

Heart Registry News



One of our key aims for the Registry is to be a reliable source of information on genetic heart conditions. Over the past two years this has grown dramatically. Our website visits have increased, we're up to our 5th newsletter, we now have nearly 700 "friends" on Facebook and more people are contacting us by email/phone.

We hope you continue to find the information and support we provide helpful. If you have any ideas or suggestions about what to include on our website or in the newsletter, please email us at registry@centenary.org.au or call us on 02 9565 6185. We'd love to hear from you!

Kind regards,
Dr Jodie Ingles, Registry Coordinator

Some people need help adjusting to an ICD

In people with a genetic heart condition who have risk factors that make them at greater risk of sudden cardiac death, an ICD is the only effective therapy. While the shock delivered by an ICD may be life-saving, some people struggle with adjusting to the fear of a shock and/or the consequences after a shock.

A study we conducted into this area, published recently in the *International Journal of Cardiology*, found a small but significant group of people with an ICD reported symptoms of anxiety (38%), depression (17%) and, for those who experienced a shock, post-traumatic stress symptoms (31%) at levels that may require specialist support services.



Lead author Dr Jodie Ingles said: "The outcome of this study reflects the real-life clinic setting, where most people cope and adjust well but there are some that don't. Our study confirms there are some people who will have difficulties adjusting to their ICD that can affect their emotional and social wellbeing. We have been presenting these findings to cardiologists and other health professionals to highlight the importance of offering patients access to interventions such as psychological care and support."

If you have any concerns or difficulties in relation to your ICD, please speak to your GP or cardiologist who can help you find the support you need to adjust to living with an ICD.

School information and first-aid plans

It's that time of the year when parents start enrolling their children into "big" school. If you or your child has a genetic heart condition, it's a good idea to notify and inform your school about the condition.

Vanessa Connell from our Royal Children's Hospital site suggests using the information sheets at www.heartregistry.org.au if your child's school, teacher, school nurse or counsellor would like general information on your child's condition. (If there's not one for your family's condition, please let us know so we can create one).

If you need specific information about your child's condition or a school first aid management plan then talk to your cardiologist who should be able to help.

Long QT syndrome study: We are starting a study on the psychosocial effects of genetic testing in people with long QT syndrome (LQTS). We are looking for people who have had genetic testing and those who haven't. If you're interested in participating, please email registry@centenary.org.au or call 02 9565 6185.

Pregnancy & genetic heart conditions

After receiving a few queries via email, phone and Facebook about pregnancy and genetic heart conditions, Lauren Hunt from our Royal Brisbane and Women's Hospital site and Prof Chris Semsarian developed an information sheet about pregnancy and genetic heart conditions.

Key points to consider include:

- ♥ Multi-disciplinary care is essential, including your cardiologist, obstetrician and GP
- ♥ See your cardiologist before becoming pregnant (or as soon as you find out you're pregnant) to discuss obstetric management in relation to your condition
- ♥ Discuss whether your current medication is safe to use during pregnancy and breastfeeding
- ♥ Most genetic cardiomyopathies and arrhythmia conditions are inherited in an "autosomal dominant" manner. Each child will have a 1 in 2 (50%) chance of inheriting the genetic alteration, with both males and females equally affected.
- ♥ Most women with a genetic heart condition will have a successful and uneventful pregnancy.



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

Yoga & ICDs study

A recent study of 26 people who participated in usual care plus an 8-week adapted yoga program (vs 20 people in usual care only) found they had decreased anxiety and even a 32% lower risk of ICD shocks. It's a small study and needs further research but suggests yoga could be worth a try. Before you sign up to a program or start a class, inform your instructor about your condition and your ICD so they can adapt moves accordingly.

Help us create an exercise information sheet

Following our Facebook discussions about the yoga study above, we plan to develop an information sheet on exercise and genetic heart conditions. We'd love your input so if you have any exercise queries you'd like us to answer, please email us at registry@centenary.org.au



Contact & Connect



registry@centenary.org.au



02 9565 6185



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