



A whole life
with half a heart

2016
Issue 5

Australian & New Zealand Fontan Registry Newsletter

Welcome to the 2016 Fontan Registry Newsletter! In this our 5th issue we are giving you an update on our newest research findings, the current Fontan Registry numbers, and a brief review of our most recent Fontan Education Day in Auckland.

Thank you to all the Fontan Registry participants who continue to support us!

Without you the Registry will not be able to make progress and provide clearer answers through research. Your participation gives continued hope for better long term outcomes, and indeed we are showing through our research that the care for people with a Fontan in Australia and New Zealand is amongst the best in the world.

Please follow our updates on our Facebook site:
<https://www.facebook.com/ANZfontanregistry>
to connect with other Fontan families like you.



*Prof Yves d'Udekem
Australian and New Zealand Fontan Registry Chair*

HAVE YOU MOVED HOUSE?

New mobile? New email address?

Please help the Fontan Registry to maintain the accuracy of your personal information by notifying us of any updates/changes.



To update your details visit:
<http://www.fontanregistry.com/participate>



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UPDATE ON FONTAN REGISTRY NUMBERS

Participation in the Registry has grown steadily to now include a total of 1,466 participants. This is set to double over the next 20 years. The graph illustrates the number of Fontan procedures conducted per year over the past 40 years. Currently the average number of Fontan operations undertaken per year in Australia and New Zealand stands at 61, a steady average performed over the

last 10 years. The average age of participants is 19 years, with just over half of the participants (57%) being male. The average age at time of Fontan operation is currently 5.7 years (ranges from less than 1 year old to 41 years old at the time of operation).

Download our annual report here:
<http://www.fontanregistry.com/annual-reports>

NEW RESEARCH

Aspirin vs Warfarin??

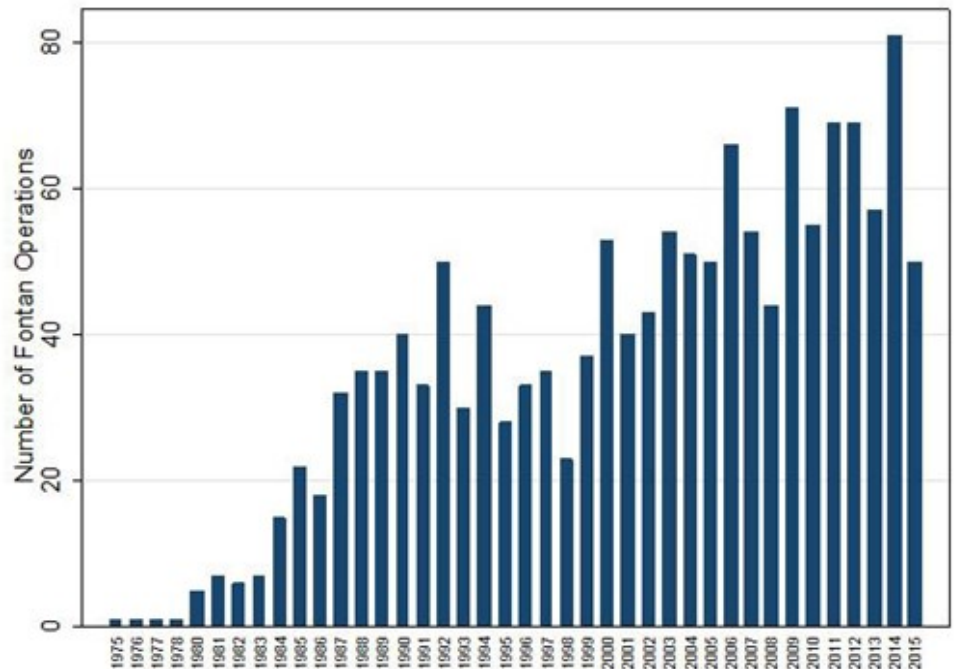
Read about our NEW research findings here...



We would like to share with you one of our latest research findings. The study looked at 475 people with an extracardiac Fontan (newest type of Fontan operation), and found no difference between aspirin and warfarin and the rate of late clotting events. While these results are interesting, please talk to your own cardiologist as there are specific situations where warfarin is preferable, and any changes in medication should be closely monitored.

