



Heaven Sent



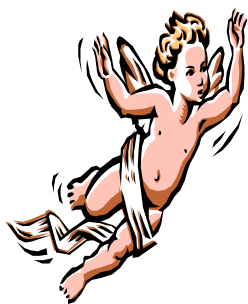
Pacific Northwest Angelman Syndrome Foundation Newsletter

Volume 11

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PNWASF Christmas Toy Giveaway



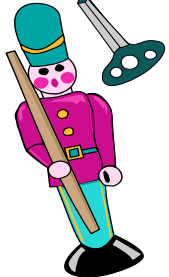
On December 18th, PNWASF parents can shop for 2 to 3 gifts for each of their children, free of charge. This unique giveaway is sponsored by Starbucks, in care of Starlight Foundation of Washington State.



Corbin Thompson will host this event, which will be held at Sedona Village Office Building in Tacoma, Washington between the hours of 11:00 am and 4:00 pm. Punch and cookies will be available while you shop. Directions are provided on the last page of this newsletter.

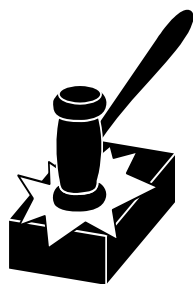


If you have questions or want more information, please call Corbin at (253) 474-4865. On the day of the event, you can reach Corbin at (253) 241-9975 or (253) 474-4865.



We want to thank Gail Loveland of the Starlight Foundation for coordinating this, and to all Washington State Starbucks for making our Angels' Christmas Season a little brighter.

Nominations for PNWASF Board Positions



The nominating committee is currently seeking nominations for three board positions for PNWASF. Elections will take place at our annual retreat on March 5th, 2005 (see retreat information on page 4 of this newsletter). The board positions are for a three year term (March, 2005—February 2008). PNWASF relies on its board members for many of the day to day decision making, as well as for fundraising activities. If you would like more information on these positions or would like to be nominated, please contact David Platts at (253) 639-1643.

KEN CAN!

By Sandy Silveria

Years ago we started wondering what Ken would do after he graduated from high school. I've been lucky enough to work in the field of developmental disabilities so I had a chance to observe how many families handled this. Unfortunately what I saw for kids as developmentally delayed as our Angels is that they don't do much. There is often funding (called transition funding) for young adults as they exit high school, to help develop jobs and do training. The Department of Vocational Rehabilitation (DVR) has funding to start this process, but your son or daughter has to have the promise of "long term support" from the state/county to benefit from DVR services. Most of our children will need "long term support". What that means is a job coach to help support them on the job – and for some individuals that means one on one for a long long time (maybe forever!)



Ken Silveria in his uniform, ready to start his job delivering bagels!

What we have done for Ken is a solution, but not an easy one. In school we all found that what Ken liked best was people. The job support specialist there started him a couple years ago delivering bagels to a couple schools and work sites. He would go with his aide, on the school bus, at a certain time each day and pick up orders at the local bagel shop. People wanting to place orders did so by faxing their order to the shop each day. He had specific sites each day and all this could be accomplished in just under an hour and a half – or less. A lot of people worked on this to make it happen – mostly the job support specialist. When we realized that this was something that Ken could do (with support) and something that he liked, we decided to start him a business – KEN CAN! We did all the paper work and got all the appropriate licenses. We couldn't do much before school was out because it was going to be a whole different operation.

It is slowly getting off the ground. We hired a young woman to help Ken. She picks him up, calls in to the restaurants to see if there are any deliveries and helps him to deliver the lunches and pick up the money. It was more complicated than I ever thought it would be. We need to have relationships with the food providers, agreements how this is going to work, etc. We need to have customers and figure out a way to have them order, and get the food to them on time. Ken had to hire a marketing person for a couple months to figure this all out and develop all the written information. We also had to hire someone to do the payroll and file all the required reports. And honestly, the amount he has made this summer had nowhere near paid all these expenses. BUT – I know this is going to work. All businesses take time. We have been lucky that we had put some money away for Ken. We are lucky that my job is flexible enough to help out with all of this. We have also been very lucky to find people to hire that believed in this and are giving us great deals and awesome support.

