As a research initiative with minimal funding we have achieved some amazing results. This is largely due to the overwhelming support we have had from people with genetic heart conditions and their families, cardiologists, geneticists, genetic counsellors and other health professionals.

As part of this success, we’re starting to gain international recognition, which has made us realise the ‘National’ in our name isn’t clear to audiences outside of Australia. We’ll now be known as the Australian Genetic Heart Disease Registry so you may notice small changes to our logo, website and materials shortly. We have also received generous funding for the Tasmanian branch and new team members have joined us in Victoria and Tasmania.

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

Vital support for Tassie branch

Generous funding from the Clifford Craig Medical Research Trust, Rotary Tasmania and some Lions Clubs will support the Tasmanian branch of the Registry for the next four years.

Over 130 Tasmanians have joined the Registry since the local branch was established in 2010 from the Clifford Craig Medical Research Trust funding. This was part of an Honours project by Jessica Kawa and Carli Armstrong, Professor Don McTaggart from Launceston General Hospital (pictured left being interviewed at the Tasmanian launch) and Dr Kathryn Ogden from the University of Tasmania.

Part of the new joint funding will support a part-time Registry Research Assistant and help promote the Registry to Tasmanian GPs and cardiologists.

Registry Chair Professor Chris Semsarian says: “We are incredibly grateful to the Clifford Craig Medical Research Trust, Rotary Tasmania and involved Lions Clubs for their generous support of the amazing team in Tasmania. This funding will go a long way in helping people with a genetic heart condition.”

For more information about how the Tasmanian branch of the Registry, please email tasregistry@telstra.com or 03 6348 8790.

New coordinator at Melbourne’s RCH

Vanessa Connell from the Royal Children’s Hospital (RCH) in Melbourne has joined us as the RCH’s new Registry Coordinator.

“While working with children and families with inherited heart conditions, I am often asked questions like ‘how many others have this, what ages, what treatments are there, what has worked?’ I believe some of these questions will be easier to answer when we have national data on all Australian families,” says Vanessa.

This position is jointly funded by RCH and the Registry.

For more information, please email vanessa.connell@rch.org.au or call (03) 9345 4239.

New information sheets online: visit www.heartregistry.org.au to view our information sheets on left ventricular non-compaction (LVNC) and Brugada syndrome.
Shocking campaign to save lives

In May 2010, 19-year-old Stephen Buckman collapsed and died from a cardiac arrest during training at his AFL club in Rupertswood, Victoria. A huge effort was made to try to save Stephen’s life, including nearly two hours of CPR involving off-duty paramedic Andrew White and others.

Stephen’s mum Sue, Andrew, family, friends and the local community were devastated by his sudden death. But they were determined to “do something” to ensure this didn’t happen again. So Sue and Andrew teamed up to create Defib Your Club, For Life (DYCFL) to get automated external defibrillators (AEDs) into Victorian football clubs.

In the event of a sudden cardiac arrest, an AED can deliver a life-saving shock to reverse a fatal heart rhythm. But for every minute a defibrillator is not used, the chance of survival plummets by 10%. In Stephen's case a defibrillator wasn’t available for 22 minutes.

In just under two years, DYCFL has installed more than 1000 AEDs in sporting clubs, schools and community organisations across Victoria! And this great initiative is now branching into other states. Much of this amazing work has been supported financially from local councils and the Bendigo Bank through its Community Bank network.

To find out more about DYCFL, visit www.defibforlife.org.au

Pictured right: Sue Buckman and Andrew White presenting an AED to Melbourne Heart Football Club senior coach and former Socceroo John Aloisi

To receive this newsletter via email, please contact us at registry@centenary.org.au