



SPECIAL FEATURE: RENAL DISEASE IN PREGNANCY

SEPTEMBER 2016
NEWSLETTER #26

In this issue

Welcome to the new-look AMOSS newsletter! Inside you'll find an update on our current research projects and an introduction to our new study, Renal Disease in Pregnancy. Dr Shilpa Jesudason, nephrologist and obstetric physician at the Women & Children's Hospital, Adelaide, provides an overview of the impact of this condition in pregnancy, and how the AMOSS study will provide critical information on the care that these women require.

News

RHD "Heart on your sleeve" campaign

Midwives, nurses and public health staff from the Faculty celebrated Winter Solstice with a lunch in June 2016, which raised \$100 towards the Rhodanthe Lipsett Indigenous Midwives scholarship fund. The lunch finished with a group photo – including the AMOSS RHD in Pregnancy study staff – wearing hearts on sleeves, in support of the campaign (#RHDmatters) to raise awareness of the impact of rheumatic heart disease.

AMOSS visits the Kimberley

In August, nearly 90 participants across remote, maternity care, Aboriginal health, and other agencies gathered at the Chronic Diseases workshop in Derby WA to hear powerful stories, including the impact of rheumatic heart disease and renal disease in pregnancy. Geri Vaughan, AMOSS' RHD Coordinator, continued with inservices and meetings in the Kimberley and Perth. The RHD in Pregnancy study highlights the importance of early (and ongoing) monitoring during pregnancy. Midwives, GPs and remote and Aboriginal health services play a critical role in checking for a history of rheumatic fever/RHD, follow-up cardiac assessment and continuing monthly bicillin injections where prescribed.

New staff

Angela O'Brien, Project Coordinator Angela holds an honours degree in Psychology and a Master of Public Health, and has 8 years' experience in public health research and project management. She also has extensive administration and office support experience in corporate and not for profit enterprises.

Nadom Safi, Research Coordinator Nadom is an overseas qualified medical doctor, has 16 years' clinical experience in primary health care in addition to his speciality in rheumatology and medical rehabilitation. Nadom has worked in different research areas including assisted reproductive technology, maternal and child health, and cancer. He has expertise in data management and analysis, and writing and preparing studies for publication.



Wearing our hearts on our sleeves – RHD in Pregnancy (L-R) Angela O'Brien, Kirisha Turnbull, Zhuoyang Li, Geri Vaughan, Sacha Kendall, Allison Cummins, Anna Doab and Fenglian Xu.

Partnerships & Publications

AMOSS values its partnerships that support surveillance and research of selected maternal conditions that reflect public health priorities. We gratefully acknowledge our current and past funding partners, including the Australian National Health and Medical Research Council (NHMRC), National Breast Foundation, International Vasa Previa Foundation, Australian Red Cross Blood Service, Royal Hospital for Women Sydney and Royal Adelaide Hospital. We also gratefully acknowledge the University of Technology Sydney (2014 -) and the University of New South Wales (2009-2014), which – as the administering institutions – have provided AMOSS with critical ongoing infrastructure support.

Peer-reviewed journal articles by AMOSS investigators have been published in the British Medical Journal, Australian and New Zealand Journal of Obstetrics and Gynaecology, Australian Health Review, British Journal of Obstetrics and Gynaecology, Midwifery, Intensive Care Medicine, BMC Pregnancy and Childbirth, and others (see publication list on our [website](#)).



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Sydney



AMOSS Team & Investigators

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AMOSS team

Australia: Angela O'Brien; Geraldine Vaughan; Zhuoyang Li; Kirisha Turnbull; Alex Wang; Nadom Safi

NZ Coordinator: Vicki Masson

AMOSS Investigators

Principal Investigator: Elizabeth Sullivan, UTS Sydney

Gestational Breast Cancer

Elizabeth Sullivan, UTS Sydney; Christobel Saunders, UWA; Jan Dickinson, UWA; Angela Ives, UWA; Jane Fisher, Monash U; Greg Duncombe, Royal Brisbane Women's Hospital; Karin Hammarberg, Monash U

Massive Obstetric Haemorrhage

Elizabeth Sullivan, UTS Sydney; Claire McLintock, Auckland City Hospital; 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 Medicine; Nolan McDonnell, King Edward Memorial Hospital for Women, WA

