

# **BATTEN DISEASE and the 31<sup>st</sup> of March**

## **Fight Battens and Help Find a Cure**

Every new parent has an inherent knowledge of the natural progression of their child. Baby's first words, first steps, first day at school, even the onset of adolescent defiance is anticipated. For parents of children with BATTEN DISEASE, these visions are drastically altered by this rare degenerative neurological disease.

Today it is the most common neurological storage disease which affects people of all ages, but especially infants, toddlers and school-age children. It begins unexpectedly and leads to early death. Once a walking, talking, active and curious young child who could see the world around them – in as little as a year develops a variety of symptoms which are difficult to explain, such as loss of vision and the alarming onset of seizures. A parent will say “we are proud to have been gifted with their love “but to watch the degeneration of your own child until bedridden is too indescribable for words. Even harder is the knowledge that they will not be with us for long”.

To date there are about 41 (known children) from all across Australia and New Zealand suffering this terrible disease.

Batten Disease is an inherited disorder carried as an autosomal recessive gene, which means that if both parents carry the gene, each child has a 25 percent chance of inheriting the recessive gene from both of his/her parents, thereby being affected, or a 50 percent chance of inheriting the recessive gene from one of his/her parents thereby becoming a carrier – resulting in the potential for occurrence in future generations.

Intensive research continues (**funded solely by donations and fundraising**): gene therapy and stem cell trials are being carried out (in America) for children with the infantile and late infantile forms of Batten Disease and for the first time in 180 years they may be able to do something about the Juvenile form of Batten Disease. There is no funding to set up this trial and the estimated start up cost is \$500,000.00. In today's world, \$500,000.00 is not a lot of money. To many of us, it does seem a huge amount but if everyone joins together, **we can make it happen**.

Every family's hope is for a therapy that might reverse this disease's progression and restore their child's neuronal function. At this stage most would be happy with the hope of not losing their child, seeing them suffer without even a chance of saving their life.

On National Batten Disease Awareness Day on the 31<sup>st</sup> of March,

participating schools throughout Australia will be creating awareness by selling our battens bears and maze pens to students; and

families and volunteers will be supporting this cause with fundraisers and the selling of merchandise in a united effort to .....

## **BOWL OUT BATTENS**

**for all the children now enduring their struggle or yet to be diagnosed**

Treatment and a cure depend not only upon the brilliance and perseverance of dedicated researchers, but also upon the world-wide awareness and availability of research funding.

YOU can help the Australian Chapter of the Batten Disease Support and Research Assoc. Inc. to assist these families by buying any of our merchandise which include: little bears, lapel pins, lanyards, pens and fun cricket stress balls or by making a donation to this worthy cause.

*All Donations over \$2 are tax deductible. Donations can be made by a simple credit donation via the website.....*

**Please visit [www.battens.org.au](http://www.battens.org.au) as the Cure Depends On Us**