



Newsletter 2015

LETTER FROM THE CHAIR

Dear Fontanfolks,

We had set up the Australia and New Zealand Fontan Registry to clarify the expectations late after the operation and build up the research necessary to improve and lengthen the life of those with a Fontan circulation. Another year has passed and we are setting more milestones. We have now clarified outcomes up to 30 years after surgery (see our annual report). People are living longer and better than ever expected and we can show that care everywhere in Australia and New Zealand is about best in the world! Because the Registry is the largest database in the world, we are seen as being at the forefront of the research. We are now sure that Australians and New

Zealanders will be therefore the first ones to benefit from any advances made in this field. As a group, we are working very hard to identify the best treatment and management to keep for the decades following Fontan surgery. But beyond this, the Registry has been the way for all people with a Fontan circulation to connect. Throughout the Education days and the Facebook page you have all been able to realise that you are not alone, that you have lived similar experiences.... and how great you all are.

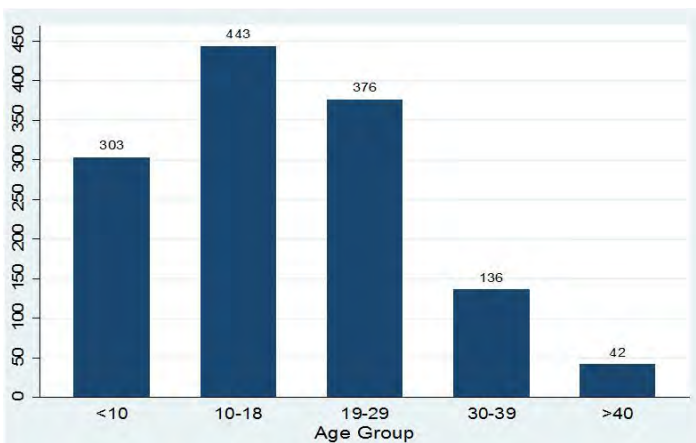
This is an incredible initiative and we all need your support (Check Fontan for Life <https://www.everydayhero.com.au/event/fontanforlife>). Keep the Registry alive. It is yours.

Yves



A/Prof Yves d'Udekem
Chair, ANZ Fontan Registry & Paediatric Cardiac Surgeon, Royal Children's Hospital

FONTAN REGISTRY NUMBERS



It's now over 40 years since the first Fontan operation was performed. The Australia and New Zealand Fontan Registry was established in 2009, and involves support from all the major paediatric and adult cardiac centres across Australia and New Zealand. We have 1489 participants on the Registry who have had a Fontan operation, making this the largest database of its kind in the world. The current average age at which the Fontan operation is performed in Australia and New Zealand, is 5.7 years (ranges from 1 to 40 years). This graph gives you an indication of the current age spread in our Registry which ranges from 3 - 67 years. The current average age of Registry participants is 19. This is set to increase to an average age of 21 by 2025, and 26 by 2035.



FONTAN EDUCATION DAY 2015 - SYDNEY

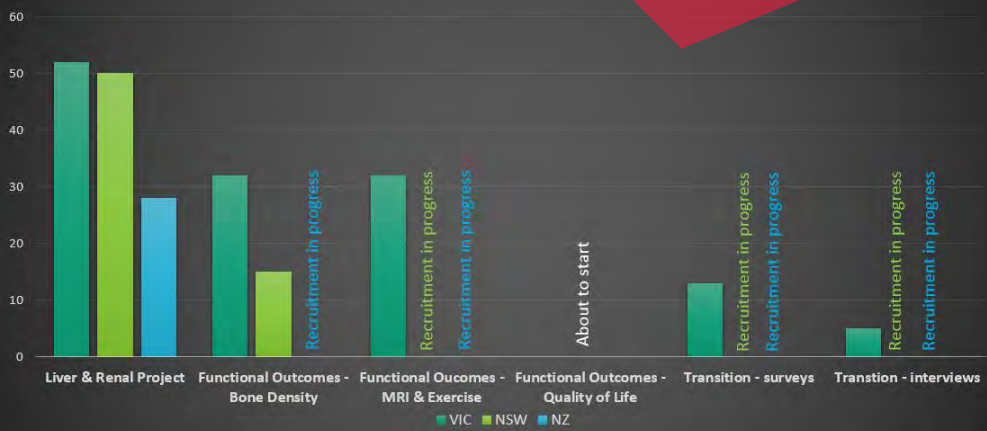
Our second annual Fontan Education Day was held on 18th October 2015 at Westmead Children's Hospital. This was a sold out event that was attended by 180 Fontan participants, their families, cardiac surgeons, cardiologists, researchers, and allied health workers. This was a wonderful opportunity for families to connect. Presentation topics included long-term care after the Fontan operation, research findings, break-out sessions around pregnancy, issues in