RHD in pregnancy NHMRC #1024206

Chief: Elizabeth Sullivan, UTS, Sydney; Lisa Jackson Pulver, UNSW Medicine; Jonathan Carapetis, Telethon Institute for Child Health Research; Warren Walsh, UNSW Medicine; Michael Peek, ANU; Claire McLintock, Auckland City Hospital; Suzanne Belton, Charles Darwin U. **Associate:** Alex Brown, Baker IDI NT; Elizabeth Comino, UNSW Medicine; Heather D'Antoine, Menzies School of Health Research; Simon Kane, Lyell McEwin Hospital, Adelaide; Juanita Sherwood, UTS Sydney; Sujatha Thomas, Royal Darwin Hospital; Bo Remenyi, Menzies School of Health Research NT; Geri Vaughan, UTS Sydney. **Project support:** Kylie Tune, Menzies School of Health Research; Faith Mahony (NZ)

Vasa Praevia

Elizabeth Sullivan, UTS Sydney; Yinka Oyelese, Jersey Shore University Medical Centre; Robert Cincotta, Mater Mothers Hospital; Greg Duncombe, Royal Brisbane Women's Hospital; Caroline Homer, UTS Sydney

AMOSS NHMRC #510298 (2008-2012)

Michael Peek, ANU; Marian Knight, University of Oxford; David Ellwood, Griffith U; Lisa Jackson Pulver, UNSW Medicine; Caroline Homer, UTS Sydney; Claire McLintock, Auckland City Hospital

Renal Disease in Pregnancy

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

New AMOSS study for 2016 – Renal Disease in Pregnancy

AMOSS needs your continued support for a brand new study!

We are excited to welcome a new team of [investigators](#) to AMOSS, who will be examining the effect of advanced chronic kidney disease and acute kidney injury during pregnancy. Development of the survey is underway, with data collection to commence in late 2016. Please see the article by Dr Shilpa Jesudason on page 3 for an overview of the importance of this study to maternal and fetal health.

Massive Obstetric Haemorrhage

Preliminary analysis is underway for this important study. Almost all cases of MOH during 2014-2015 have been entered by our data collectors – if you have any unreported cases or incomplete surveys, please complete or contact us if you have any concerns.

AMOSS collaborations

- ❖ AMOSS works with other groups to **promote improved data monitoring** on the impact of pregnancy in specific conditions. Pregnancy status is now included as a data item in the ANZ Breast Cancer Registry, and is a recommended data item in the RHD Data Collection System.
- ❖ **Partnership with health services and community**, with ongoing communication and dialogue to promote awareness and education. This is particularly important in conditions such as rheumatic heart disease in pregnancy, where missed diagnosis in this disease of (overall) low prevalence can have serious impact in pregnancy.
- ❖ **Strong international collaboration.** AMOSS works closely with the UK Obstetrics Surveillance System (UKOSS), and is a founding member of the International Network of Obstetric Surveillance Systems (INOSS).
- ❖ **Ongoing collaboration with Professional Colleges** and other bodies, including Royal Australia and New Zealand College of Obstetrics and Gynaecology (RANZCOG), Australian College of Midwives (ACM), Society of Obstetric Medicine of Australia & New Zealand (SOMANZ), Perinatal Society of Australia and New Zealand (PSANZ) and Australian and New Zealand Intensive Care Society (ANZICS) and jurisdictional and national bodies including the Perinatal and Maternal Mortality Review Committee (PMMRC) in New Zealand.
- ❖ AMOSS demonstrated the value of a **national surveillance network** during the 2009 H1N1 pandemic, when we collaborated with the Australian and New Zealand Intensive Care Society (ANZICS) Clinical Trials Group to investigate the epidemiology of H1N1 in pregnant women admitted to intensive care in Australia and New Zealand. The ANZICS Clinical Trials Group and AMOSS co-authored the first paper internationally on the impact of the 2009 pandemic, with findings published in the British Medical Journal in March 2010.

Data collectors:

Are you leaving?

Please send us an email if you are no longer your hospital's AMOSS data collector.

Do you have your AMOSS folder?

Please let us know if you need a new folder and we will send one to you. The folder contains all of the important instructions and condition criteria that you need to complete the surveys.

Do you have your log sheet?

