

## SPECIAL FEATURE: RHEUMATIC HEART DISEASE IN PREGNANCY

It is the paradox of rheumatic heart disease in Australia and New Zealand that highlights the importance of our AMOSS research. AMOSS studies rare and serious events. Less than four in 10,000 pregnant women in Australia have rheumatic heart disease (RHD) – yet over two in a hundred Aboriginal and/or Torres Strait Islander women in the Northern Territory journey through pregnancy with this condition each year. Similar high prevalence is seen in the North Island of New Zealand.

The serious complications of RHD are often due to undiagnosed disease, or sequelae of an increased cardiac workload during pregnancy exacerbating already diagnosed RHD. Conversely, early diagnosis and careful monitoring during pregnancy can optimise good outcomes for mother and baby.

This special AMOSS feature on rheumatic heart disease reviews the progress of our NHMRC-funded research, which is in the last year of a four-year mixed methods study on the impact of the disease in pregnant women. We are analysing findings of the two-year quantitative study on the clinical pathways of pregnant women. Principles of care of women with rheumatic heart disease in pregnancy (RHD-P) are highlighted by those obstetricians, midwives and cardiologists who provide health services. Suzanne Belton is leading a qualitative study in the NT of women's journeys with RHD-P, while Geri Vaughan explores the challenges of health services and RHD across Australia.

Underpinning our study is the commitment by all those who care for women with RHD in pregnancy, a disease that should be long gone; and the expert support provided by the reference group, investigators and study team. Thank you to all the AMOSS sites and data collectors who have been part of that process and supported the study.



Enjoy reading this newsletter.

Professor Elizabeth Sullivan  
Principal Investigator AMOSS

The rheumatic fever (RF) and RHD landscape is changing. RHD Australia recently led a landmark series of events in Sydney, including workshops and a symposium for health services, and a day-long colloquium to drive solutions. The week-long events were in partnership with Poche Centre for Indigenous Health, Heart Foundation NSW, Agency for Clinical Innovation, Aboriginal Health and Medical Research Council and NSW Health. It brought together other key RF/RHD initiatives including the END GAME for RF/RHD CRE and RhEACH, a global advocacy venture. **Announced at the workshop was the NSW Health proposal to list RF and RHD as notifiable conditions and establish an RF/RHD Register.**

Across the water, New Zealand is spearheading some exciting strategies to combat RF and prevent RHD – see below.

### Fighting the fever to stop RHD– the NZ story

Claire McLintock, Chief Investigator AMOSS and Faith Mahony, NZ Coordinator

In April this year NZ Health Minister Jonathan Coleman committed \$65 million over six years to combat rheumatic fever (RF). This substantial investment reflects the burden of untreated RF leading to RHD in NZ. Funding supports a multi-tiered approach. An online, TV and radio media campaign commenced in April. This is being run alongside sore-throat checks at drop-in clinics (16,000+ students to date) and over 200 school-based programs. See [rheumaticfever.health.govt.nz](http://rheumaticfever.health.govt.nz) for more information.

A lot of the initiatives to fight RF in New Zealand are out of the box. At the 2015 NZ inaugural 'Health Hackathon: Solving self-care – a think-fest and competition to develop collaborative approaches to novel health care solutions' - the 'Fight the Fever' group had a landslide victory. Their innovation helps young people who've had RF to help manage monthly antibiotic injections over a ten year period. A multi-phased project has been developed to evaluate and refine a Fight the Fever mobile App for young people with RF/RHD. This app - co-designed with those that have the disease - will promote self-management, and increase understanding of the RF/RHD management. Its whānau ora approach means young people can engage their social network to support antibiotic compliance, clinic attendance and self-management.



Claire McLintock and Faith Mahony

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**Massive obstetric haemorrhage study**

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**Rheumatic heart disease study**

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**Gestational Breast Cancer**

Professor **Elizabeth Sullivan**, University of Technology Sydney, Winthrop Professor **Christobel Saunders**, University of Western Australia; Professor **Jan Dickinson**, University of Western Australia; Dr **Angela Ives**, University of Western Australia; **Professor Jane Fisher**, Monash University; A/Professor **Greg Duncombe**, Royal Brisbane Women's Hospital; Dr **Karin Hammarberg**, Monash University

**Massive Obstetric Haemorrhage**

Professor **Elizabeth Sullivan**, University of Technology; Dr **Claire McLintock**, Auckland City Hospital; A/Prof **Erica Wood**, Monash University; Dr **Zoe McQuilten**, Monash University; Professor **David Ellwood**, Griffith University; Dr **Wendy Pollock**, La Trobe University; A/Prof **Andrew Bisits**, Royal Hospital for Women; Dr **Amanda Henry**, UNSW Medicine

