

Heart Registry News



Our Registry has become a major source of information about genetic heart conditions in Australia (and even the world). By being part of the Registry, you've helped us improve our understanding of these conditions. And we've been able to share this knowledge with health professionals across Australia and the world to improve care and outcomes for patients.

We've presented at major international conferences in the UK, US, Asia and Europe, most recently Norway and the Netherlands. These presentations give us a chance to share new findings and better ways to care for patients and their families. But this is only made possible through your ongoing support and involvement with the Registry so THANK YOU!!

Dr Jodie Ingles & Prof Chris Semsarian (pictured left on their recent trip to highlight our research and look at different clinical models but still making time to stay heart healthy by going for runs)

First major study of LQTS in Australian families

Familial long QT syndrome (LQTS) is a primary rhythm disorder characterised by QT prolongation on ECG. It is estimated 1 in 2,500 people have LQTS, which means that more than 9,000 Australians are affected by this condition.

We are undertaking a major study to describe key clinical and genetic features of Australian families with LQTS. This is the first clinical and genetic study of this size to be carried out in Australia.



Charlotte Burns and Dr Jodie Ingles will analyse in-depth family and medical histories, detailed medical information and survey results about genetic testing.

This study will allow us to better understand LQTS and, ultimately, provide better

management and treatment for people with LQTS and their families. We hope to share these results with you soon.

If you or a family member has LQTS and you would like to be part of this study please email c.burns@centenary.org.au or call (02) 9565 6144.

Beware of energy drinks

There are a number of reports of potentially deadly side effects on the heart from energy drinks in the general population and in people who have an underlying genetic heart condition.

Anyone with a family history of sudden cardiac or unexplained death or unexplained fainting/passing out (known as syncope), should avoid energy drinks altogether.

Even if you are of generally good health with no obvious health problems you should avoid energy drinks or, at the very least, limit energy drinks consumption each day.

There is a strong case against energy drinks. To find out more about this issue, read the full article from Prof Chris Semsarian at the Heart Registry website: www.heartregistry.org.au

Do you have Brugada syndrome?

Cardiologist Dr Belinda Gray is coordinating a Brugada syndrome study at Sydney's Royal Prince Alfred Hospital. The study will look at the clinical, imaging and cardiac rhythm factors that may account for differences in symptoms and risk of cardiac events. Our findings could lead to significant changes in the care and treatment of people with Brugada syndrome. If you would like to participate please email b.gray@centenary.org.au or call (02) 9565 6295.

This is one of the most frequently asked questions from people who have an implantable cardioverter defibrillator (ICD). It can be confusing as people with an ICD are advised not to do competitive, high-level sport but regular activity is important for general health. So here is a brief summary on this issue.

The current guidelines state people with an ICD should not participate in high-intensity, competitive sports. The guidelines define “competitive sport” as: an organised team or individual sport with regular competition against others, sport that emphasises excellence/achievement, and sport that requires some form of systematic training.

The guidelines recommend people with ICDs should be discouraged from most competitive sports. The risks include dangerous arrhythmias not treated by the ICD, damaging the ICD, extreme heart rates that could increase shocks, and losing consciousness or having an ICD shock that can lead to temporary loss of body control and cause injury.

However, recent research suggests competitive sport may not be as dangerous as originally thought. There is mixed data about the risks of an “adrenaline surge” with studies showing ICDs work less effectively in some instances. Another study showed many patients can participate in competitive sports without injury or death from arrhythmias.

Overall recommendations: overall, the guidelines state people with an ICD should not participate in competitive sports. We support these guidelines with a few additional comments:

1. Talk to your doctor or cardiologist to discuss the recommendations for you and your specific condition.
2. Certain sports, particularly contact sports (e.g. football, basketball or martial arts) are higher risk for various reasons so these are generally best avoided.
3. Everyone (including people with a genetic heart condition and/or ICD) should do some form of gentle exercise to maintain a healthy weight and general health. According to the physical activity guidelines for general health, we should all aim for 150 minutes of moderate-intensity activity (e.g. brisk walking) each week.

For the full information sheet, please visit www.heartregistry.org.au

Patient Days – Sydney & Melbourne: Saturday 13 September

Meet leading experts and people with similar conditions at two events coming up in September. Prof Chris Semsarian and his team are organising a Patient Information Day in Sydney (contact: Laura Yeates on (02) 9565 6187 or l.yeates@centenary.org.au) while the Cardiomyopathy Association of Australia (CMAA) will hold their patient seminar in Melbourne (details: www.cmaa.org.au).



Contact & Connect

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***Update your details – personal, medical or family:** If you’ve changed your address/email, if you’ve had a change to your treatment of (or received new information about) your heart condition or if you have anything to add to your family’s medical history, please contact Tanya on (02) 9565 6185 or registry@centenary.org.au