



## **Angelman Syndrome Foundation Takes Major Step Toward Furthering Research Efforts**

July 30, 2009 – Orlando, FL – The Angelman Syndrome Foundation, [www.angelman.org](http://www.angelman.org), today announced the formation of the Angelman Treatment and Research Institute (ATRI), which will direct the organization's rapidly increasing research funding. The ATRI will also serve as a hub for more than 30 organizations, researchers and scientists worldwide to share discoveries and treatments for this neuro-genetic disorder. The announcement of the ATRI was made during the Angelman Syndrome Foundation's biennial conference in Orlando, Fla.

ATRI will realize the Angelman Syndrome Foundation's "scientific roadmap" that directs its aggressive funding of Angelman Syndrome (AS) research. AS occurs in one in every 15,000 live births and exhibits symptoms such as: developmental delay; lack of speech; seizures; inappropriate laughter; and walking and balance disorders. Short term focus of the roadmap is to fund research that finds treatments that may cure symptoms of AS while continuing ongoing research and clinical trials involving UBE3A, the gene with abnormalities in AS patients. Since AS shares symptoms with several other disorders, including autism, cerebral palsy, epilepsy, Rett Syndrome, and Prader-Willi Syndrome, any progress toward treating and curing symptoms has the potential to positively affect more than 12 million people.

"The creation of the Angelman Treatment and Research Institute is exciting and timely. The priorities as established by the ATRI are right on in recognizing the continued need for expanding our fundamental knowledge of UBE3A and its role in brain development and function." said Michael D. Ehlers, M.D., Ph.D., Department of Neurobiology at Duke University Medical Center. "The Angelman Syndrome Foundation is to be applauded in having the vision to recognize the critical importance of basic research and in setting this research on a trajectory toward a cure. I see a future of great opportunity and advance in neurodevelopmental disorders with Angelman Syndrome and the ATRI leading the way."

Research funding will also focus on new therapies for symptoms, pharmaceuticals, biological agents, adaptive devices, surgical and diagnostic procedures. An emphasis on adult AS patients will extend the scope of clinical trials to include a wide age group and investigate and advance life and self-help skills, vocational training, and access to community programs and health services.

"The Angelman Syndrome Foundation is committing \$125,000 in seed funding to start ATRI with an ultimate goal of raising \$2 million within two years," said Eileen Braun, Angelman Syndrome Foundation Executive Director. "Funding will be used to implement program goals while the Angelman Syndrome Foundation's Scientific Advisory Committee will continue administering grant reviews and making funding recommendations for innovative research."

ATRI will allow scientific members to conduct Web-based meetings and symposiums, and convene as necessary to discuss research progress and activities.

### About Angelman Syndrome

Identified by Dr. Harry Angelman, AS occurs in one in every 15,000 live births and exhibits symptoms such as: developmental delay; lack of speech; seizures; inappropriate laughter; and walking and balance

disorders. It is a life-long neuro-genetic disorder usually identified in patients between two and five years old. AS is often misdiagnosed as Autism and a cure has not yet been developed.

#### About Angelman Syndrome Foundation

The Angelman Syndrome Foundation, the leading resource for AS information, support and AS research funding was founded more than 20 years ago with the mission of advancing the awareness and treatment of AS through education and information, research and support for individuals with AS, their families and other concerned parties. Since 1996 the Angelman Syndrome Foundation has funded 51 research grants totaling over \$2.5 million. The Angelman Syndrome Foundation has awarded a majority of these funds (\$2.2 million) beginning in 2005. In November 2008, the Angelman Syndrome Foundation received Charity Navigator's 4-star rating for sound fiscal management. Only a quarter of all charities evaluated by Charity Navigator receive this distinction of demonstrating the ability to efficiently manage and grow its finances. For more information, please visit [www.angelman.org](http://www.angelman.org).

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