

What is PNWASF?

The Pacific Northwest Angelman Syndrome Foundation (PNWASF) was formed in 1994 for the purposes of increasing public awareness of AS, and serving as a resource and support for individuals with AS and their families. The organization is comprised of elected officers and directors, and the membership is open to interested individuals, families and professionals. PNWASF is associated with the National Angelman Syndrome Foundation and has contacts with various other national and international AS organizations.

The goal of all of our activities is to provide a network of support and information which is so critical to families adjusting to life with an AS child. Our group participates financially and otherwise in the organization of conferences on AS, and providing scholarships for families to attend these conferences. We have established and are currently maintaining a website at www.pnwASF.org. PNWASF is continuing to pursue funding for future research studies related to AS.



Foundation Activities

- ◆ Quarterly newsletters
- ◆ Parent to Parent support
- ◆ Annual Adult Retreat
- ◆ Informational brochures
- ◆ Annual Family Camping weekends
- ◆ North end and South end Family Picnics
- ◆ Annual Dave “Hendu” Henderson Golf Tournament
- ◆ Information booths at Disability fairs and conferences



What Kind of Research is Being Done?

Angelman Syndrome is being researched by numerous professionals in order to more accurately describe its origin, physical signs, symptoms and behavioral characteristics. Genetic studies have identified several classifications of AS. The majority of the children diagnosed are deletion positive which means they have a tiny deletion in chromosome #15. Other groups include those individuals receiving two copies of chromosome #15 from their fathers, those with UBE3A mutations, and those that have imprinting defects. Still there are those children whose diagnosis remains a clinical one because even though they fit all of the characteristics no genetic change has yet been identified.

As children with Angelman Syndrome are studied, many educational and behavioral interventions have been shown to be effective in the areas of communication, schooling, sleep disturbances and general behavior. In addition, physical and occupational therapies, speech and language interventions, behavior modifications and parent training have proven worthwhile. A major focus is communication, as children with AS seem to have much greater receptive language ability than expressive ability.

What is Angelman Syndrome?

Angelman Syndrome (AS) is a genetic disorder first described in 1965 by Dr. Harry Angelman, an English pediatrician. Once thought to be rare it is now believed to affect about 1 in 15,000 people. AS has been found to affect males, females, and all racial/ethnic groups equally. Some of the major characteristics include:

- Behavioral uniqueness, frequent laughter or smiling, apparent happy demeanor, easily excitable personality often with hand flapping movements, short attention span
- Unstable, jerky gait, usually with uplifted arms
- Speech impairment, minimal or no use of words
- Developmental delay, functionally severe
- Seizure disorder
- Excessive chewing/mouthing behaviors
- Sleep disturbance
- Wide mouth, wide-spaced teeth
- Attraction to/fascination with water

Other features often noted are flattened back of the head, excessive drooling, hyperactivity, feeding problems in infancy, and small head size

Where Can More Information About AS be Obtained?

Both early diagnosis and intervention can be beneficial when AS is suspected. Diagnosis can be accomplished within the first few weeks of life. Therefore, a physician familiar with the disorder can be an important resource.

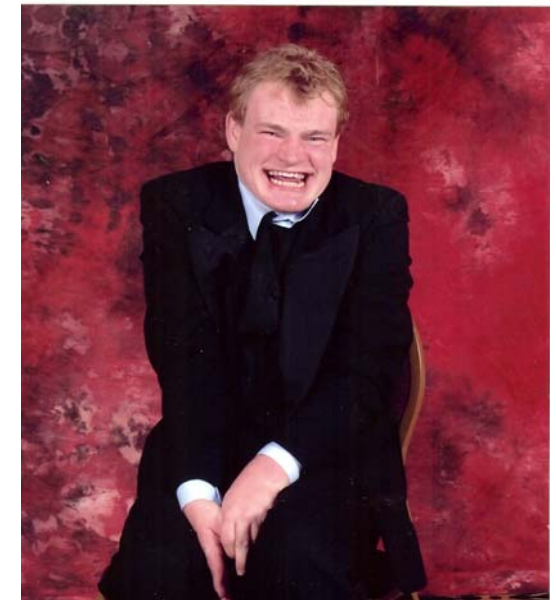
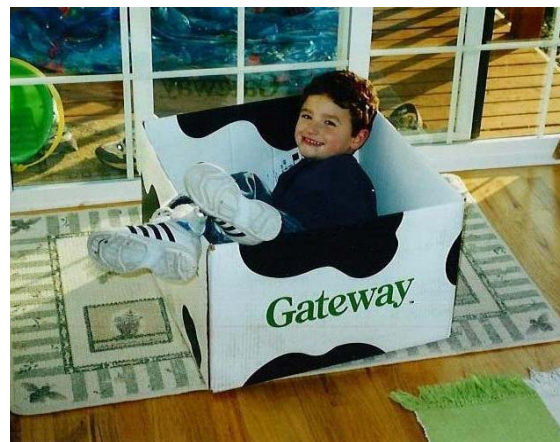
PNWASF, with its network of families in the Pacific Northwest and its relationships with regional, national, and international AS groups, is available to provide information, education and support to families and professionals interested in AS. Please contact us for more information.

Pacific Northwest Angelman Syndrome
Foundation

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Pacific Northwest

ANGELMAN

Syndrome Foundation



Oregon, Washington, and Alaska