



SPECIAL FEATURE: RHEUMATIC HEART DISEASE IN PREGNANCY

APRIL 2017 NEWSLETTER #27

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) (<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) (<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.



Professor Elizabeth Sullivan
Principal Investigator AMOSS,
Professor of Public Health,
Director, Australian Centre
for Public and Population
Health Research, Faculty of
Health and Assistant Deputy
Vice-Chancellor (Research),
University of Technology
Sydney

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).



AMOSS Investigators & Team

Faculty of Health

University of Technology (UTS) Sydney

Tel 02 9514 4579

E amos@uts.edu.au URL: www.amos.com.au

First time mums with cardiac disease (NSW only)

Elizabeth Sullivan, UTS Sydney; Rachael Cordina, Royal Prince Alfred Hospital (RPAH), USyd; Lisa Simmons, RPAH, USyd; Michael Peek, ANU, The Canberra Hospital; Marilyn Clarke, Grafton Base Hospital; David Celermajor RPAH, USyd. Assoc: Wendy Pollock, La Trobe U; Karin Lust, Royal Brisbane & Mothers' Hospital (RBWH), UQ; Dominica Zentner, Royal Melbourne Hospital; Jon Hyett, RPAH, USyd; Debra Kennedy, UNSW, Prince of Wales Hospital (POW); Will Parsonage, RBWH, UQ; Geraldine Vaughan, UTS; Zhuoyang Li, UTS.

Renal disease in pregnancy

Shilpa Jesudason, Women's and Children's Hospital (WCHA), Adel U; Elizabeth Sullivan, UTS Sydney; Stephen McDonald, CNARTS; William Hague, WCHA, Adel U; Mark Brown, St George Hospital, UNSW; Angela Makris, UNSW

Gestational breast cancer

Elizabeth Sullivan, UTS; Christobel Saunders, UWA; Jan Dickinson, UWA; Angela Ives, UWA; Jane Fisher, Monash U; Greg Duncombe, RBWH; Karin Hammarberg, Monash U.

Massive obstetric haemorrhage

Elizabeth Sullivan, UTS; Claire McLintock, Auckland City Hospital (ACH); Erica Wood, Monash U; Zoe McQuilten, Monash U; David Ellwood, Griffith U; Wendy Pollock, La Trobe U; Andrew Bisits, Royal Hospital for Women; Amanda Henry, UNSW; Nolan McDonnell, KWMHW, UWA.

RHD in pregnancy NHMRC #1024206

Chief: Elizabeth Sullivan, UTS Sydney; Lisa Jackson Pulver, UWS; Jonathan Carapetis, Telethon Kids' Institute; Warren Walsh, UNSW, POWH; Michael Peek, ANU; Claire McLintock ACH; Suzanne Belton, CDU. Assoc: Alex Brown, SAMRI SA; Elizabeth Comino, UNSW; Heather D'Antoine, Menzies School of Health Research (MSHR); Simon Kane, Lyell McEwin Hospital; Juanita Sherwood, USyd; Sujatha Thomas, Royal Darwin Hospital; Bo Remenyi, MSHR; Geri Vaughan, UTS Sydney. Project team: Kylie Tune, MSHR; Faith Mahony (NZ).

Vasa praevia

Elizabeth Sullivan, UTS; Yinka Oyelese, Jersey Shore University Medical Centre; Robert Cincotta, Mater Mothers Hospital; Greg Duncombe, RBWH; Caroline Homer, UTS Sydney.

AMOSS NHMRC #510298 (2008-2012)

Michael Peek, ANU; Marian Knight, U Oxford; David Ellwood, Griffith U; Lisa Jackson Pulver, UWS; Caroline Homer, UTS; Claire McLintock, ACH NZ.

AMOSS team

Australia (UTS Sydney): Alex Wang; Zhuoyang Li; Angela O'Brien; Geraldine Vaughan; Kirisha Turnbull; Nadom Safi. NZ Coordinator: Vicki Masson.

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](#).



Rhiana Honeysett presents her work with the AMOSS team: (L-R) Zhuoyang Li, Kirisha Turnbull, Geri Vaughan, Rhiana, Alex Wang and Nadom Safi.

AMOSS at World Congress of Public Health Melbourne April

Look out for AMOSS at the UTS Public Health booth and our presentations on the AMOSS and RHD -P. AMOSS is one of the many projects under the recently launched **Australian Centre for Public and Population Health Research (ACPPHR)** at UTS Sydney.



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.

