Bringing new hope to our 'Silent Angels' so other families won't suffer the same fate as the Aitken family.

Support Angel Week 23rd - 27th November 2009

Rett Syndrome, a debilitating genetic disorder, is the second most common form of severe mental retardation in females. It affects one in 8,500 births by the age of 15.

This years Angel Week will be dedicated to 'Ashli Aitken' who tragically passed away this year at only 11 years of age. Ashli, (daughter of Olympic Gold Medallist Brett Aitken) has been the face of our Christmas Angel Commercial over the past years and was a beautiful angel with the biggest smile.

Exciting new research in Australia has revealed another gene for Rett Syndrome which could lead to new treatments for the disorder. This recent research project by scientists from Australia and Israel has identified a genetic variation that influences the severity of symptoms in Rett Syndrome which could lead to new treatments for the disorder.

The scientists have established a correlation between the severity of clinical symptoms and a common brain-derived neurotrophic factor (BDNF) polymorphism and they say patients with the normal BDNF genetic variant had less severe symptoms, with later onset and frequency of seizures.

Affected girls, known as 'Silent Angels', develop normally for the first six to twelve months of life. Then, development stops and then even reverses. The disorder results in severe disability and for most, impairs speech and mobility. The care required for a young woman with Rett Syndrome is comparable to that required for a high-level quadriplegic.

This is the second major breakthrough Australian Scientists have made, the first being when the team discovered the second gene responsible for Rett Syndrome in 2004.

However, further funds are needed to continue this important research to help Rett Angels like "Ashli". This research will make such a crucial difference in the lives of these little girls – our Silent Angels – and their families.

The Rett Syndrome Australian Research Fund which is a voluntary organisation raises ongoing funds to keep this vital research going. From **23-27 November 2009**, the Rett Syndrome Australian Research Fund will launch *Angel Week* with a goal to raise $50,000 for Rett Syndrome research team. Angel merchandise, including Christmas ornaments can be purchased through **Ed Harry** stores nationally or online. All merchandise will sell for $5-00 each.

Donate today by visiting www.rettsyndromeaust.org.au or phone 1800 177 111 to give these silent angels back their wings.

Rett syndrome facts

- Rett syndrome is predominantly caused by a sporadic mutation in the *MECP2* gene on the X chromosome.
- The syndrome becomes apparent from around six months of age when development stagnates and acquired skills, such as coordination, speech, communication skills and cognitive function deteriorate. Other problems can include, breathing, cardiac function, chewing, swallowing, and digestion.
- Rett syndrome has often been misdiagnosed as cerebral palsy, and shares some similarities with autism. A blood test, as well as symptoms and clinical history, helps to diagnose the disorder.
- The average life expectancy of a girl with Rett syndrome is less than 50 years and she will require maximum assistance with every aspect of daily living.
- In Australia, Rett syndrome affects about 1 in 8,500 females by the age of 15 years.

Media contact: Janelle Lillis (02) 46 512575 Email: support@rettsyndromeaust.org.au