This isn't for everyone, but everyone needs to be thinking of what his or her son or daughter will do after school. Employment and day program services are not entitlements. Even though it is good to get out of the school environment, the adult world is no picnic either. Talk to your child's case manager. Let them know that you want employment services and residential services and ways for your child to recreate in the community. Asking for these services does not mean that you are going to get them. But when we ask it sends a message to the government that those services are needed. Talk to people, attend workshops and lectures, and ask questions. Don't wait until the last minute. Your child's future depends on your knowledge of the system and how to navigate through it.

Please contact Sandy Silveria at (360) 892-9552 or e-mail JustSandy00@aol.com if you have any questions or comments on this article.



Summer Picnic Brings Smiles for Everyone



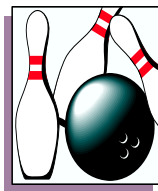
Our annual summer picnic was held on September 11th at the home of Rhonda and Jim Wregglesworth up in Stanwood, Washington. Luckily the weather co-

operated, and we enjoyed a great day. The Wregglesworth's opened up their new home to approximately 60 people. The kids enjoyed seeing all their farm animals, as well as riding horses and being pulled around in a cart lead by a llama. There were many smiles (and a couple tears), and everyone enjoyed great food and conversation, as well as getting to know the many families who attended this event.

We want to thank Rhonda and Jim for hosting this event, as well as their friends and relatives who helped serve up hamburgers and hot dogs. We all had a fantastic time, as you can see from the pictures!

OREGON BOWLING FUN

Thanks to Meagan Watts and Jennifer Cyrus for planning a family bowling event on November 28th at Town and Country Lanes in Keizer, Oregon. Although the turnout was small, the families who attended had a great time. We hope that there will be more activities planned in the future for families who live in Oregon or the southern portion of Washington. If you have an event you would like to host for PNWASF families, please let us know. We'd be happy to help with the planning.



MOM'S NIGHT OUT

The next Mom's Night Out is scheduled for Tuesday, December 14th at 7:00 p.m. at Olive Garden at Northgate Mall. The address is 300 N.E. Northgate Way. Take some time out of the busy Holiday season, and enjoy some great company and conversation! Please contact Lory Tossey at (206) 524-8078 or e-mail her at lorytossey@earthlink.net if you plan to attend, so she knows how many are coming.

Angel Tips/Tidbits

Did you know that most public places that charge admission offer special prices for the caregiver (parent) of a child or adult with a disability? Some examples are Enchanted Village/Wild Waves, Woodland Park Zoo and Sea World. Be sure to ask for these discounts when attending with your Angel.

Mark your calendars — the 2005 National Angelman Syndrome Foundation conference will be held in Anaheim, California at the Hyatt Regency Orange County in Garden Grove. Families from Washington and Oregon are already making plans to attend this conference. For more information, call ASF at 1-800-432-6435 or check out their website at Angelman.org.

Enclosed with this newsletter is the updated PNWASF Directory. If your name is not in the directory, it is because you did not give permission to do so. If you would like to be included in the next directory, please feel free to send us your information. You can mail it to PNWASF, 12932 SE Kent-Kangley Rd., #375, Kent, WA 98031 or e-mail the information to Reinfour@aol.com.

Adult Annual Retreat Coming Soon!



The annual adult retreat has been scheduled! It will be held March 4th - 6th at the Quinault Beach Resort and Casino in Ocean

Shores, Washington. We have reserved 18 rooms, which can be reserved on a first come-first served basis by Angelman families. To reserve your spot, please call Sherri Rein at (253) 638-6241 or e-mail your request to Reinfour@aol.com. Reservations must be made by February 4, 2005. After that date, reservations will be subject to availability by the resort. A donation in the amount of \$75 is requested from each family attending the retreat. PNWASF has reserved a meeting room for Saturday, starting at 11:30 a.m. for our annual membership meeting. Lunch will be provided. All other meals are the responsibility of each family.

