



6th Edition

Hi everyone,

Thank you for joining our mailing list, feel free to pass this along to your friends or suggest they join the mailing list and Jake's Gift fan page on facebook.

<http://www.facebook.com/?ref=logo#!/pages/Jakes-Gift-Fan-Page/325564511630?ref=sgm>

We would love to see more people on the fan page and mailing list!

We often read or hear on the news about individuals whose anti social behaviour leaves us questioning the type of world we live in and what it might be like when our children grow up, but sometimes our lives are touched by the kindness of strangers. I received an email from one of these strangers, Cherie from Poetic Images <http://www.poeticimages.com.au/>. Cherie had stumbled across Jake's fan page on Facebook and so kindly offered her time, skills and services as a professional photographer to take photos of the Memory Keepers. I was absolutely thrilled by her offer and cannot thank Cherie enough; the photo's she has taken are stunning. You are able to view the pictures on Jake's webpage or at Cherie's webpage.

Thank you Cherie, I know I have said it more than once but I truly appreciate all that you have done for Jake's Gift.

Tracey



*A memory is a gift
worth keeping*

Poetic Images 
Photography

www.jakesgift.org.au

www.poeticimages.com.au

www.jakesgift.org.au jakesgift@aapt.com.au ABN: 474 684 408556



HEART TALK.....

- The word 'CONGENITAL' refers to the disease or defect being present at birth
- Congenital heart defects are one of the biggest killers of infants less than one year old.*

* <http://www.aihw.gov.au/cvd/congenital.cfm>

WHAT IS CARDIOMYOPATHY

- Cardiomyopathies are diseases of the heart muscle, also known as the myocardium, in which the actual muscle cells and surrounding tissues are sick

Cardiologists classify Cardiomyopathy into three categories:

1. **Dilated Cardiomyopathy (DCM):** It is also known as congestive Cardiomyopathy. Dilated Cardiomyopathy is most notable for an enlarged heart that contracts poorly.
2. **Hypertrophic Cardiomyopathy (HCM):** Hypertrophic Cardiomyopathy is most notable for thickening of the heart muscle.
Hypertrophy, or thickening, particularly of the left ventricle, can result in problems with obstruction to forward flow and problems with relaxation of the left ventricle, and can thereby affect the ability of the heart to fill. Children with hypertrophic Cardiomyopathy are also at increased risk for arrhythmias.
3. **Restrictive Cardiomyopathy (RCM):** Restrictive Cardiomyopathy is most notable for abnormal relaxation of the ventricles and well preserved pumping function. As a result, the upper chambers of the heart, the atria, become enlarged while the lower pumping chambers, the ventricles, remain normal in size. This is a rare form of Cardiomyopathy in children.

WHAT CAUSES CARDIOMYOPATHY?

The cause of most cases of Cardiomyopathy is unknown. A common cause is a viral infection of the heart, or myocarditis, which weakens the heart muscle



THE SIGNS AND SYMPTOMS OF CARDIOMYOPATHY

Dilated Cardiomyopathy presents with signs and symptoms of congestive heart failure (CHF). Infants with this disease may demonstrate fast and heavy breathing with feedings, sweating with feedings, lethargy or inactivity, or poor weight gain. Older children may have difficulty with exercise, difficulty with breathing, abnormal heart beats, dizziness, or weight loss due to nausea or decreased appetite

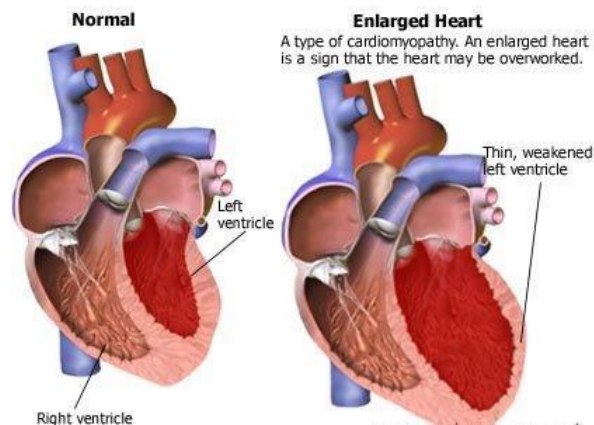
Reference <http://www.cincinnatichildrens.org/health/heart-encyclopedia/disease/cardiomyopathy.htm>

LONG TERM PROGNOSIS

When children are diagnosed at an early age, the prognosis may be poor depending on the form of Cardiomyopathy and the stage of the disease. For example, dilated Cardiomyopathy can progress quite rapidly when diagnosed in young children. Up to 40% of diagnosed children with dilated Cardiomyopathy fail medical management within the first year of diagnosis and of those that survive many have permanently impaired heart function. Children diagnosed with hypertrophic Cardiomyopathy seem to fare better but the outcome is highly variable.