The log sheet is a vital support tool for you and us, to help make it easier to follow up a case if there are any queries. The MRN is logged along with the AMOSS study case ID and base case details on the log sheet and kept securely at your site.

You can download the log sheet and user notes [here](#) or [email](#) us.

Thanks to all of our data collectors, maternity staff, and research governance and ethics officers.



Dr Shilpa Jesudason



The challenge of renal disease in pregnancy

The prevalence of chronic kidney disease is rising in the community, and it is a major health problem in Australia. Kidney disease is often associated with diabetes, high blood pressure and cardiovascular disease. We often think of kidney disease as a disease of older people; in fact, kidney disease may affect 3% of women in their childbearing years.

Kidney disease has a substantial impact on pregnant mothers. Depending on the severity and type of kidney disease, pregnant women with kidney problems are at risk of complications such as high blood pressure, pre-eclampsia, worsening of kidney function and sometimes require dialysis. Their babies are more likely to be born prematurely, and be of low birth weight.

The ability to deliver this care is currently hampered by a lack of understanding around prevalence and outcomes.

This prospective, national study will investigate severe kidney disease in Australian mothers to define the prevalence, distribution, risk factors and morbidity; evaluate management practices and gaps; and provide Australian-specific evidence to develop improvements in clinical care. The evidence-base from this study will:

- ❖ inform policy and guidelines;
- ❖ translate into improvements in clinical care; and
- ❖ develop intervention studies targeting this high-risk cohort.

“These vulnerable mothers require integrated multi-disciplinary care to manage a complex and often difficult clinical situation.”

There are several categories of significant and severe kidney disease in pregnancy:

- 1. Acute kidney injury (AKI)** – where the mother develops a sudden, severe decline in kidney function and may sometimes require dialysis temporarily.
- 2. Advanced chronic kidney disease (CKD)** – where women have advanced kidney disease when they become pregnant. Their kidney function may deteriorate further in pregnancy and they may sometimes require dialysis.
- 3. Kidney Failure treated with Chronic Dialysis** - where women become pregnant after kidney failure has developed and they are already receiving chronic dialysis therapy.
- 4. Kidney Failure treated with Kidney transplant** – where women become pregnant after kidney failure has developed, and they have a functioning kidney transplant.

These pregnancies are rare, but immensely challenging to manage

Renal Disease Research Team

Dr Shilpa Jesudason, Nephrologist and Obstetric Physician; AMOSS Investigator

Prof Elizabeth Sullivan, Perinatal Epidemiologist; AMOSS Principal Investigator

Prof Stephen McDonald, Nephrologist; Executive Officer, ANZDATA Registry

Prof William Hague, Obstetric Physician; AMOSS Investigator

Prof Mark Brown, Director, Renal Unit St George Hospital, Sydney

Dr Angela Makris, Nephrologist, UNSW

We will answer fundamental questions that are currently unknown:

- ❖ How prevalent is significant maternal kidney disease in the Australian birth cohort?
- ❖ Who is most at risk? Who should be targeted for counselling to avoid unplanned pregnancies and optimise outcomes?
- ❖ What are the obstetric and maternal outcomes, and the burden of morbidity?
- ❖ How does maternal kidney function alter during pregnancy, and what are the risk factors for decline in function during pregnancy?
- ❖ What are the neonatal outcomes, and severity of morbidity for these neonates? Is there an impact on longer-term health?
- ❖ How are these pregnancies managed? What gaps in care need to be addressed?
- ❖ What intervention is required to improve outcomes?

This AMOSS study will place a national spot-light on the issue of significant renal disease in pregnancy, with heightened awareness in 300 maternity units, obstetric and renal healthcare providers across the country.



Albany Regional Hospital, WA
 Albury Wodonga Health, VIC
 Alice Springs Hospital (ASH), NT
 Angliss Hospital, VIC
 Ararat Campus, VIC
 Armadale Health Service, WA
 Armidale 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
 Bega Hospital, NSW
 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
 Busselton 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
 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
 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
 Kerang & District Hospital, VIC
 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
 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
 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
 Seymour District Memorial Hospital, VIC
 Shoalhaven District Memorial Hospital, NSW
 Singleton District Hospital, NSW
 South Coast District Hospital, SA
 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, 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
 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
 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