

Newsletter Edition 2 September 2012

Fontan
REGISTRY

Dear Fontan Registry Participants,

It has been a year since our last newsletter and we would like to share our progress with you. We can now proudly say that the Australia and New Zealand Registry has become the largest database of Fontan patients in the world!! With almost 700 patients currently enrolled!

Current Status:

Recently, we reviewed our Fontan surgical experience in 1030 patients across 2 nations. The results of this study showed that we are now operating on patients with more complex heart conditions, who tend to have longer hospital stays. By the end of this year, we expect to have a large-scale analysis of the Fontan patients currently enrolled in the registry. This will give us an idea of health outcomes 20 years post Fontan and beyond.

Research:

Liver and kidney function study: We will begin recruiting for this study in the coming months. This project is important in determining how these two major organs will tolerate the higher vein pressures generated after Fontan surgery.

Fertility and Childbearing study in the female Fontan population: This is a current study we are undertaking. Although it is not advisable for female Fontan patients to have children, many still do or have a desire to become parents. For this reason, this study draws attention to fertility, delivery outcomes and health status of both Fontan mothers and their babies.

Future research: We endeavour to investigate the distinct effects of aspirin and warfarin (blood thinning medication) in Fontan patients. This study will focus on the side effects and outcomes of long-term usage of these medications. We also hope to initiate research in identifying drugs that will increase patients' exercise capacity after Fontan surgery.

Press Campaign:

The Fontan registry launched a press campaign in September 2011 to raise public awareness about the Fontan registry. Since the press campaign we have had an increase in the number of enrolments as well as an increase in funding encouraging our research.

Recruitment and supervision:

We have now improved the way we invite families into the project and hope this will improve participation in this wonderful project.

We believe that your perspectives are crucial to the success of this project. We are pleased to announce that two parents have now joined our steering committee!

For further information on the ANZ Fontan Registry, research projects or general enquiries please visit our website www.fontanregistry.com or contact the Fontan Research Team at info@fontanregistry.com or on **0431 659 911**

Finally, we would like to thank all participants of the ANZ Fontan Registry and appreciate your support.

Kindest Regards,

Australia and New Zealand Fontan Registry Steering Committee


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