SPECIAL FEATURE:
RHEUMATIC HEART DISEASE IN PREGNANCY
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In this issue

The NHMRC-funded AMOSS Rheumatic Heart Disease in pregnancy (RHD-P) project grant finished end of 2016. The landscape has certainly changed since 2012, when one of our research team was told there was ‘no RHD in Australia’!

We’ve forged strong collaborations with other institutional and individual heroes who provide care for women with RHD-P: Aboriginal, remote health, cardiac services, public health groups, jurisdictional RHD programs, other RHD advocacy groups, our Reference group. Of course, none of the study would be possible without the ongoing support of participating AMOSS maternity services and other stakeholders across ANZ. Thank you.

AMOSS and RHD Australia have worked to promote better awareness among community and health services of the impact of RHD-P, including a video produced with the TAKEHEART crew. See the AMOSS RHD website (http://amoss.com.au/rhdinpregnancy) for this and other resources, and read more in this newsletter about work being done on educational curriculum resources for midwives.

Our work continues in RHD-P. Peer-reviewed publications on RHD are in progress, including public health impact, cardiac outcomes and challenges of surveillance. A recent case study with lead author NT Investigator Suzanne Belton, ‘Yarning about that heart problem’, highlights perspectives of remote-dwelling NT women journeying through pregnancy with RHD. See the current publication list on our website (http://amoss.com.au/publications).

State-wide and local initiatives are growing, particularly with the Western NSW Aboriginal Maternal Infant Health Strategy (AMIHS) – see more over the page. Jurisdictional RF/RHD control registers now include SA and NSW, as well as the existing registers and programs in NT, WA and Qld.

The NHMRC five year END RHD Centre of Research Excellence, headed by Jonathan Carapetis with Heather D’Antoine and Alex Brown (all part of our RHD-P team), continues to work towards a roadmap to end RHD in Australia (see over).

Research on the impact of RHD in pregnancy continues at UTS Sydney. We congratulate Geri Vaughan, who continues her doctorate on the challenges of health services for women with RHD-P, supported by an NHMRC postgraduate scholarship and UTS Chancellor’s Award.

The landscape has changed, but the fact remains that we should not have RHD. The ‘causes of the causes’ – poverty, overcrowding, poor housing – persist in Aboriginal and Torres Strait Islander and Maori and Pacifica women, as well as women from resource poor countries. We look forward to RHD in pregnancy becoming a redundant topic in the midwifery and obstetric curricula in both high and low income settings.

Other AMOSS news: world-first study on cardiac disease in pregnancy

With an outstanding team of investigators from cardiac and obstetric medicine and Aboriginal health, Liz Sullivan has been awarded the Heart Foundation NSW Cardiovascular Network Women and Heart Disease Grant 2016. This is the first-ever NSW longitudinal population-based study of first-time mothers with cardiac disease and their babies. While it is recognised that the additional workload on the heart during pregnancy can result in sometimes catastrophic complications, the long term impact of cardiac disease in pregnancy on surviving women is poorly understood. The study will establish a national research resource that provides an evidence base to governments, clinicians, advocacy groups and women of reproductive age with heart disease. The CVRN funding will be supported by UTS Sydney with a doctoral scholarship and data linkage funding. See next page for full list of investigators, and our next newsletter for more info.

Funding partners

We gratefully acknowledge current and past funding partners, including the Australian National Health and Medical Research Council (NHMRC), Heart Foundation, National Breast Foundation, International Vasa Previa Foundation, Australian Red Cross Blood Service, Royal Hospital for Women Sydney and Royal Adelaide Hospital. Also our administering institutions UTS Sydney (2014-) and UNSW (2009-2014).
Getting close to the End Game

The End Rheumatic Heart Disease Centre for Research Excellence (END RHD CRE) is now half-way through its five-year plan. This is the first time that any country has had an opportunity to build a comprehensive, evidence-based strategy for ending RHD. The project represents a tremendous challenge and an untold opportunity to tackle the disparity between Indigenous and non-Indigenous Australians.

The CRE has begun to identify a set of costed interventions designed to reduce the incidence of acute rheumatic fever and bring the prevalence of RHD for Indigenous Australians down to the same level as non-Indigenous Australians. It has put individuals and communities living with RHD at the centre of this work.

The CRE is collating existing research knowledge, identifying gaps and understanding the effect of potential interventions. Its research agenda and activities focus on developing the recommendations into a National Endgame Strategy presented to the Australian Government in 2020.

A newly-formed END RHD Coalition supports the Strategy and acts as the critical link between the research of the END RHD CRE and the health workers, families and organisations that will work together to end RHD in Australia. The founding members are:

- END RHD CRE based at Telethon Kids Institute
- Australian Medical Association
- Australian Heart Foundation
- RHD Australia based at Menzies School of Health Research
- National Aboriginal Community Controlled Health Organisation
- Aboriginal Medical Services Alliance Northern Territory

The END RHD CRE is funded by the National Health and Medical Research Council through a Centre of Research Excellence Grant to the Telethon Kids Institute, University of Western Australia.

Women with RHD: their journeys, their babies and communities

Info materials for the RHD-P study now feature a beautiful work by Rhiana Honeysett of Ngala Nanga Mai pAReNt Group Program. Funds raised at the presentation went to Rhodanthe Lipsett Indigenous midwives fund.
Several years ago, a midwife in a regional centre wrote to one of our RHD-P investigators, concerned that a woman under her care had had a missed diagnosis of RHD, with severe complications. Luckily, she survived. Others do not.

Since 2012, AMOSS has worked with Western NSW LHD Aboriginal Maternal Infant Health Strategy (AMIHS) to raise awareness and hear perspectives on care needs for Aboriginal women. The work that AMIHS throughout NSW LHDs - where Aboriginal health workers/educators and midwives work together under a partnership model - is improving health outcomes for Aboriginal women and non-Aboriginal women with Aboriginal partners during pregnancy and birth (see review).

Linda Bootle, AMIHS midwife and representative of the AMOSS RHD-P reference group comments... "The initiative has proved invaluable in helping us develop awareness and strategies around the importance of RHD in pregnancy, and our role in providing informed care. Although it’s overall rare, out here we’ve been surprised at the incidence and impact of RHD – including among our AMIHS staff. We have a good collaborative model that straddles maternity, Aboriginal and child health services, so we’ve been able to improve awareness and knowledge across the sectors."

Through the work of western NSW LHD AMIHS, AMOSS and others, a more detailed series of prompt questions has been added to the ObstetriX perinatal data system, helping to avoid possible missed diagnosis of RHD at the antenatal booking visit.

In 2014, NSW commenced an RHD Register. Acute rheumatic fever is now a notifiable condition in NSW, and RHD is notifiable in NSW in people under 35.