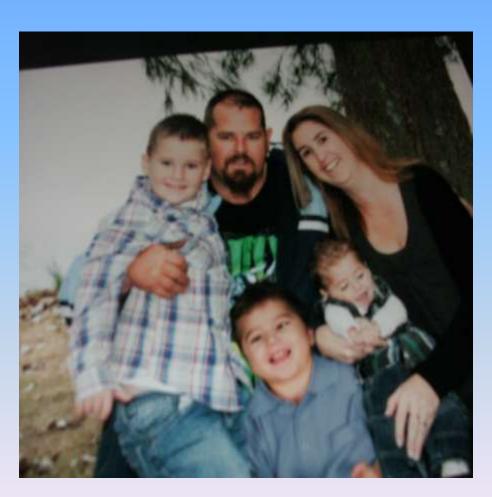
### Our Family Journey 2004-2011



### Cody Darren Sheppard Born 28th April 2004







### Pontocerebellar Hypoplasia Type 2

- Abnormally small cerebellum & brain stem.
- Pregnancy is normal.
- Problems with breathing, sucking & feeding problems at birth.
- No motor or mental development.
- No milestones are met.
- No verbal or non-verbal communication.

### Pontocerebellar Hypoplasia Type 2

- Visual fixation is poor.
- Seizures & epilepsy are frequent.
- Abnormal movements.
- Disease is fatal early in life.
- Death during early childhood has been attributed to respiratory & infectious complications.
- Approx 20 cases registered in world.

## Cody with therapists & special equipment





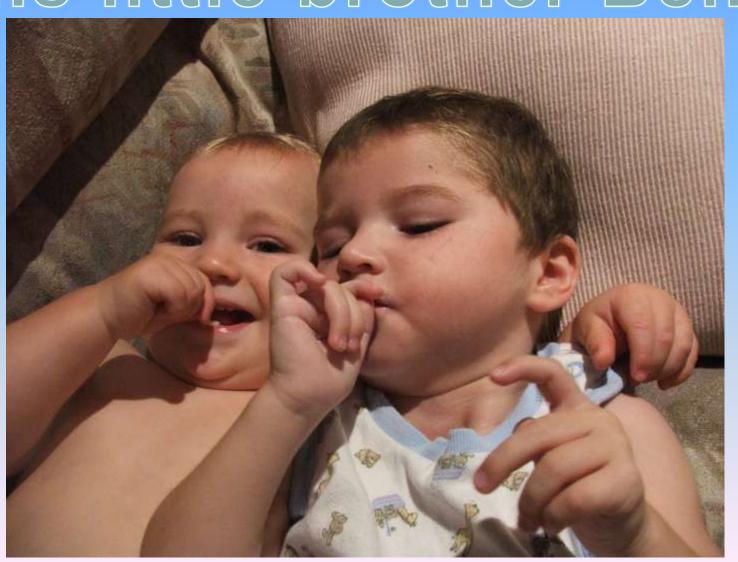








### In 2005 along came his little brother Ben



### He spent a short time at Malkara Special School!









#### Cody & happy times!







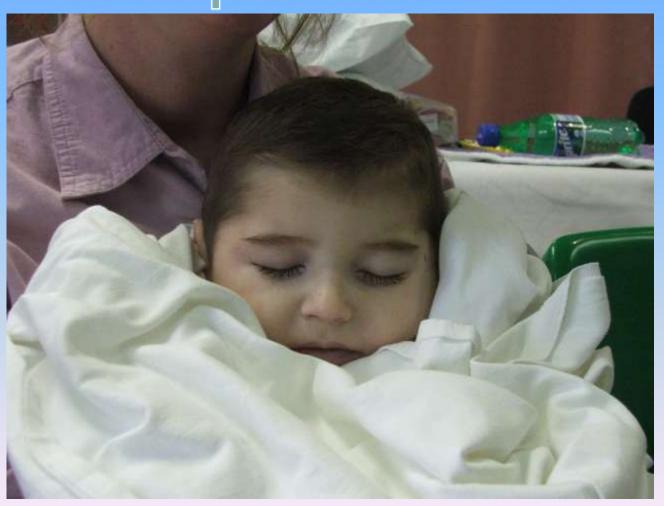


# Many challenging days & nights at home & in hospitals





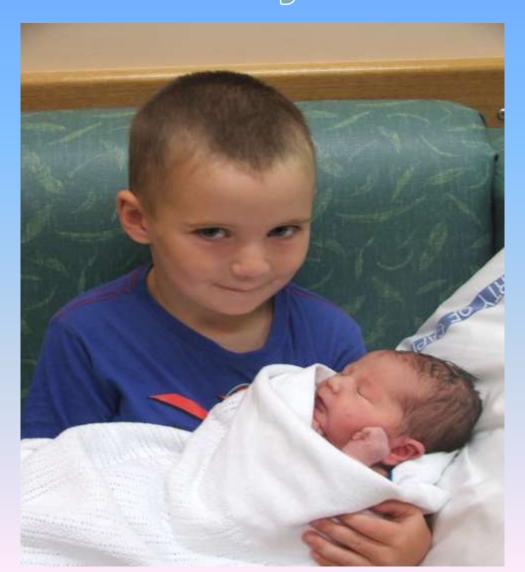
# Cody passed away peacefully in our arms in September 2007



# Our key challenges as parents

- Unaware of Palliative Care Australia (PCA) & ACT Palliative Care Society services.
- Delay in diagnosing his condition (6 years after birth).
- Inability to find reliable information & treatment options.
- Lack of understanding of the condition by the medical profession.
- Lack of funding & access to financial support for specialized equipment.
- Cody being in constant pain.
- The physical & emotional stress & pain felt as a couple and a family.
- Preparation for death & the grieving process.

### Ben with his new brother Dylan Born May 2010



# This time around — Its about quality of life!







#### Not quantity of life!









### ACT Palliative Care Society join our journey

The staff at ACT Palliative Care Society & the PCA publication Journeys, have supported us in the following ways:

- •Better equips us for the situation & issues we face.
- •Helps us to improve Dylan's quality of life.
- •Supports our family choices & quality of life.
- •Supports our end of life plan for Dylan.
- •Offers honest & open communication.
- •Provides support to help us keep Dylan comfortable.
- Provides treatment options.
- •Supports symptom management.



### ACT Palliative Care Society join our journey

- Provides 24 hour support, 7 days a week.
- Supports & understands our needs as parents & as a family.
- Arranges access to oxygen machine for home.
- Provides us with advice & resources to other supportive networks.
- Provides access to a social worker.
- Provides end of life & funeral preparation & planning.
- Loss & grief support.



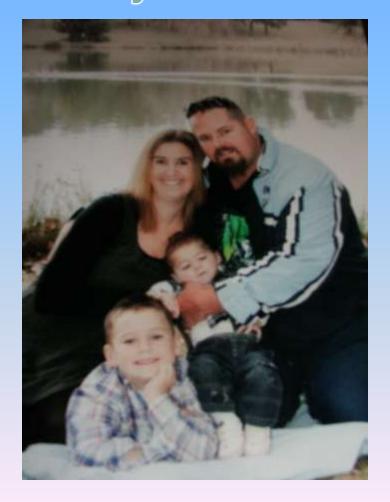
#### ACT Palliative Care Society Quality care at the end of life

Dylan had Whooping Cough earlier this year. His GP introduced us to ACT Palliative Care Society.





# With ACT Palliative Care Society joining our journey we have never looked back — only forward!





#### Cody's website

#### www.codysheppard.com

