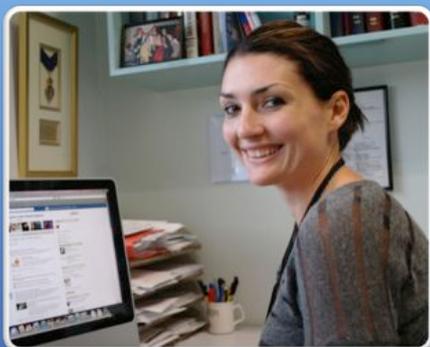


# Heart Registry News



2015 has been a busy but exciting year in the field of inherited genetics. Prof Chris Semsarian and I have been part of the Clinical Genome Resource (ClinGen), an international initiative that aims bring together genetic testing expertise worldwide. By working together as an international community we hope to better understand the role of gene variants in causing disease.

This issue of Registry News highlights some of our centres outside of Sydney, Melbourne & Brisbane. We are really excited to have Newcastle and Adelaide join us and to be able to introduce you to some really dedicated health professionals.

Thank you again to all of our families for your continued support!

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

## Dr Samuel Sears Jr, Ph.D. “Making a Cardiac Comeback – Confident Living with an ICD” –Ann Kirkness

The ICD Support group meeting at Royal North Shore Hospital in August was delighted to host Dr Sam Sears, a leading expert in the psychological care of cardiac patients with implantable cardioverter defibrillators (ICDs).

Dr Sears is a Clinical Psychologist and Professor in the Departments of Psychology and Cardiovascular Sciences at East Carolina University, USA. He has published numerous articles and produced a number resources for people living with an ICD. The focus of this presentation was how to live confidently and well with an ICD. Whilst Dr Sears acknowledged the very real challenges that some people face, he emphasised the importance of building a good “support team,” being well informed, and suggested that exercise and regular activity (at an appropriate intensity) play an important role in both physical and emotional wellbeing. Dr Sears reminded everyone that whilst they cannot necessarily control the shocks, they can control their impact – the strong message was to look at what you **can** do versus what you can’t and how to make that shift from victim to survivor.



If you would like more information about Dr Sears recent presentation or the ICD Support Group/Young ICD Network please contact Ann Kirkness, Cardiac Rehab, RNSH Phone: 9463 1701.

## Meet Catherine

Catherine O’Donnell is the newest member of our Sydney-based team. Catherine is a cardiac nurse and has just moved from the Family Heart Screening Clinic in Dublin. She has over 10 years experience in genetic heart disease.

Welcome Catherine!



## 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.

Please contact us on (02) 9565 6185 or [registry@centenary.org.au](mailto:registry@centenary.org.au)

## NEWCASTLE – NSW

Dr Anne Ronan (Geneticist) and Genetic Counsellor Angela Ingrey have established a multidisciplinary genetic heart disease clinic. The Hunter Cardiac Genetics Service sees patients from the Hunter, outskirts of Sydney, northern NSW up to the Queensland border and farwest NSW. Recognising a need for better services for patients, Anne and Angela have worked with Cardiologist A/Prof Jonathan Silberberg, Pathology North Molecular Geneticists Cliff Meldrum and Susan Dooley, Forensic Pathologists Dr Allan Cala and Dr Leah Clifton, and Liaison Psychiatrist Dr Marina Vamos to establish the service. A key focus of the clinic is the Australian Genetic Heart Disease Registry.



For more information on the Hunter Cardiac Genetics Service visit: [www.kaleidoscope.org.au/site/hunter-genetics](http://www.kaleidoscope.org.au/site/hunter-genetics) or email: [HNELHD@hnehealth.nsw.gov.au](mailto:HNELHD@hnehealth.nsw.gov.au)

## ADELAIDE – SA

Since the start of 2015, South Australia's public health sector pathology provider, SA Pathology, has offered genetic testing for hypertrophic cardiomyopathy by Next Generation Sequencing. From July, cardiologists have been able to request testing directly from SA Pathology, having previously needed to refer their patients to the SA Clinical Genetics Service. It is planned that testing for Long QT syndrome, and possibly other genetic heart diseases, will be offered in the future. This important development will enable South Australians to access genetic testing as part of routine care by their cardiologist. The initiative has been linked with active recruitment of South Australian patients to the Australian Genetic Heart Disease Registry and is currently coordinated by Prof Eric Haan (Clinical Geneticist), Ms Gemma Correnti (Associate Genetic Counsellor) and Dr Jess Marathe. This is an exciting development for South Australian families.



For more information email [Gemma.Correnti@sa.gov.au](mailto:Gemma.Correnti@sa.gov.au) or phone (08) 8161 6995.



## Contact & Connect

[www.heartregistry.org.au](http://www.heartregistry.org.au)

✉ [registry@centenary.org.au](mailto:registry@centenary.org.au)

☎ 02 9565 6185

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