

# **FONTAN REGISTRY NEWSLETTER**

Edition 1: June 2011

It is now a year since we started the Australia and New Zealand Fontan Registry, and it is our pleasure to let you know the progress so far.

## **Recruitment**

To date, 361 patients aged 2-63 years have enrolled in the Registry. We believe around 1000 adults and children are living in Australia and New Zealand with a Fontan circulation, so it seems that we have approximately one third of them included in the Registry. Our plan is to continue building up the Registry over the next two years.

The most valuable research results come when as many people as possible take part in a project. Therefore, for this project to work we need as many patients as possible to enrol in the Registry. To help increase the number of people taking part, we have designed an information flyer that we are asking doctors and specialists to give to their patients.

## **Research Projects**

The Registry will be the world's largest database of Fontan patients. We believe the Registry will become a unique source of health information that will benefit all adults and children who have had a Fontan operation.

One of the first research studies that will be done aims to find out the medications that patients are taking after a Fontan procedure, in particular those used usually to decrease blood pressure and those used to thin the blood (eg aspirin or warfarin).

Another study that will start soon plans to look at women of childbearing age. While it is not recommended that women who have had a Fontan procedure to become pregnant, we know that some have had children. We want to know more about their fertility, the impact of pregnancy on their health, and all the details that can help us to make better recommendations in the future.

## **Website**

We are in the final stage of creating a website for the Registry. You will be able to access it at [www.fontanregistry.com](http://www.fontanregistry.com). We hope that it will become a helpful resource to keep you up-to-date with our research. Watch this space!

We would like to extend a big thank-you to everyone who has decided to be a part of the Registry.

The Australia and New Zealand Fontan Registry steering committee