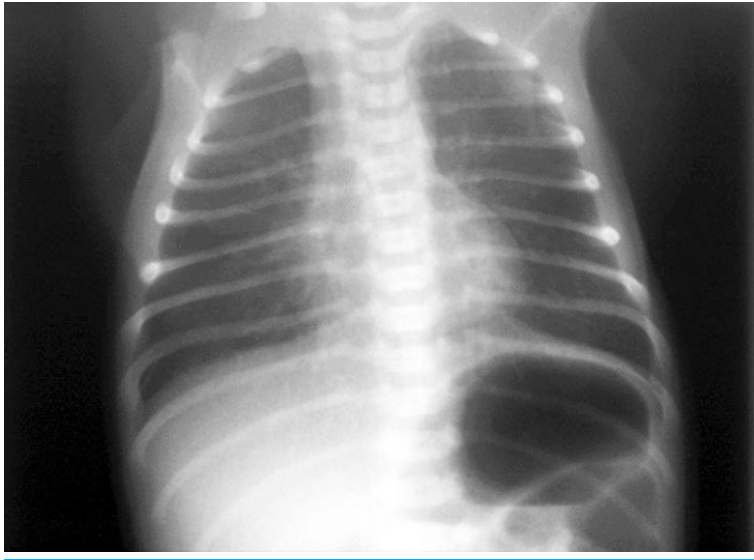
Mortality and heart transplant rates of childhood cardiomyopathies are much higher than in adults due to the rarity and uncertainty of the disease. Less than optimal outcomes may be attributed to the more fragile state of infants and young children or it may be a function of the disease's advanced progression associated with another genetic disorder. Another unfortunate reason is that Cardiomyopathy is not usually detected until the end stage when obvious symptoms of heart failure are apparent. Cardiomyopathy can be easily missed in routine check-ups when there are no obvious symptoms (i.e. heart murmur) or when there is no reason for diagnostic testing (i.e. no family history of the disease).

Reference <http://www.childrenscardiomyopathy.org/site/overview.php>





Jake's Gift



A normal infant's heart



This is an x-ray of Tracey's son Jake's enlarged heart.



Jake's Gift

IN THE NEWS

Hold on to memories

Mother finds way to help deal with death

By MARIELE DAWSON

SERIOUS heart conditions are a major killer of young children but Sunshine Coast mum Tracey Cahill is devoted to making sure their lives are not forgotten.

After losing her son Jake, a twin, to a very rare heart defect in 2008, Tracey established the foundation Jake's Gift.

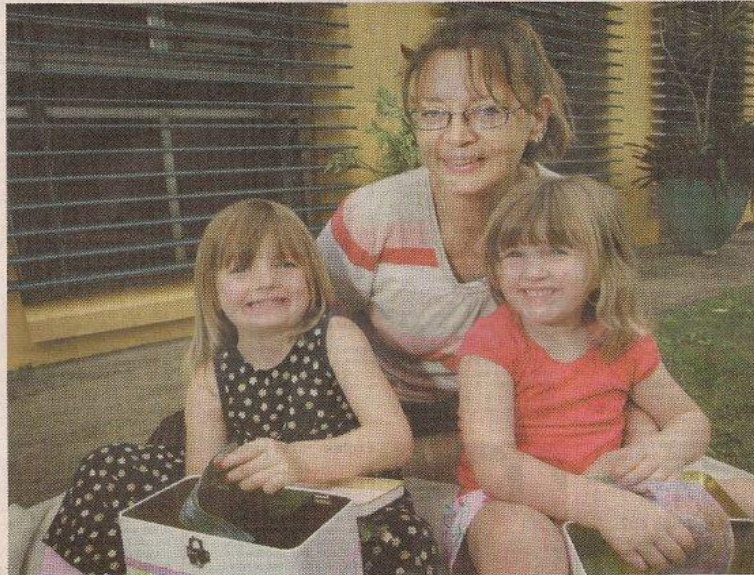
Jake was only 52 days old when he died of dilated cardiomyopathy - an unpredictable and incurable disease of the heart muscle.

In honour of her son's short life, Tracey's not-for-profit organisation is helping raise awareness of paediatric heart conditions and offers comfort to families who have also lost a child.

"I can't have lost him for nothing," Tracey said. "I want the world to know he was here."

After her loss, Tracey said she did not want other mothers and families, who experienced similar deaths, to leave hospital without something they could "eventually treasure".

"Generally, they (parents) leave with nothing, just their child's belongings in a bag - it's a bit unfair," Tracey said.