RHD in pregnancy in the midwifery curriculum

Awareness – knowledge – empowerment for midwives about rheumatic heart disease

RHDAustralia is working closely with AMOSS to increase knowledge resources for midwives about their roles in caring for women with RHD. Each year about 100 Australian women with RHD become pregnant or are newly diagnosed during pregnancy. RHD complicates the patient journey during pregnancy. Midwives must *'Think RHD'* in at risk population groups such as Aboriginal & Torres Strait Islander; Maori & Pacifica women, migrants and refugees. Kylie Tune of RHDAustralia comments *'I am really happy to see so many midwifery leaders and educators take up the call to better address this disease of social inequality.'*

Midwives are well placed to play a significant role in the care of women with RHD. A steering committee with representatives across ANZ has been established to focus on building awareness and knowledge of the disease. Undergraduate midwifery education is the initial focus, followed by the post graduate education curricula. RHDA is working towards accrediting resources with the Australian College of Midwives (ACM) with CPD points.

The RHD Midwifery Working Group is:

- exchanging ideas to build knowledge and awareness for midwives of the impact of RHD-P;
- providing high level advice on the development of an

RHD education module for midwives and undergraduates;

- monitoring development of the module, which will reflect local needs, while ensuring national content;
- providing feedback / problem-solving and strategic advice on progress milestones and policy directions;
- ensuring that RHDA jurisdictional programs and others working in RHD remain informed;
- assisting in the implementation of education modules;

This work is a direct result of the mixed methods research undertaken through the AMOSS RHD-P study. Investigator Suzanne Belton says; *'It will empower midwives to better detect women at risk and support them through pregnancy and childbirth. It is important that health research gets applied into practice and doesn't just sit in journals.'*

More information:

RHDAustralia website www.rhdaustralia.org.au

Email kylie.tune@menzies.edu.au

Diagnosis app www.rhdaustralia.org.au/apps

[RHDAustralia is the National Coordination Unit supporting the control of RHD in Australia. Funded under the Australian Government's Rheumatic Fever Strategy, it is based at Menzies School of Health Research in Darwin.]

AMOSS Data collectors:

Are you leaving?

Let us know! amos@uts.edu.au

Do you have your log sheet?

The log sheet is a vital support tool to help make it easier to follow up a case if there are any queries. You can download the log sheet and user notes [here](#).

Thanks to all of our data collectors and supporting units.

AMOSS studies 2017

Renal disease in pregnancy –
commencing mid 2017

Longitudinal study first time mums with cardiac disease – commencing mid 2017 (NSW only)

