

Heart Registry News



The Registry has now grown to over 1,500 people! Thanks to this growing number of people enrolled we have been able to conduct some really meaningful research (with more to come).

We can learn so much by evaluating information not only about people affected by a genetic heart condition but also from first-degree relatives without the condition. If you have any parents, brothers/sisters or children (with or without the condition) you think might be interested in joining the Registry, please get in touch with us at 02 9565 6185 or registry@centenary.org.au

Thanks for your ongoing support!
Dr. Jodie Ingles, Registry Coordinator

Research finds better way to predict likelihood of genetic result in HCM

Genetic testing for hypertrophic cardiomyopathy (HCM) has been commercially available for almost a decade now. However, low detection rates and costs have been a barrier. Using information from the Registry, we were able to identify other factors that could help predict the likelihood that a genetic result will be found.



Our research discovered that gene alterations were more likely to be detected in people with an established family history of disease (72% v 29%). Of this group, people with a family history of sudden cardiac death had a further increased detection rate (89% v 59%). Other factors that proved important included being female and greater left ventricle wall thickness. Even in those people who were tested with no family history, women were more likely to have a genetic diagnosis made (41% v 24%).

Lead author Dr Jodie Ingles said: "Our research will help cardiologists and clinical geneticists to inform their patients better of how likely they are to receive a genetic test result based on their personal history and circumstances."

This research was recently published in *Genetics in Medicine*
nature.com/gim/journal/vaop/ncurrent/abs/gim201344a.html

Flu shot or not?

As winter approaches, a common question many patients ask is "Should I have the flu vaccine?" Prof Chris Semsarian answers:

The influenza vaccine is strongly recommended and free for everyone aged 6 months and over with a chronic disease, such as all forms of heart disease. So long as there are no contraindications (other factors/reasons to withhold the vaccine).

You will need to be assessed by your GP or cardiologist to consider your individual circumstances. In particular, if you have **Brugada syndrome** you may need to take extra care such as being monitored for a short while after the vaccine is given and finding out how to immediately treat any fevers that may occur following vaccination.

Full article at heartregistry.org.au

Join our medical care study: We are conducting a study on the medical management of hypertrophic cardiomyopathy. If you and/or any affected family members (even if they aren't on the Registry) would like to participate, please contact Jodie or Renee on 02 9565 6293.

Facebook: “great way” to get information and be part of a community

My name is Kathy and on 8/8/2009 my world fell apart. That day my son, Ben, passed away and no one could tell me why!

Luckily, Ben’s godfather had read about the work Prof Chris was doing and suggested we contact him. After months of testing, it was confirmed that Ben and I have one of the genetic mutations for long QT syndrome. The support and understanding from Prof Chris and all his staff has been amazing.

Part of the support I receive is through being a member of the Australian Genetic Heart Disease Registry Facebook page. It is a great way to keep up to date with any new developments as well as being a quick way to get advice on matters that may relate to my condition. I enjoy reading what other sufferers have to say and to be involved in discussions on issues that affect us all.

I would encourage anyone thinking about joining the Registry on Facebook to do so. You do not have to comment or even be involved in general discussions. The fact that you can get information easily and be part of a community that is specifically designed to help you is of great benefit.

To join our Facebook group, visit facebook.com/heartregistry



We also thank the **Mamma Lena & Dino Gustin Foundation** for their generous \$5,000 grant to support the Registry’s awareness initiatives. The Foundation award these grants in honour of the kind-hearted spirit and acts carried out by Mamma Lena and her husband Dino Gustin during their lifetime.

To receive this newsletter via email, please contact us at registry@centenary.org.au



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