**RHD in pregnancy**

Chief: Professors **Elizabeth Sullivan**, University of Technology; **Lisa Jackson Pulver**, UNSW Medicine; **Jonathan Carapetis**, Telethon Institute for Child Health Research; Dr **Warren Walsh**, UNSW Medicine; Professor **Michael Peek**, University of Sydney; Dr **Claire McLintock**, Auckland City Hospital

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**Vasa Praevia**

Professor **Elizabeth Sullivan**, University of Technology; A/Prof **Yinka Oyelese** Jersey Shore University Medical Centre; A/Prof **Robert Cincotta**, Mater Mothers Hospital; A/Professor **Greg Duncombe**, Royal Brisbane Women's Hospital; Professor **Caroline Homer**, University of Technology Sydney

**LISTENING AND SEEING WITH TWO CULTURES**

**Qualitative study into RHD in pregnancy in the Northern Territory**

Dr **Suzanne Belton**, **Kylie Tune**, **Heather D'Antoine**, **Quitaysha Thompson**, **Menzies School of Health Research, Darwin**



*Quitaysha Thompson, Suzanne Belton, Kylie Tune*

Having a diagnosis of RHD adds a level of risk to a woman's pregnancy journey. Globally, rheumatic heart disease is overwhelmingly seen in those women who are most disadvantaged and vulnerable. In Australia, Indigenous women are more likely to die during pregnancy and childbirth than non-Indigenous women. Living in remote places, often vast distances from health and welfare services, the women we are seeing in the Northern Territory with RHD-P are indeed disadvantaged and vulnerable. They face problems of accessing maternity services and cardiac care. They face problems in understanding their caregivers who often do not speak the same language. They face problems of long periods of time away from their husbands, children and families if they need specialised or even ordinary maternity care. They are sometimes sent thousands of kilometres interstate for specialised care. And they are susceptible to co-morbidities and often serious complications - including death.

Our intention was to recruit any pregnant woman with a diagnosis of RHD in the NT. Yet only Indigenous women seem to have this disease in the Northern Territory.

The pregnancy journeys of eight Indigenous women with rheumatic heart disease from different parts of the Northern Territory, who have different parities, different levels RHD, and different social backgrounds – have been followed for the duration of their pregnancy by a team based at Menzies School of Health Research. The women are invited to converse with the researchers as they attend health services or at home about their lives and living with RHD. The women are remarkably resilient and cope with extreme overcrowding in housing, poverty, violence and a confusing health system that does not necessarily link primary and tertiary services or cardiac and maternity services well.

Our research questions are quite simple: What specific cultural, community and social needs do Aboriginal women have that are not currently addressed in health services, counselling and clinical management of RHD in pregnancy, and how does that vary across the Northern Territory? What degree of health literacy and awareness exists amongst women with RHD in relation to this condition and its impact in pregnancy? And how can health services more effectively meet the needs of these women, including access, education, counselling and clinical management of RHD in pregnancy? The answers may be more challenging.

Led by Dr Suzanne Belton, the local research team is formed from experts in Indigenous knowledges, health care and qualitative research. The project is guided by Indigenous and non-Indigenous researchers Professors Sue Kruske, Lisa Jackson Pulver, Juanita Sherwood, Elizabeth Sullivan and Geri Vaughan who contribute to the methodology and interpret the meanings. The importance of this research in revealing the women's stories is realised by the research team, who have found the work a privilege and a challenge.

Meeting in July in Darwin, the research team is preparing to analyse the stories, using qualitative methods and reflection to find the patterns within these journeys. And while the journeys are different on one level, all tell a story of survival, resilience and of hardship. A hardship that we believe is unacceptable in this country, Australia.

## RHD IN PREGNANCY: CLINICAL & HEALTH SERVICE ISSUES

Data from the two-year AMOSS quantitative study of RHD-P are currently being analysed, but what do we know already?

The obvious clinical implications for pregnant women who have RHD is that the extra work (30-50%) that happens in a normal pregnancy is being done by a heart that is not working as it should.

While there are risk factors associated with many of the conditions that AMOSS studies, they are often unpredictable – for instance, a catastrophic amniotic fluid embolism event cannot usually be anticipated. In contrast, many of the principles that prevent complications and support good outcomes of women with RHD and their babies are premised on awareness, careful monitoring and collaborative care during pregnancy.