REACHING OUT: Tracey Cahill, with daughters Lillie and Aytah, lost her son Jake to a heart disorder and has created the Memory Keeper, used to store belongings and items for people who have lost a child. PHOTO: DANNY SMITH/2014

CONTINUED ON PAGE 17

cannot be used as a basis for breastfeeding," she said. The ABA and Breastfeeding Promotion Sunshine Coast have

positive and breastfeeding Welcome Here stickers. The two groups hope to have 20

feeding," she said. "Some people I've met through

Support is available in the grieving process

FROM PAGE 16

TRACEY said she had come up with the idea to give parents Memory Keepers: decorated containers that could be used to store belongings and items of their lost child.

She said Melbourne's Royal Children's Hospital had been looking for something to give to these families and had told her the Memory Keepers were perfect.

Tracey decorates each Memory Keeper herself and, inside each container, she leaves a warm message and shares her own story.

Today, the Jake's Gift foundation delivers Memory Keepers to paediatric, maternity and cardiac wards at Sunshine Coast and Brisbane hospitals, as well as Melbourne's Royal Children's Hospital. "I would like to give Memory

Keepers to every ward in every hospital Australia-wide, but unfortunately finances will dictate," Tracey said. A busy mum of six, including two sets of twins, Tracey is also an active member of the Australian Multiple Birth Association.

She said AMBA had helped her cope with Jake's death and was her "saving grace". She is now the bereavement contact for the Sunshine Coast Multiple Birth Association.

Tracey said AMBA was a great support and information network for all mothers and parents - whether or not they

had multiple births. She said she found AMBA's online forum extremely valuable because it allowed her to connect with mothers and parents from across the country at any time of day.

Tracey said the forum was ideal for discussing all parenting issues or just "having a vent". Despite being a not-for-profit organisation, The Sunshine Coast Multiple Birth Association donates some of its proceeds to Jake's Gift to support Tracey's cause.

"They offer so much help. I'm very lucky," Tracey said. She said that looking after her big family consumed most of her time, but she hoped to expand Jake's Gift to help as many families as possible.

"Nothing is difficult any more after losing him," Tracey said.

"I would like to give Memory Keepers to every ward in every hospital Australia-wide, but unfortunately finances will dictate."



Jake's Gift



Photo's courtesy of www.poeticimages.com.au



Jake's Gift

JAKE'S GIFT CURRENTLY SUPPLIES THE
FOLLOWING HOSPITALS:-

The Sunshine Coast Private Hospital, Buderim – Maternity
Nambour General Hospital, Nambour – Children's Ward
The Mater Children's Hospital, Brisbane – Cardiac Ward
The Royal Children's Hospital, Brisbane – Palliative Care Ward
The Royal Children's Hospital, Melbourne – Cardiac Ward

HOW TO DONATE

Jake's Gift relies solely on the kindness of others; each donation is greatly appreciated regardless of the amount. \$10 enables Jake's Gift to supply a bereaved family with a Memory Keeper after the tragic loss of their precious child.

If you would like to donate to Jake's Gift, you can donate money to the following details:

Name: Jake's Gift **Bank:** CBA **Account:** 10014610 **BSB:** 064226



Jake's Gift

Supporters

Ricochet Web Solutions

If you're looking for a web designer who can deliver, fast, friendly and professional Service, email Richard:
richdean77@gmail.com
 Visit <http://jakesgift.org.au/> to see Richards work first hand.



www.waxywonders.com.au

Candles are used to remember special people in our lives and each Memory Keeper is supplied with a tea light. When a loved one passes away, we commemorate the life or memory of the person who passed.

Please contact Marc and Sherril to place an order.

Poetic Images

Photography

<http://www.poeticimages.com.au/>



Multiple Birth Parents is an Australian based online community forum for parents or carers with twins, triplets, or a higher order of multiples from all over the world. There is also a special section for bereaved families to share in their stories.

www.multiplebirthparents.com



Twinsane is a small online store owned and operated by a TWINSANE mum & dad of identical boys, out of Perth, Western Australia.

Our passion for this store started after we had our boys and had so much trouble trying to source various items for them from Australia.

We aim to provide our customers with prompt, friendly service offering a range of affordable, practical and fun items for your multiples.

Some of our items include: hand and feet moulds, inkless print kits, twin feeding pillows, car signs and heaps more.

Visit www.twinsane.com.au to view our full range, or e-mail enquiries@twinsane.com.au if you would like more information.



Remembering our angels always... grief and loss support, baby memorial books, keepsake jewellery, urn jewellery and poems honouring baby loss.

<http://www.keepituniquekeepsakes.com.au/>