

From the Heart

CHD awareness month February 2017

We would like to send our very warmest wishes to you and your loved ones. Thank you for your contribution to the **From the Heart** study and the **Australia and New Zealand Fontan Registry**.

FROM THE HEART STUDY NEWSLETTER FEBRUARY 2017

We're excited to share with you an update on the **From the Heart** study in partnership with the Fontan Registry.

Since launching the study earlier this year, 900 families have been invited to participate in **From the Heart** including families from every state and territory across Australia and New Zealand.

We know that many of you are interested in the results and would like to share a brief update with you now.



ABOUT OUR STUDY PARTICIPANTS

So far, there are 491 participants currently enrolled in **From the Heart**. This includes:

- 163 are people with a Fontan circulation;
- 118 mums and 73 dads; and
- 137 brothers and sisters!

IT'S NOT TOO LATE TO BE PART OF THIS IMPORTANT STUDY!

If you've already received a From the Heart survey, please complete it as soon as you can. If you'd like to learn more about how you can take part, contact us at fromtheheart@mcri.edu.au

WHAT IF I'M WAITING FOR MY SURVEY TO ARRIVE?

We send out surveys as soon as we receive your request!

- If you have requested an **online survey** and haven't received it, it may have accidentally landed in the 'Junk' folder of your email. Please check your junk folder, just in case.
- If you have requested a paper questionnaire and haven't received it, please contact Laura by phone on 1800 025 509 or email at fromtheheart@mcri.edu.au

SOME OF THE FINER DETAILS



At the time of joining **From the Heart**:

- The average age of **people with a Fontan** is 19 years old. About 40% of participants with a Fontan are under 12 years old, about 20% are teens, and about 40% are adults. Half are male and half are female.
- The average age of **siblings** is 13 years old. About 40% are aged under 12 years, 30% are teenagers, and 30% are adults. Sibling gender is also an even split, with half males and half females.
- Overall, **parents** have an average age is 47 years old. The average age of mums is 46 years old, while dads average 48 years old. 60% of parents are mums and 40% are dads.

Participating families are	TOTAL
New South Wales	137
Victoria	92
Queensland	83
South Australia	36
Western Australia	50
Tasmania	13
Australian Capital Territory	9
Northern Territory	1
New Zealand	69
USA	1
TOTAL	491

WHAT YOU HAVE SAID ABOUT PARTICIPATING IN FROM THE HEART

"Thank you for giving us the opportunity to take part in this research. I was desperate for answers 22 years ago but there was no money for research then. Hopefully we can help the lives of new HeartKids and their families - understand what is happening and be more supported and knowledgeable about CHD than we were all those years ago." [Parent]

"I am happy to have completed it and it has helped me to reflect on what our son had experienced." [Parent]

"This gave mum and dad a lot of insight into me." [Child with Fontan]

"Thank you for doing this fantastic research! I believe we really need to address what we know about the impact of raising a child with a Fontan circulation and what it means for the child. We have certainly struggled a lot of the 15 years of our son's life and found difficulty in trying to access services that understood my child's health." [Parent]

WHY IS MY INVOLVEMENT IN 'FROM THE HEART' IMPORTANT?

The purpose of the **From the Heart** study is to learn all that we can about **health, well-being, views and experiences** of children, young people and adults with a Fontan circulation, and their parents, and siblings. The results of this research will be used to guide the development of new and existing programs and services for people with a Fontan circulation and their families. The study findings will also be used to increase community awareness and understanding of the experiences and needs of families affected by congenital heart disease.

The study involves filling out one questionnaire at home, and participants can choose whether they'd prefer to complete their questionnaire online or on paper.

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ABOUT HEARTS AND MINDS RESEARCH

Our **Hearts and Minds Program** was established in 2010 at the Heart Centre for Children. We are Australasia's first and largest integrated psychology research program and clinical service dedicated to childhood heart disease. Our research spans across all developmental ages and stages. We focus on the issues that are important to children and families, understanding the challenges posed by childhood heart disease, and developing new and better ways of transforming these challenges.

To learn more about support for families at the Heart Centre for Children, visit our website:
<http://www.heartcentreforchildren.com.au/support-for-families.html>

THE FONTAN REGISTRY

The Australia and New Zealand Fontan Registry is the world's largest registry for people with a Fontan circulation. The Registry is committed to working with clinicians, and most importantly, families to understand more about the impact of a Fontan circulation.



HAVE YOUR DETAILS CHANGED?

We would like to keep in touch with you so we can send you updates on findings from the study and to ensure that you receive your study packages. If you've moved or changed your phone number or email address, please let us know by contacting us (see below).

CONTACTING OUR FROM THE HEART TEAM

If you would like to get in touch with us or provide any feedback on this study or share your thoughts about what it's like to be a part of this study, please don't hesitate to contact us. We love hearing from our **From the Heart** families!



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MANY THANKS FOR 2016 AND ONWARDS THROUGH 2017



On behalf of the **From the Heart** team, we send our heartfelt thanks to all families who have taken part in this research or your dedication and commitment to this research. With your help, we are learning all about the experiences and needs of people with a Fontan circulation.



Medicine