If you have not been to this event before, it is usually attended by 12 to 16 families (adults only), and it is a great time to get to know each other or renew old friendships. Feel free to bring current pictures of your family to share. Other than the membership meeting on Saturday, there are no specific activities planned.

Check in time is 4:00 p.m. on Friday, March 4th. If you want to get more information on the resort, their website is www.quinaultbeachresort.com. You can get directions on their website or call the resort at 1-888-461-2214.



Angel of the Quarter

By Dean Barrus

Jessica Barrus is our Angel of the Quarter. She is a deletion positive young lady, and is the joy of our lives. She is the fourth of our five children. She was diagnosed very early through the work done at Oregon Health Science Center. Through her early years she had re-occurring seizures that have now been controlled with Clorazepate medication. She is now 16 years old and has not suffered a major seizure for several years. She is able to attend her special education school and summer programs which give her activities to do and social experiences that she enjoys. Jessica's normal day is spent in school; then she returns home to wander in the yard or channel surf on the TV. She knows which buttons to push and surfs until she finds an action movie or a cute guy actor. She thinks it's funny when there are "fights" in action movies. She laughs and laughs until we are all laughing. She also enjoys wandering outside when we are out working in the yard. We live on 5 acres so she can wander all she wants without too much concern. When we go somewhere, everyone within her sight has to come also. We call this her "shepard collie" routine because she herds us all together and does not want anyone left out.

Like many angels, Jessica loves to eat! Especially cheese, fruit, and some sweets. She does not enjoy meat very much and she is very aware of what she wants and does not want at the dinner table. She will let us know, in her own way what she wants, and keeps fussing until we give in or put it out of sight. She is a little overweight or "fluffy" as we call it. She needs more exercise for the amounts of food she eats but complains when she has to walk too far. We try very hard not to give her too much food but her smiles make it difficult to say no. She has difficulty sleeping and we give her "over the counter" diphenhydromine which helps her get to sleep. She sleeps in a bed that we modified to act like a large crib. She needs to wear diapers but is "letting us know" when she needs to have a bowel movement. We walk her to the bathroom and most times she is succeeding at her task.

Jessica continues to learn at her own pace. We often comment that she seems to understand more than we think she can. She is forever happy with a very sweet disposition. Even when she is sick she will try to smile. She has taught all of our family much more than any spoken word could. Her care is sometimes difficult, and has certainly required sacrifice and patience from all of us, but it is because of that same sacrifice and Jessica's loving ways that our family is very close. We all love her very much. As my wife and I get older, we have more and more concerns over Jessica's care when we are not able to provide it. We are also concerned over the quality of her life when "school" is over and she does not have that social interaction every day. We are considering creating a "home" for two or three other angel kids and sharing the cost of this care with the other families. This would take a lot of planning for the years to come but we see this as a possible alternative for us. We are interested in learning what other families have done. We want to be her caregivers as long as we are able but also recognize that age will one day preclude it. We would welcome any thoughts or plans other families have made as I'm sure we are not the only ones concerned about our "Angel's" care in the future. My wife (Marianne) or I can be reached at our home phone 360-887-8369.

I believe we are all blessed to have these special children in our homes.

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
PNWASF website PNWASF.org

DIRECTIONS TO CHRISTMAS TOY GIVEAWAY AT SEDONA VILLAGE

Coming from the Northend : Coming from the Southend:

Take 1-5 South to Exit 127, Hwy 512E, towards South Tacoma Way/Puyallup. Take the Steele Street exit and turn right onto Steele St. S. Turn slight right onto Sales Rd. S. Turn left onto 106th St. S. Turn Left onto 19th Ave. S. Turn right onto 105th St. Ct. S. Follow signs to the Sedona Village office building.

Take 1-5 North to Exit 127, Hwy 512E, towards Puyallup/Mt. Rainier. Take the Steele Street exit and turn right onto Steele St. S. Turn slight right onto Sales Rd. S. Turn left onto 106th St. S. Turn Left onto 19th Ave. S. Turn right onto 105th St. Ct. S. Follow signs to the Sedona Village office building.