Link to study below:

[www.fontanregistry.com/
fontan-research-publications](http://www.fontanregistry.com/fontan-research-publications)



AUSTRALIAN & NEW ZEALAND FONTAN ADVISORY COMMITTEE (ANZFAC)



Carers Groups

ANZFAC held 3 informal face-to-face gatherings for parents/carers/guardians of people with a Fontan circulation in Melbourne and Brisbane. The hope is to have these groups (and online groups) in other locations within Australia and New Zealand going forward. If you are interested in helping out with organising these in your city, please contact: rachel.maree@mcri.edu.au



REDEFINING EXPECTATIONS OF LONG TERM SURVIVAL AFTER THE FONTAN

This study examined the follow-up of all 1006 survivors of the 1089 patients who underwent a Fontan procedure in Australia and New Zealand. It was published in the notable *Circulation Journal* by Fontan Registry investigators. The main finding is that:

"The long-term survival of the Australian and New Zealand Fontan population is excellent"

Link to article:

[www.fontanregistry.com/
fontan-research-publications](http://www.fontanregistry.com/fontan-research-publications)



MEDICARE LINKAGE DATA - AUSTRALIA

We know you have other issues besides your heart and we would like to understand the full cost of all of these. To do this we need to link to your Medicare data which captures all health-related costs. Participants enrolled in the Registry should have received either a text, email or written letter informing you about our new research project regarding linking your individual Medicare data to our secure Fontan Registry. This information will be very useful to the researchers as it will give us the full picture of costs associated with having a Fontan circulation. If you have not returned your consent form, or filled in our online option for consent, you can do so by following the links below. Consent to this project is optional, but your involvement is always greatly appreciated as we continue to strive towards improving the lives of those who have had a Fontan operation.

The link below takes you to the forms for linking your Medicare:
<http://www.fontanregistry.com/how-to-participate>

OTHER RESEARCH PROJECTS UPDATE

We have now completed recruitment for the Liver and Kidney Function study. Thank you to all the participants and their families who supported us in gathering data for this project.

We are currently analysing the data. Also, we are still recruiting individuals for our Functional Outcomes study: participants must be aged 13 years+ with a Fontan circulation to take part in Melbourne, Sydney (also now at Royal Prince Alfred) and Auckland based research. This study will look at the impact of blood thinning medication and fenestration on bone density, heart and brain function, exercise capacity, and quality of life.

If you are interested in participating in this project, please email us:
info@fontanregistry.com

FONTAN EDUCATION DAY 2016 - AUCKLAND

Our third annual Fontan Education Day was held on 11th September 2016 at the University of Auckland in New Zealand (see photos below). This event was attended by 150 Fontan participants, their families, cardiac specialists and researchers. Similar to previous years, this was a great opportunity for families to connect with each other and hear about the most recent research results from the Fontan Registry.

Here is a link to the videos of the day:

<http://www.fontanregistry.com/seminar-videos-2016>



Highlights of the day included: a thorough outline of the Fontan procedure 'plumbing', results from our liver renal research project, lived experiences, the journey of the Father of a Fontan child, and in-depth break-out sessions which gave people the chance to explore topics further. The day was very well received with lots of positive feedback! Thank you to our wonderful Auckland team and the planning committee for their exceptional efforts in hosting another great event! We look forward to seeing you in Brisbane next year.

Announcement:
Fontan Education Day Brisbane Date: 10 September 2017

SEASONS GREETINGS

We wish all the Fontan participants and families a safe and happy festive break!

We would also like to take the time to thank everyone in the Fontan Registry team for their hard work and dedication this year.

Best wishes to All for a wonderful 2017!



FONTAN REGISTRY FUNDRAISING

We will be hosting some events in 2017 to help with fundraising for the core business of supporting the Fontan Registry and its associated research projects. Look out for these through our Facebook site:

- Fondue for Fontan Trivia Night, Melbourne
- Footy for Fontan online tipping with some great prizes
- Fontan Fairies Fun Run

We are currently looking for donated prizes (small or large and anything in between!) to support these fundraising events. Please contact us directly to talk about donated prizes:

info@fontanregistry.com or call: 0431 659 911

If you would prefer to donate directly to the Fontan Registry (we now also support regular giving), and be one of our #fundraisingheroes please visit our site: <http://www.fontanregistry.com/donations>



Your continued support is much appreciated!!