

Some rare and serious conditions in pregnancy are well known, gain a lot of media coverage, have associated support groups and are the focus of much research – and rightly so. However, there are others that lead to just as much morbidity, but slip through with little attention. Rheumatic heart disease in pregnancy is one such example. It is a condition associated with poverty and deprivation and is a neglected public health problem. Aboriginal and Torres Strait Islanders and Maori and Pacific Islander peoples have among the highest documented rates of rheumatic heart disease in the world.

AMOSS with its nearly 300 connected maternity units is carrying out a mixed methods study of women with rheumatic heart disease in pregnancy across Australia and New Zealand. This NHMRC funded project will help provide an evidence base including prevalence, geographic distribution, severity, current models of care and outcomes to help guide future care.

Conditions such as rheumatic heart disease in pregnancy - that have a higher incidence in rural and remote areas compared to urban areas - are very difficult to study. Strengths of AMOSS include its collaboration across disciplines and its coverage across two nations. This gives it an ability to look at such conditions without bias.

Our November newsletter profiles some of the stories and challenges of maternity care in remote settings as it relates to the AMOSS study.

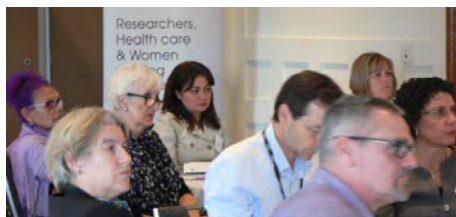
Many thanks to all involved in AMOSS at the many different hospitals and health services. Without you we would not be able to conduct these studies which will improve care.



Michael Peek, Chief Investigator AMOSS and the RHD in pregnancy study

#### AMOSS RHD in pregnancy Reference Group meeting August 2013

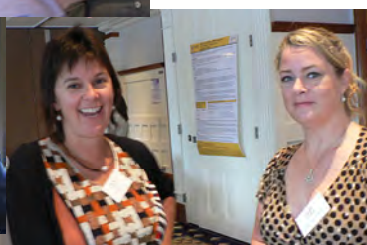
Professor Chris Baggoley, Australian Government Chief Medical Officer opened the Reference Group meeting where nearly 30 obstetricians, midwives, cardiologists, researchers from ANZ came together to discuss the study and its progress.



Karen Atkinson, Sue Jacobs, Desley Williams, Nasrin Javid, Mitchell Smith, Sue Heath, Simon Kane, Sue Kruske



Heather D'Antoine, Geri Vaughan, Aunty Ali Golding, Jariah Kaissis and Imogen



Kylie Tune, Claire Boardman

#### AMOSS Team, UNSW Medicine

Nasrin Javid, AMOSS Project Coordinator

Michele Partridge

Tel 02 9382 1068

E [amos@unsw.edu.au](mailto:amos@unsw.edu.au) URL: [www.amos.com.au](http://www.amos.com.au)

#### NZ Coordinator

Vicki Masson, PMMRC

Tel 09 923 4440 E [v.masson@auckland.ac.nz](mailto:v.masson@auckland.ac.nz)

#### RHD Coordinators

Geraldine Vaughan, UNSW Medicine

Tel 02 9382 1564 E [geri@unsw.edu.au](mailto:geri@unsw.edu.au)

Kylie Tune, Menzies School of Health Research

Tel 0448 777780 E [Kylie.Tune@menzies.edu.au](mailto:Kylie.Tune@menzies.edu.au)

Faith Mahony, Auckland City Hospital NZ

Tel 09 3074949 Ex25342 E [FaithMa@adhb.govt.nz](mailto:FaithMa@adhb.govt.nz)

#### AMOSS Investigators

Chief: Professor Elizabeth Sullivan, UNSW Medicine; Professor Michael Peek, University of Sydney; Professor Marian Knight, University of Oxford; Professor David Ellwood, Australian National University; Professor Lisa Jackson Pulver, UNSW Medicine; Professor Caroline Homer, University of Technology Sydney; Dr Claire McLintock, Auckland City Hospital, NZ; Associate: Prof Elizabeth Elliott, APSU: The Children's Hospital Westmead; Dr Tessa Ho, Mary Aikenhead Ministries; A/Prof Nolan McDonnell, King Edward Memorial Hospital for Women, WA; Dr Wendy Pollock, La Trobe University/Mercy Hospital for Women, Victoria; A/Prof Yvonne Zurynski, APSU, The Children's Hospital Westmead, Sydney

#### Gestational Breast Cancer Investigators

Professor Elizabeth Sullivan, UNSW Medicine 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; Dr Greg Duncombe, Royal Brisbane Women's Hospital; Dr Karin Hammarberg, Monash University

#### RHD Investigators

Chief: Professor Elizabeth Sullivan, UNSW Medicine; Professor Lisa Jackson Pulver, UNSW Medicine; Professor 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  
Associate: Dr Suzanne Belton, University of Sydney; Professor Alex Brown, Baker IDI NT; A/ Professor Elizabeth Comino, UNSW Medicine; Ms Heather D'Antoine, University of Sydney; Dr Simon Kane, Lyell McEwin Hospital, Adelaide; Professor Juanita Sherwood, University of Technology Sydney; Dr Sujatha Thomas, Royal Darwin Hospital, Darwin; Dr Bo Remenyi, Menzies NT; Ms Geri Vaughan, UNSW Medicine