Amniotic fluid embolism – continues

Albany Regional Hospital, WA
 Albury Wodonga Health, VIC
 Alice Springs Hospital (ASH), NT
 Angliss Hospital, VIC
 Ararat Campus, VIC
 Armadale Health Service, WA
 Armadale Hospital, NSW
 Ashford Hospital, SA
 Atherton Tableland Hospital, QLD
 Auburn Hospital, NSW
 Auckland City Hospital, NZ
 Ayr Hospital, QLD
 Bairnsdale Regional Health Service, VIC
 Ballarat Health Services, VIC
 Bankstown-Lidcombe Hospital, NSW
 Bathurst Base Hospital, NSW
 Bay of Plenty DHB, NZ
 Beaudesert Health Service, QLD
 Benalla & District Memorial Hospital, VIC
 Bendigo Health Care Group, VIC
 Bentley Health Service, WA
 Biloela Hospital, QLD
 Blacktown Hospital, NSW
 Bowral Hospital, NSW
 Box Hill Hospital, VIC
 Bridgetown District Hospital, WA
 Broken Hill Health Service, NSW
 Broome District Hospital, WA
 Bunbury Regional Hospital, WA
 Bundaberg Hospital, QLD
 Burnside War Memorial Hospital, SA
 Busseton District Hospital, WA
 Caboolture Hospital, QLD
 Cabrini Health, VIC
 Cairns Base Hospital, QLD
 Cairns Private Hospital, QLD
 Calvary Bruce Private Hospital, ACT
 Calvary Health Care, SA
 Calvary Health Care Riverina, NSW
 Calvary Health Private, TAS
 Calvary John James, ACT
 Campbelltown Hospital, NSW
 Canterbury Hospital, NSW
 Carnarvon Regional Hospital, WA
 Casey Hospital, VIC
 Central Gippsland Health Service, VIC
 Charleville Hospital, QLD
 Chinchilla Hospital, QLD
 Christchurch Women's Hospital, NZ
 Coffs Harbour Base Hospital, NSW
 Cohuna District Hospital, VIC
 Colac Area Health, VIC
 Collie District Hospital, WA
 Cooma Hospital, NSW
 Cootamundra Hospital, NSW
 Cowra Health Service, NSW
 Dalby Hospital, QLD
 Dandenong Hospital, VIC
 Darwin Private Hospital, NT
 Deniliquin Hospital, NSW
 Derby Regional Health, WA
 Djerriwarrh Health Services, VIC
 Dubbo Base Hospital, NSW
 Dunedin Hospital, NZ
 Echuca Regional Health, VIC
 Emerald Hospital, QLD
 Epworth Freemasons Hospital, VIC
 Esperance District Hospital, WA
 Fairfield Hospital, NSW
 Figtree Private Hospital, NSW
 Fiona Stanley Hospital (Kaleeya), WA
 Flinders Medical Centre, SA
 Flinders Private Hospital, SA
 Forbes Hospital, NSW
 Frances Perry House, VIC
 Frankston Hospital, VIC
 Gawler Health Service, SA
 Geraldton Regional Hospital, WA
 Gippsland Southern Health Service, VIC
 Gisborne Hospital, NZ
 Gladstone Hospital, QLD
 Gladstone Mater Hospital, QLD
 Glen Innes Hospital, NSW
 Glengarry Private Hospital, WA
 Gold Coast University Hospital, QLD
 Goondiwindi Hospital, QLD
 Gosford Hospital, NSW
 Goulburn Base Hospital, NSW
 Goulburn Valley Health, VIC
 Gove District Hospital, NT
 Grafton Base Hospital, NSW
 Greenslopes Private Hospital, QLD
 Grey Base Hospital, NZ
 Griffith Base Hospital, NSW
 Gunnedah Hospital, NSW
 Gympie Hospital, QLD
 Hawke's Bay Hospital, NZ
 Hawkesbury District Health Service, NSW
 Hedland Health Campus, WA
 Hervey Bay Hospital, QLD
 Hobart Private Hospital, TAS
 Hornsby Ku-ring-gai Hospital, NSW
 Hurstville Private Hospital, NSW
 Hutt Valley Hospital, NZ
 Innisfail Hospital, QLD
 Inverell Health Service, NSW
 Ipswich Hospital, QLD
 Jessie McPherson Private Hospital, VIC
 John Flynn Gold Coast Private Hospital, QLD
 John Hunter Hospital, NSW
 Joondalup Health Campus, WA
 Kalgoorlie Regional Hospital, WA
 Kapunda Hospital, SA
 Kareena Private Hospital, NSW
 Katherine Hospital, NT
 Kempsey District Hospital, NSW
 King Edward Memorial Hospital For Women, WA
 Kingaroy Hospital, QLD
 Knox Private Hospital, VIC
 Kununurra District Hospital, WA
 Latrobe Regional Hospital, VIC
 Launceston General Hospital, TAS
 Leeton Hospital, NSW
 Lismore Base Hospital, NSW
 Liverpool Hospital, NSW
 Logan Hospital, QLD
 Longreach Hospital, QLD
 Loxton Hospital Complex, SA
 Lyell McEwin Hospital, SA
 Mackay Base Hospital, QLD
 Macksville Hospital, NSW
 Maitland Hospital, NSW
 Manning Base Hospital, NSW
 Mansfield District Hospital, VIC
 Mareeba Hospital, QLD
 Margaret River District Hospital, WA
 Maryborough District Health Service, VIC
 Mater Misericordiae Hospital Mackay, QLD
 Mater Misericordiae Hospital Rockhampton, QLD
 Mater Mothers Hospital Brisbane, QLD
 Mater Private Hospital Redland, QLD
 Mater Women's and Children's Hospital Hyde Park, QLD
 Mercy Hospital for Women, VIC
 Middlemore Hospital, NZ
 Mildura Base Hospital, VIC
 Milton-Ulladulla Hospital, NSW
 Mitcham Private Hospital, VIC
 Monash Medical Centre, VIC
 Moree Hospital, NSW
