

# Heart Registry News



I recently attended an international conference on arrhythmogenic right ventricular cardiomyopathy or ARVC. The conference highlighted some great advancements in this condition that we will put into practice in our clinics, share with our colleagues in Australia and New Zealand and incorporate into our research. While we've come a long way in learning about this rare genetic heart condition, there's still so much we don't know or fully understand.

At the conference, our Registry was acknowledged as one of only nine registries worldwide as having relevant clinical information to contribute to the international body of knowledge on ARVC. Chris gave a presentation on our Registry and informed attendees about how we act as a truly national registry involving multiple centres and patients from all over the country.

*Dr Jodie Ingles, Australian Genetic Heart Disease Registry National Coordinator*

## Positive response to genetic heart disease information day

Around 200 people attended the genetic heart disease information day in September organised by Professor Chris Semsarian and his team. The feedback from people attending the day was very positive with most people saying they learnt something new.



Prof Semsarian said: "The patient information day was a great way to let people know about recent advancements in genetic heart disease. People were able to hear from our researchers and ask questions of our expert panel. The day also gave people a chance to meet others with a similar condition."



The Q&A sessions with the expert panel proved to be very popular. These sessions ran well over time and questions continued on during the breaks.

With such positive feedback, the team hopes to make the information day an annual event.

## When should families have genetic testing?

While it does depend on which disease, the general principle is testing should be conducted first in a person with a definite clinical diagnosis of disease. Having a family history of the disease also increases the chances of finding the disease-causing gene variant. The chance of finding the genetic cause also varies with different diseases, e.g. up to 70% in long QT syndrome and as low as 25% in Brugada syndrome.

Once a gene result has been identified, it can be used to test other relatives at risk of the disease (this is known as predictive genetic testing). Genetic testing should always be performed in the setting of a specialised clinic with genetic counselling a critical part of the entire process.

*Prof Chris Semsarian*

## Anything changed recently? Please let us know

If you've had a change of address, phone number or email please get in touch with us. Also if there's anything new to add about your genetic heart condition in you or your family, we'd love to hear from you so we can update your information. For updates, please contact us on **(02) 9565 6185** or [registry@centenary.org.au](mailto:registry@centenary.org.au)

## Meet the team: Lauren Hunt, Genetic Health Queensland Spring 2016

### **Lauren coordinates the Australian Genetic Heart Disease Registry site for the Royal Brisbane and Women's Hospital.**

Lauren is a certified genetic counsellor who coordinates the Queensland Cardiac Genetics Clinic with cardiologist Associate Professor John Atherton and geneticist Associate Professor Julie McGaughan. This team helps promote the Registry in Queensland and have contributed significantly to a number of our national research projects.

“I enjoy being a genetic counsellor because I love the integration of genetics and working with people,” says Lauren. “I particularly enjoy talking with patients to help them understand complex genetic information, such as their genetic risk and the implications of this diagnosis, for them, their children and other relatives.”

Lauren recently presented key highlights of the Queensland Cardiac Genetics Clinic at the inaugural International Clinical Cardiovascular Genetics Conference to cardiologists, geneticists and genetic counsellors from across the country.

Since opening their doors in February 2007, the clinic has helped 730 people with a genetic heart disease and their families. People were more likely to be referred for a personal diagnosis (59%) than for a family history (41%). Lauren also presented the Sudden Unexpected Death in the Young Patient Pathway the team has developed with Forensic Pathology to ensure better care of families who experience the tragic death of a young loved one. While Lauren loves her job she acknowledged it's not without it's challenges including the interpretation of genetic results and the increasing demand for the service.


For more information on the Queensland Cardiac Genetics Clinic, visit: [www.health.qld.gov.au/ghq/qcgc/](http://www.health.qld.gov.au/ghq/qcgc/)



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