

## Rheumatic heart disease (RHD) *a preventable disease with increased impact in pregnancy*

RHD - a serious consequence of repeated episodes of rheumatic fever, caused by Group A streptococcus - results in heart valve damage. It is a preventable disease and neglected public health problem, associated with poverty and overcrowding. Aboriginal and Torres Strait Islanders in remote regions of Australia and Māori and Pacific Islander peoples in New Zealand have among the highest documented rates of RHD in the world. In the Northern Territory in 2008, over 2.5% of 25-34 and over 3% of 35-44 year olds had RHD<sup>1</sup>. A group of Aboriginal and non-Aboriginal researchers based at UNSW has received a four-year NHMRC funding grant (2012-2016) to study RHD in pregnancy using the AMOSS (Australasian Maternity Outcomes Surveillance System).

### What we know

Increased cardiac demands of pregnancy (including 40-50% increased blood volume) often unmask undiagnosed RHD. The impact of pregnancy can be particularly severe and sometimes catastrophic for women who have mechanical heart valves. The choice of anticoagulation medication for these women provides clinical dilemmas as all anticoagulant options carry maternal and/or fetal risks.

Yet the impact of RHD on women in pregnancy is under-researched. Most recommendations are based on generic studies of severe RHD in non-pregnant adults, and there are even fewer about the disease in pregnant Aboriginal and Torres Strait Islander and Māori and Pacific Islander women.

Optimal management can be hampered by limited cardiac services in remote areas, turnover of health staff, and delayed attendance at clinics due a lack of trust and sense of cultural safety. Consequently, even advanced valvular disease may be unrecognised.

### The RHD in pregnancy study

The mixed methods research includes a quantitative study with nearly 300 maternity units across ANZ and a qualitative study exploring women's journey with RHD. It aims to provide an evidence base with a view to improving clinical care and outcomes for women with RHD in pregnancy and their babies. It will investigate the largest population based group of pregnant women with RHD ever systematically studied globally and outline patterns of health risk, diagnosis, course, management and pregnancy outcomes.

The study will enable benchmarking to identify key attributes of successful, culturally safe models of health care for women with RHD in pregnancy, based on working with those who experience RHD and its impact. It will inform approaches to RHD in pregnancy in ANZ and internationally with other RHD stakeholders in the Pacific region, and have direct benefit to over 1500 disproportionately Indigenous women with RHD likely to give birth in ANZ over the next ten years.

### About AMOSS

The RHD in pregnancy study is one of the conditions being studied within the Australasian Maternity Outcomes Surveillance System (AMOSS), a proven bi-national surveillance and research system of rare and severe obstetric conditions. The AMOSS research system is located in the Perinatal Reproductive Epidemiology Research Unit (PRERU), based at UNSW Medicine.

### More information?

Web: [www.amoss.com.au](http://www.amoss.com.au) [www.amoss.co.nz](http://www.amoss.co.nz) Email: [amos@unsw.edu.au](mailto:amos@unsw.edu.au) Tel: 61-2-9382 1068

<sup>1</sup> Parnaby MG and Carapetis JR, *Rheumatic fever in Indigenous Australian children*, Journal of Paediatrics and Child Health 46 (2010) 527-533