

Dear Fontan Registry Participants,

The Australia and New Zealand Fontan Registry is a growing success. We have currently more than 800 participants enrolled in the registry and our participation rate is still growing.

The research generated by the Registry has given us excellent news. We can now say that Fontan patients are living longer than some had predicted, and we can assume that the majority of the patients operated today will see more than 30 years after their Fontan. Because we are performing 60 Fontan procedures per year, we can now be certain that the size of the Fontan population will double within 15 years.

This is just a beginning and we now hope to generate the research necessary to improve the life of all Fontan patients. There are concerns that high pressures in the veins may put strain on the liver and the kidney of Fontan patients and we are currently performing the largest investigation to-date of these two organs. We are trying to find solutions for the patients who had the first version of the Fontan operation. These patients see the channel created in their hearts dilate and are prone to rhythm disturbances and failure. We hope to finally find out the best anti-coagulation (blood thinning) medication as well as find out what will give these patients the best quality of life and exercise capacity, and are currently trying to raise funds for this research

We have received a lot of requests from you to be in contact with other Fontan patients and families. A lot of you have questions and do not always know who to turn to for answers. We are therefore proud to announce the launch of our new Facebook page <https://www.facebook.com/ANZfontanregistry>. By joining the social media forum, you can help us to educate and raise awareness of the Fontan procedure and the existence of the Registry among the general public.

We are in dire need to raise funds for our research projects and we also believe that we need to raise the awareness of Fontan patients so that everybody knows about this growing Fontan population. To this end, in November & December, we will be holding an appeal and a media campaign. The campaign, called "*Fontan for life*," will be based on the ambition of giving every Fontan patient the best possible chance to live a healthy life. We would really love every one of you to contribute or participate in some way, whether it is to help with the fundraising event ideas, volunteering or donating. Any assistance would be greatly appreciated to help spread the word and support us in achieving our goal. If any participants or parents are interested in donating or helping us organise the fundraiser, please contact us, we would love to hear from you!

If you would like further information on research projects, volunteering or general enquires please contact our research team on info@fontanregistry.com or on **0431 659 911**. You can also visit the Fontan Registry website for information and updates.

Warm Wishes,

Australian and New Zealand Fontan Registry Steering Committee