Dr Warren Walsh, chief investigator and cardiologist at Prince of Wales Hospital in Sydney, agrees. He stresses the importance of early assessment – ideally before pregnancy. *“Women do get missed. A stethoscope is not very reliable, and it’s easy to miss mitral stenosis and aortic regurgitation even by experienced clinicians. An echocardiogram is absolutely essential for any woman with suspected RHD or a cardiac history.”* Service delivery in regional areas provides challenges. *“It’s improved over the last few years with portable echo machines – initiatives such the Poche Centre for Indigenous Health sponsorship of echo machines help outreach work – but we still have a long way to go”,* Dr Walsh continues. *“You need skilled operators and clinicians to perform and read those echos. We know about the high prevalence in NT, Qld and WA, and the north island of New Zealand, but regions such as western NSW have gaps in services – and so women get missed, and then end up in hospital with complications that are often avoided with earlier diagnosis and management. More cardiac outreach services are critical to support local health services that provide care for the women.”*

Unsurprisingly, the features of care that promote good outcomes for pregnant women with RHD align with initiatives to make maternity services more accessible and culturally appropriate. Services such as the NSW Aboriginal Maternal and Infant Health Service (AMIHS) build on existing available maternity services whilst adding an innovative approach, underpinned by culturally appropriate and collaborative care[1], with Aboriginal and non-Aboriginal midwives and Aboriginal Health Workers working to care for women through pregnancy.

Linda Bootle, Clinical Midwife Consultant in the Western NSW Local Health District AMIHS describes her group: *“Our teams work with Aboriginal mothers and babies across Western NSW with many sites geographically isolated. We have been educating the AMIHS teams and midwives on RHD in pregnancy so they ask further questions during their history taking, in particular if they received monthly injections as a child. The awareness is so important. In one education session one of our senior Aboriginal Health Workers commented that ‘I had that when I was young’. Good history taking is crucial with further medical consultation arranged during the pregnancy. Geographical isolation and distance can be a barrier to receiving specialised care and we work hard to make sure the women don’t miss the care they need”.*

Professor Elizabeth Sullivan, Principal Investigator on the RHD-P study, comments *“We are discovering many different stories and clinical pictures of women. A 38 year old refugee woman from Sudan has a very different story from a young Wiradjuri woman from western NSW, and different again from a Maori woman in urban Middlemore – but the features of care that Warren and Linda highlight- early (ideally pre-pregnancy) diagnosis of RHD, better access to diagnostic and treatment services, collaborative care, are all*

### Thanks and chocolates to ...

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### Challenges of health services and RHD in pregnancy

A mixed methods doctoral study of the barriers to access of timely, best practice maternal and cardiovascular care for pregnant women with RHD, through 1) a quantitative study of surveillance and health information systems related to RHD in pregnancy; and 2) a qualitative examination of health professionals’ knowledge, experiences of and attitudes to provision of care for pregnant women with RHD. Contact Geri Vaughan for more info [g.vaughan@uts.edu.au](mailto:g.vaughan@uts.edu.au)

(cont)

*critical priorities to minimise the impact of RHD in pregnancy. I would also add that there is an imperative to improve health systems that talk to each other more effectively. We need to make it easier to monitor history and treatment of women with RHD in pregnancy: it’s a critical part of an effective model of care.”*

1. Best E: Closing the gap through innovative maternity care (The Aboriginal Maternal and Infant Health Service). Women and Birth 2011, 24, Supplement 1(0):S16.



*Thanks to the following participating AMOSS sites*

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 Bega Hospital, NSW  
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 Casey Hospital, VIC  
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 Charleville Hospital, QLD  
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 Collie District Hospital, WA  
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 Cowra Health Service, NSW  
 Dalby Hospital, QLD  
 Dandenong Hospital, VIC  
 Darwin Private Hospital, NT  
 Deniliquin Hospital, NSW  
 Derby Regional Health, WA  
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 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  
 Galliers Private Hospital & Specialist Centre, WA  
 Gawler Health Service, SA  
 Geelong Hospital, Barwon Health, VIC  
 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  
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 Joondalup Health Campus, WA  
 Kalgoorlie Regional Hospital, WA  
 Kapunda Hospital, SA  
 Kareena Private Hospital, NSW  
 Katanning District Hospital, WA  
 Katherine Hospital, NT  
 Kempsey District Hospital, NSW  
 Kerang & District Hospital, VIC  
 King Edward Memorial Hospital For Women, WA  
 Kingaroy Hospital, QLD  
 Kununurra District Hospital, WA  
 Kyabram District Health Service, VIC  
 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  
 Manning Base Hospital, NSW  
 Mansfield District Hospital, VIC  
 Mareeba Hospital, QLD  
 Margaret River District Hospital, WA  
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 Mater Misericordiae Hospital Mackay, QLD  
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 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  
 Mersey Community Hospital, TAS  
 Middlemore Hospital, NZ  
 Mildura Base Hospital, VIC  
 Millicent & District Hospital, SA  
 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  
 Mt Waverley Private Hospital, VIC  
 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  
 Narrrogin 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  
 Seymour District Memorial Hospital, VIC  
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 St John of God Mt Lawley Hospital, SA  
 St Vincents Private Hospital, QLD  
 St Vincents 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  
 Swan Kalamunda Health Service, WA  
 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  
 Waitakere Hospital, NZ  
 Waitemata DHB, NZ  
 Wallaroo Hospital, SA  
 Warwick Hospital, QLD  
 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  
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 Yarrawonga District Health Service, VIC  
 Young Hospital, NSW