

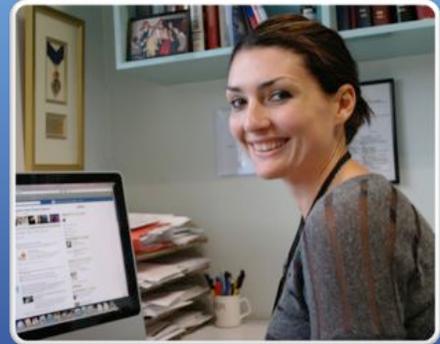
Heart Registry News

Enrolments for the National Genetic Heart Disease Registry continue to climb

This increase in information means we can rely less on international data and use local knowledge to improve care for Australians living with a genetic heart disease.

We also just completed our first Registry-only survey on the psychological impact of ICDs. Thanks to everyone who participated!

Dr. Jodie Ingles, Registry Coordinator
registry@centenary.org.au



Genetic testing: saving lives and costs

Genetic testing is a valuable tool in identifying gene faults in family members who are at-risk-of disease. But a new study based on data from the Registry has found it can save costs as well as lives.

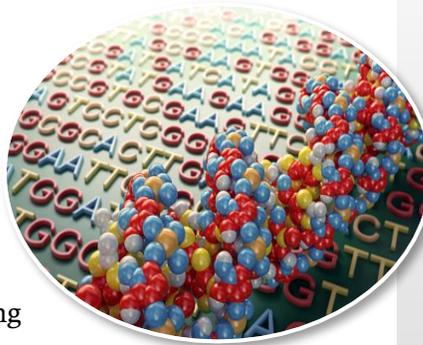
Published in the prestigious *Heart* journal, the study found genetic testing of families with hypertrophic cardiomyopathy (HCM) is more cost-effective than clinical screening alone.

Although genetic testing seems marginally more expensive than clinical screening alone, there were clear gains for patients such as a longer, happier life. The research found adding genetic testing may actually save healthcare costs when the price of the gene test is reduced, which is expected to happen in the next year due to vast improvements in technology.

A genetic test can identify people who don't carry their family's gene fault so it means they don't need a lifetime of regular cardiologist visits. This can also free up resources to help people with disease and reduce demands on our healthcare budget.

If you'd like to find out more about genetic testing, please email us at registry@centenary.org.au or call (02) 9565 6185.

Dr Jodie Ingles



Caffeine & Your Heart

I was asked online about caffeine and heart disease. High levels of caffeine can increase your heart rhythm, blood pressure and may even lead to sudden death, especially if you have an underlying heart condition.

I suggest people with heart rhythm diseases (LQTS, CPVT, Brugada) limit coffee to 1-2 standard cups per day AND avoid energy drinks high in caffeine and additives, like guarana or taurine.

Ask me a question or share a thought on Facebook (Heart Registry) or Twitter @CSHeartResearch.

Professor Chris Semsarian



* Find out the CLUES to get reluctant family members checked (page 2)

CLUES for reluctant family members

Getting at-risk family members to see a cardiologist isn't always that easy. To answer this challenge, **genetic counsellor Laura Yeates** shares how to drop CLUES for reluctant family members.

Credible information

Give your first-degree relatives credible, unbiased information about your heart condition from your doctor or reliable websites such as www.heartregistry.org.au

Leave information sheets with contact numbers

Place sheets with contact numbers and websites around the house so your family members can call or ask questions.

Use your regular check-ups as a reminder

Casually mention that you met your doctor recently who asked if the family has been checked.

Ease up – don't hassle them too much

Remind your family every so often but do not push them too much. Over time they may change their mind.

Share your suggestions with others

We'd love to hear more ideas from you on Facebook (Heart Registry) or via email registry@centenary.org.au



If you'd prefer to view future copies of our updates online, please email us at registry@centenary.org.au



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