#### Vasa Praevia Investigators

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

## AMOSS conditions & data collection periods

### Current studies

- Amniotic fluid embolism (since 2010)
- Antenatal pulmonary embolism (2010 –2013)
- Gestational breast cancer (2013-14)
- Rheumatic heart disease (2013-2014)
- Vasa praevia (2012-2013)
- Massive obstetric haemorrhage (2014)

### Completed studies

- Morbid obesity (BMI > 50)
- Influenza – ICU admission
- Eclampsia
- Peripartum hysterectomy
- Placenta accrete

## Chocolates and thanks...

To maternity unit staff at **Mt Isa Hospital** Qld: Rebecca Sibbick, Dianne Jeans, Dianne Owens, Chris King, Elena Kreimer. Mt Isa has been part of AMOSS since 2010. This region cares for a disproportionate number of women with rheumatic heart disease.

## Funding

We gratefully acknowledge the following funding:

**NHMRC**; [AMOSS #510298; Rheumatic heart disease (RHD) # 1024206]; **National Breast Cancer Foundation** [Novel Concept Award]; **International Vasa Previa Foundation**: [Vasa previa study]; **UNSW Major Research Equipment and Infrastructure Initiative (MREII)**; **Royal Hospital for Women Foundation Board**: (Massive obstetric haemorrhage study)

## RHD in pregnancy: key messages

**Importance of early diagnosis:** High-risk populations include Aboriginal and Torres Strait Islander women (across Australia); Māori and Pacific Islander (Australia as well as NZ); Migrants and refugees from resource-poor countries

**During pregnancy:** Importance of early assessment, multidisciplinary care and monitoring

**Echocardiogram reports:** include in medical notes if women are transferred

**Bicillin during pregnancy:** no evidence of teratogenicity - see Guidelines

**Mechanical heart valves** – see Guidelines

(refer to pp57, 98 [Australian guidelines ARF/RHD](#))

## Kimberleys visit

Kununurra, a town of 4000 in the remote eastern Kimberleys of Western Australia, recently hosted a well-attended Child and Maternal Health workshop coordinated by the Kimberley Population Health Unit. Around 70 health professionals from across the Kimberley region joined together to talk about health issues, projects and updates. Kylie Tune presented on the AMOSS - particularly RHD in pregnancy - and how the Kimberley is involved. The midwives in the audience were very interested in supporting the study, and lots of pathways were planned.

*"I walked away from this workshop with such admiration for the dedicated professionals who work in such a remote part of Australia", said Kylie, NT project coordinator for the RHD study. "Despite difficulties with systems, patient information and isolation, these midwives, RN's, obstetricians and health workers provide a very high level of care."*

## AMOSS and the RHD study: building pathways

*"Having partnerships is so important. We all have the same goal – healthy mums and bubs."*

Rheumatic heart disease in pregnancy highlights many of the challenges of providing integrated quality maternity care for women in rural and regional settings. There are many dimensions to this - multidisciplinary care, information sharing, travel and transfer, cultural safety – and we've needed to extend beyond our usual model to make sure the data collection processes work. This article highlights some of the issues and work that's been done to make it happen, focussing on a few of the sites that the research team has worked with.

Many of the features of remote settings have provided associated challenges for the RHD in pregnancy study. Collaboration has been the key in providing optimal notification for our study. From the Northern Territory to the Kimberleys (*see separate feature this page*) and far North Queensland to Dubbo NSW and Waikato New Zealand, strategies are being developed to make sure that all eligible women are included.

While maternity units remain the hub of AMOSS, we've been working to build collaborative models. In most sites,

systems have been established to reduce data collection load (the echo reports are now sent to us directly) and streamline notification systems. This process continues but (lots of ethics amendments later!) we're building a model that is working well, and which helps foster networks across disciplines and locations. Darwin, Alice Springs, Katherine, Mount Isa, Townsville, Cairns, Mareeba, Kununurra, Broome, Gladstone, Derby, Kalgoorlie, Broken Hill, Dubbo: these are a few of the regional/remote Australian locations with participating AMOSS sites.

## Across Top End and Central Australia

In the Northern Territory, multiple tiers of notification include the maternity units, perinatal and hospital data reporting, remote care data systems, cardiac data systems, along with working closely with the Midwifery Group Practices, Aboriginal medical services, cardiac care nurses, remote health services and RHD control registers.

*“Is the care we provide woman-centred and individualised? – Yes. Is it effortless? No”. (Elena Kreimer, Obstetrician Mt Isa Hospital)*

In northern Queensland, similar themes are voiced as other regional/remote settings. Located in north-west Qld, Mt Isa Hospital and its health service provides care for 35,000 people, servicing an area of some 300,000 km<sup>2</sup>(!) Of the 550 women who give birth at Mt Isa annually, around 40% are Aboriginal and/or Torres Strait Islander. Women may have to travel vast distances at least three times during pregnancy, and then move to Mt Isa – away from family and community - at 36 weeks for delivery, where there is a lack of suitable, affordable housing. There are limited echocardiographic services – vital for monitoring any problems during pregnancy.

