart Heights Pool in Tacoma. Cold sandwiches, drinks, side dishes and fun were had for many families that attended.

A thank you goes out to Corbin for organizing the gathering.

Oregon Picnic 2014

It was another hot one for the Oregon picnic. We still had a few families and caregivers come including one new family, The Newell's from Stayton. The Newell's along with The Kirtland's from St. Helens, The Zeedyk's from Eugene and the Marx's from Coburg all gathered by the river at Island Park in Springfield. PNWASF provided a great sandwich buffet with drinks and the families brought side dishes to share. It was great seeing everyone and getting to know each other a little better.



Camp Prime Time

September brought great weather for the campers and their families in Washington this year at Camp Prime Time. All meals were cooked and served to the families by the generous volunteers at the camp. This year the campers were able to enjoy a campfire while parents, family and caregivers enjoyed each other's company. A fantastic day on the lake brought many smiles to the faces. Some explored the tree house while others relaxed in their cabins. This camp is only available to our group every other year so be sure to mark your calendar for the summer of 2016.



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Dave "Hendu" Henderson Mid-Summer Golf Classic

With the effort of many volunteers and the special partnership of PNWASF members, Jeannie and Tim Adam, the 2014 Mid-Summer Golf Classic this last July at the beautiful Washington National Golf Club was a huge success. This is our only fundraiser for the year and supports all functions of the foundation. We had great weather, great golfers, a top notch silent auction and many Angels to fill the day with fun.

A huge thank you to all that participated!

Great Wolf Lodge

All available rooms have already been reserved for the upcoming GWL trip this December 13th with fellow PNWASF members and their families. This year the event will be held in the winter when we all could use some warmth.

Always a PNWASF favorite! Be sure to look for the 2015 date in the near future.



ASF Invests \$1.5 Million to Open 17 AS Clinics in the US

The ASF has strategically identified locations that are within a four hour driving distance for more than 85% of the AS population in the US. Seattle has been determined as one of the 17 potential locations for a clinic. The purpose of the clinics is to provide AS individuals a medical and psychosocial resource from birth to adulthood, access to clinical geneticists, neurologist, psychiatrist, psychologists, speech language pathologists, physical & occupational therapists, genetic counselors, social workers and nutritionists all in one location. To learn more and to read further about the two existing clinics visit:

<http://www.angelman.org/about/angelman-syndrome-clinics/>

Complex Communication Workshop held in Vancouver, WA

Saturday August 2nd we were able to host a one day workshop with Mary-Louise Bertram here in the beautiful Pacific Northwest. Mary-Louise tackled topics such as literacy, inclusion and "It's never too late.." in our children with Angelman Syndrome. The day was packed full of information for our parents ranging from tips during the IEP process, how to get a literacy assessment implemented in our child's educational plan, 1:1 help programming our children's communication device as well as peer support from other parents and members of the PNWASF. It was a wonderful time of fellowship and we all walked away encouraged and with a renewed direction and some new tools for success. Mary-Louise was impressed with our group and is looking forward to coming back again soon. Stay tuned for our next workshop happening in 2015!



PODD book photo courtesy of novita.org.au

Biennial AS Conference — Chicago, July 15 - 17, 2015

The 2015 Angelman Syndrome Foundation Biennial Conference will feature **FREE REGISTRATION** as part of the ASF's dedication to supporting individuals with AS and their families.

2015 Biennial Conference Highlights

Face-to-face, personal interaction with other families who are dealing with the same issues you face every day, including families who have traveled this road before you and can share their experiences and expertise.

- Medical issues in adults and children
- The latest in research, clinical trials and therapeutics
- Hands-on workshops, including financial planning assistance workshop
- Developmental techniques and day-to-day best practices
- Beneficial resources

2015 Adult Retreat

Save the date! 2nd weekend of March 2015 in Vancouver, WA

PNWASF

12932 Kent-Kangley Road, #375
Kent, WA 98031

Contact Us

PNWASF

12932 Kent-Kangley
Road, #375
Kent, WA 98031

Visit us on the web at

www.pnwASF.org

General Information:

pnwasf@pnwasf.org

Newsletter/Submissions/
Mailing List:

pnwasf.news@gmail.com

Find us on [Facebook](#)

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.

PLACE
STAMP
HERE