 Moruya District Hospital, NSW
 Mount Barker and Districts Soldiers Memorial Hospital, SA
 Mount Gambier & District Health Services, SA
 Mount Isa Hospital, QLD
 Mudgee District Hospital, NSW
 Mullumbimby Hospital, NSW
 Murray Bridge Soldiers' Memorial Hospital Inc, SA
 Murwillumbah District Hospital, NSW
 Muswellbrook District Hospital, NSW
 Nambour General, QLD
 Naracoorte Health Services, SA
 Narrabri Hospital, NSW
 Narrandera Hospital, NSW
 Narrogin Regional Hospital, WA
 Nelson Hospital, NZ
 Nepean Hospital, NSW
 Nepean Private Hospital, NSW
 Newcastle Private Hospital, NSW
 North Eastern Community Hospital, SA
 North Gosford Private Hospital, NSW
 North Shore Private Hospital, NSW
 North West Brisbane Private Hospital, QLD
 North West Private Hospital Burnie Campus, TAS
 Northam Regional Hospital, WA
 Northeast Health Wangaratta, VIC
 Northern Beaches Maternity Services, NSW
 Northpark Private Hospital, VIC
 Norwest Private Hospital, NSW
 Orange Base Hospital, NSW
 Osborne Park Hospital, WA
 Palmerston North Hospital, NZ
 Parkes Hospital, NSW
 Peel Health Campus, WA
 Peninsula Private Hospital, VIC
 Pindara Private Hospital, QLD
 Port Augusta Hospital & Regional Health Services, SA
 Port Lincoln Health Services Inc, SA
 Port Macquarie Base Hospital, NSW
 Port Pirie Regional Health Service, SA
 Portland District Health, VIC
 Proserpine Hospital, QLD
 Queanbeyan District Hospital & Health Service, NSW
 Redcliffe Hospital, QLD
 Redland Hospital, QLD
 Riverland Regional Health Service, SA
 Rockhampton Hospital, QLD
 Rockingham General Hospital, WA
 Roma Hospital, QLD
 Rotorua Hospital, NZ
 Royal Brisbane and Women's Hospital, QLD
 Royal Darwin Hospital, NT
 Royal Hobart Hospital, TAS
 Royal Hospital for Women, NSW
 Royal North Shore Hospital (RNSH), NSW
 Royal Prince Alfred Hospital (RPAH), NSW
 Ryde Hospital, NSW
 Sandringham Hospital, VIC
 Scott Memorial Hospital, NSW
 Shoalhaven District Memorial Hospital, NSW
 Singleton District Hospital, NSW
 South Coast District Hospital, SA
 South East Regional Hospital Bega, NSW
 South Gippsland Hospital (Foster), VIC
 South West Health Care (Camperdown), VIC
 South West Health Care (Warrnambool), VIC
 Southern Flinders Health - Crystal Brook Campus, SA
 Southland Hospital, NZ
 St Andrew's Ipswich Private Hospital, QLD
 St George Hospital, NSW
 St George Hospital Queensland, QLD
 St George Private Hospital, NSW
 St John of God Geelong, VIC
 St John of God Geraldton, WA
 St John of God Health Care Ballarat, VIC
 St John of God Health Care Berwick, VIC
 St John of God Health Care Bunbury, WA
 St John of God Health Care Midland, WA
 St John of God Health Care Subiaco, WA
 St John of God Hospital Bendigo, VIC
 St John of God Hospital Murdoch, WA
 St John of God Mt Lawley Hospital, WA
 St Vincent's Private Hospital Toowoomba, QLD
 St Vincent's Private Hospital Melbourne, VIC
 Stanthorpe Hospital, QLD
 Stawell Regional Health, VIC
 Sunnybank Private Hospital, QLD
 Sunshine Hospital, VIC
 Sutherland Hospital, NSW
 Swan Hill District Hospital, VIC
 Sydney Adventist Hospital, NSW
 Sydney Southwest Private Hospital, NSW
 Tamworth Rural Referral Hospital, NSW
 Tanunda Hospital, SA
 Taranaki Base Hospital, NZ
 Tauranga Hospital, NZ
 Temora District Hospital, NSW
 The Bays Hospital Mornington, VIC
 The Canberra Hospital, ACT
 The Kilmore & District Hospital, VIC
 The Mater Hospital Sydney, NSW
 The Northern Hospital, VIC
 The Royal Women's Hospital, VIC
 The Sunshine Coast Private Hospital, QLD
 The Tweed Hospital, NSW
 The Wesley Hospital, QLD
 The Whyalla Hospital & Health Services, SA
 Thursday Island Hospital, QLD
 Timaru Hospital, NZ
 Toowoomba Base Hospital, QLD
 Townsville Hospital, QLD
 Tumut Hospital, NSW
 Wagga Wagga Base Hospital, NSW
 Waikato Hospital, NZ
 Waikerie Health Services, SA
 Wairarapa Hospital, NZ
 Wairau Hospital, NZ
 Waitemata DHB, NZ
 Wallaroo Hospital, SA
 Warwick Hospital, QLD
 Waverley Private Hospital, VIC
 Wellington Hospital, NZ
 Werribee Mercy Hospital, VIC
 West Gippsland Hospital, VIC
 Western District Health Service (Hamilton), VIC
 Westmead Hospital, NSW
 Westmead Private Hospital, NSW
 Whanganui Hospital, NZ
 Whangarei Hospital, NZ
 Wimmera Health Care Group (Horsham), VIC
 Wollongong Hospital, NSW
 Women's and Children's Hospital, Adelaide, SA
 Wonthaggi Hospital (Bass Coast Regional Health), VIC
 Wyong Hospital, NSW
 Yarrawonga District Health Service, VIC
 Young Hospital, NSW