

Denver Again Teams with 11 Other U.S. Cities Hosting The 2006 Angelman Syndrome Foundation National Walk-A-Thon On Saturday, May 20

On Saturday, May 20, 2006, Metro Denver will host the Angelman Syndrome Foundation (ASF) Walk-A-Thon for a second year. The 1.3-mile walking event will again be held at the Adams County Regional Park (Fairgrounds), 9755 Henderson Road, Brighton, CO 80601. Registration begins at 8:45 a.m. and the Walk-A-Thon starts at 9:45 a.m. A BBQ lunch will be available after the walk for those purchasing a ticket. Other cities hosting the 2006 ASF Walk-A-Thon include: Atlanta, Birmingham, Chicago, Grand Rapids, Houston, Jacksonville (FL), Orange County (CA), Philadelphia, Pittsburgh, St. Louis, and Washington, D.C. This is the eighth year nationally for the event.

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Registration information is available by calling 1-800-432-6435, or checking online for registration information at <http://www.angelman.org/angel/index.php?id=178>. Sponsors of the event in Metro Denver include Brighton Early Rotary Club at the Sustaining Level; and Jones & Keller, P.C., PASCO, and Valley Bank and Trust at the Enduring Level. The local coordinator is Cindy Snyder (cinnredsnyder@juno.com).

Funds raised from the 2006 ASF National Walk-A-Thon will enable ASF to continue all aspects of our mission to advance the awareness and treatment of Angelman Syndrome through education and information, research and support for individuals with Angelman Syndrome, their families and other concerned parties. Those participating in the walk can go to <http://www.firstgiving.com/angelmanwalk> to set up a personal fundraising webpage.

Angelman syndrome (AS) is a genetic disorder which causes severe developmental delay. It is caused by a missing or "faulty" genetic code on chromosome #15. The most striking symptoms are mental retardation, a severe speech disorder (*in most cases, lack of speech*), motor difficulties, a short attention span as well as some behaviorally unique features such as hand flapping, hypermotoric behavior, an easily excitable personality and a frequently happy demeanor. In addition, some individuals with AS exhibit a suck/swallowing disorder and/or frequent tongue thrusting, sometimes accompanied by drooling. Other common features include wide-spaced teeth and hypopigmentation (lighter skin and hair than their family members).

Some of the most difficult issues faced by families and caregivers include the common onset of seizures during childhood, a difficult sleep pattern (individuals with AS often seem to need hardly any sleep at all), and communication. Communication is an especially complex issue, because even though most AS individuals don't have any speech at all, they understand a lot of what is said to them. In order for them to be able to express themselves, alternative methods of communication have to be established, which can be a long and difficult process.

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AS is difficult to diagnose and in the past has often been miss-diagnosed with other developmental disabilities, such as cerebral palsy and autism. AS has been reported throughout the world among divergent racial groups. In North America, the great majority of known cases seem to be of Caucasian origin. Although the exact incidence of AS is unknown, an estimate of between 1 in 15,000 to 1 in 30,000 is the norm.

Thus, statistically, there are between 155 and 310 estimated Angleman cases in the State of Colorado, of which 86-172 would be in the Metro Denver area.

A local case study can be found at <http://www.OurAngelTyler.com> about a Henderson, CO, four-year-old named Tyler Davis. Tyler was diagnosed with AS at 16 months of age, three months after his seizures began. As you'll read at the website, Tyler's parents have diligently sought extensive early intervention therapies such as speech language pathology (SLP), occupational therapy (OT), physical therapy (PT), a type of therapeutic horse riding therapy called hippotherapy and preschool, which have all helped Tyler to achieve dramatic improvements in his ability levels. Tyler has also been on the medically supervised Ketogenic Diet. His seizures have abated during the past three years that he has been on the special diet.

About ASF

ASF's mission is to advance the awareness and treatment of Angelman Syndrome through education and information, research, and support for individuals with Angelman Syndrome, their families and other concerned parties. The Foundation sponsors AS research through grants to researchers pursuing promising avenues of discovery. Since 1996 nearly \$500,000 has been awarded. In 2005 the ASF Board awarded \$200,000 in grant funding. The foundation may be reached at 1-800-432-6435 or by email at info@angelman.org. The website is <http://www.angelman.org>.

Contact:

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[Angelman Syndrome Foundation, Inc.](http://www.angelman.org) 1-800-432-6435 <http://www.angelman.org>



[Tyler Davis, a Colorado 4-year-old diagnosed with Angelman Syndrome when he was 16 months of age, is seen participating in a form of therapeutic horse riding therapy called hippotherapy. AS is genetic disorder involving chromosome #15.](http://www.OurAngelTyler.com)

Learn more about Tyler and the early interventions his parents have sought out for him at <http://www.OurAngelTyler.com>.