Rebecca Sibbick, MUM at Mount Isa highlights some of the data collection challenges: *“We’re coordinating different care providers, getting information from multiple sources. The high turnover of staff also provides challenges to embedding regular processes and systems appropriate to the particular information needs of remote Australia”*. Midwives Rebecca, Mary Lucas and Dianne Jeans, together with Dianne Owens, Aboriginal Health Worker and Natalie Thomas, RHD Control Register Coordinator have worked to set up effective systems for AMOSS notification.



**The Mt Isa team:** Rebecca Sibbick, Chris King, Elena Kreimer, Mary Lucas, Natalie Thomas, Dianne Owens

## Working with RHD Control Registers

Registers (supporting notification of acute rheumatic fever and the penicillin secondary prophylaxis programs to prevent/worsening RHD) are established in NT, Qld, WA and SA, and have become an integral part of the AMOSS RHD study.

Louise Axford-Haines of the Queensland RHD Control Program recently had coffee with Townsville AMOSS midwives Annie Lawrence, Cherie Bonaface and National RHD Coordinator Geri Vaughan. *“These partnerships are so important”*, said Louise. Her role as coordinator spans a huge territory across far north Queensland. *“We [the RHD program] work hard to build awareness of RHD and the importance of the secondary prophylaxis – women can miss their [penicillin] injections whilst away from community to give birth.”* Louise works with Annie and

Cherie, putting them in touch with communities such as Doomagee and Normanton, and making sure the information provided is complete.

Natalie from Mt Isa RHD Control Register highlights the importance of cultural safety. *“A lady from Camooweal had been lost to follow up for cardiology review, echo’s and bicillin. But she felt very supported with the care she received when she had her baby in Mt Isa and now attends the Camooweal clinic for Bicillin every 28 days, with cardiology follow-ups in Mt Isa and in Townsville. Both mum and baby are doing well”*. The Mt Isa Outreach Midwifery Service and Mobile Women’s Health Service identify any ARF/RHD patients in the communities and link with the RHD CNC for patient information and access to Outreach Cardiology Services.

## RHD: not just up north!

While the prevalence of RHD is significantly higher in Top End and Central Australia, many of the women (over 35%) live in NSW, Vic and SA. Therein one of the challenges: with prevalence so much lower, there may not be as much awareness of the risks and impact of this disease. RHD diagnosed during pregnancy is usually associated with higher rates of complications.

Miguel Marquez, senior registrar O&G at Dubbo NSW echoes many of the concerns related to maternity care in regional settings. *“Many specialised investigations are only available in larger metropolitan hospitals. Due to the burdens on patients such as travel, financial and impact on family, many don’t seek treatment until very late”*. On the other hand, the relationship with the various specialist groups is very close knit and it’s easy to seek assistance. Roger Chatoor, cardiologist at Dubbo Hospital travels across western NSW and is a member of the AMOSS RHD Reference Group. Given the large region covered and the fact that it is the referral centre for delivery, Dubbo maternity relies on practitioners to provide services. *“Our VMO obstetricians attend outreach clinics in neighbouring towns - Mudgee, Bourke, Walgett, Coonamble, Cobar – and we rely strongly on GP shared care and midwives from these communities”*, says Miguel.

## New Zealand

While the geographic distribution profile in NZ is very different - RHD is clustered predominantly in urban settings of the North Island – surveillance challenges exist here too. NZ coordinator Faith Mahony works closely with AMOSS coordinators across the district health boards, as well as the RHD control register body to ensure that all eligible women are included.

These challenges of data collection for the AMOSS study mirror in part many of the issues faced in regional and remote maternity care settings. The processes and collaborations that have been established for the study continue with the aim of getting the best information we can.

Rebecca from Mt Isa summed up ... *“This study about RHD in pregnancy is important. There is still so much to learn”*.



*Thanks to the following hospitals that have responded to AMOSS over the last three months*

**All three months**

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

**Two months**  
Armadale Health Service  
Auburn Hospital  
Bairnsdale Regional Health Service  
Bundaberg Hospital  
Caboolture Hospital  
Casey Hospital  
Dunedin Hospital  
Gippsland Southern Health Service  
Griffith Base Hospital  
Mareeba Hospital  
Redcliffe Hospital  
Sandringham Hospital  
St George Hospital Queensland  
St John of God Health Care Ballarat  
Sutherland Hospital  
The Northern Hospital  
Waitemata DHB

**One month**  
Attadale Private Hospital  
Bendigo Health Care Group  
Dalby Hospital  
Geelong Hospital, Barwon Health  
Hobart Private Hospital  
Mater Misericordiae Hospital Mackay  
South West Health Care (Camperdown)  
Southland Hospital  
St George Hospital  
St John of God Health Care Subiaco  
West Gippsland Hospital