school-aged kids, transition to adult care, neurodevelopment, and specialised workshops for young people. The day was well-received with plenty of opportunity for discussion and questions. Thank you to our wonderful Sydney team for their generosity in hosting the event and a stimulating program! We look forward to seeing you in Auckland next year (date to be confirmed). For updates follow us on Facebook and check our website: www.fontanregistry.com





www.fontanregistry.com
 www.facebook.com/anzfontanregistry
 Mobile: +61 431 659 911



CURRENT RESEARCH PROJECTS

Our research projects are progressing well - thank you to everyone who has participated thus far! The Liver and Renal project examining liver and renal function in people 3 or more years after the Fontan operation is starting to wrap up. Melbourne and Sydney have completed recruitment, and Auckland will complete this project by April 2016. Results from this project will be shared as soon as data collection and analysis are complete.

The Functional Outcomes project is the first population based cross-sectional study to analyse the impact of fenestration and anticoagulation (warfarin & aspirin) on bone density, exercise capacity, cardiac function, neuroimaging, and quality of life. This is the first time that such a large cross

section of Fontan participants are performing exercise during cardiac MRI (see picture top right), so we can see the variations in blood flow during exercise and at rest. Recruitment for people who meet the criteria (e.g., 5 years or more on aspirin/warfarin) is well underway in various centres.

We are also taking a close look at people's experiences of transitioning from paediatric to adult care. This project will involve collecting surveys from young people and their parents/caregivers, as well as phone interviews. Data collection for this project has begun and will continue over the next few years. We hope to use the results to develop comprehensive transition support between paediatric and adult hospitals.

Download our Annual 2014 Report:
<http://www.fontanregistry.com/research/current-research-projects.aspx>

HAVE YOU MOVED HOUSE RECENTLY?



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 information or enrol in the Registry please follow the link below:

<http://www.fontanregistry.com/enrol-update-your-info.aspx>



www.fontanregistry.com

www.facebook.com/anzfontanregistry

Mobile: +61 431 659 911

ANZFAC Australian & New Zealand Fontan Advisory Committee



ANZFAC Committee Members (from left to right)

Front row : Rachel Maree (Vice-Chair), Kirsty Robertson, Tracy Stanley, Ingrid King, Rebecca Peters.

Back row: Louise Pickford, Jonathan Mackley (Chair), Yves d'Udekem, Brian Rose

(not pictured: Matthew Orchard)

ANZFAC was started after the Fontan Education day in August 2014. They are an enthusiastic group comprised of adults with a Fontan circulation, parents/guardians of adults/children with a Fontan circulation, health professionals and other individuals who are involved in the Fontan community. Their vision and aim is to achieve consistency of care, represent a whole journey view and advocate for children, young people and adults with a Fontan circulation. Their first project was to send out surveys to identify what matters most to the Fontan community. They

will continue to support the Fontan community to achieve better health outcomes, and act as "their voice"...

Following further analysis of the survey results, the committee will determine some immediate and long-term action plans. You can follow this group through their web presence on the site:

www.fontanregistry.com/anzfac.aspx or contact them by email for more information: anzfac@fontanregistry.com

FIND US ON FACEBOOK

Did you know that you can connect with other people in Australia and New Zealand with a Fontan circulation, through Facebook? This is a great way to share stories and keep in touch with the Fontan community.

Follow our page to receive updates on the research findings from the Fontan Registry and hear about events such as Fontan Education Day.

www.facebook.com/ANZfontanregistry

USEFUL LINKS

www.fontanregistry.com

www.heartkids.org.au

www.beyondblue.org.au

National Youth Mental Health Foundation:
<http://headspace.org.au/>

Kids Help Line: 1800 55 1800

Lifeline: 131 114