Our new home at University of Technology Sydney has provided fantastic opportunities for AMOSS during 2015 to take stock, harness resources and plan for the future.

**AMOSS studies**

See the recently published paper on super obesity in pregnancy and its association with social disadvantage and adverse perinatal outcomes.

Quantitative data collection for rheumatic heart disease and massive obstetric haemorrhage studies have ended, with analysis in progress on these and other studies. We continue our work exploring the impact of RHD on the women who journey through pregnancy with this condition, and on the challenges in health services.

**This newsletter**

We hope you like reading this newsletter in its new format! - with the long overdue revamp of the AMOSS website. This issue focuses on amniotic fluid embolism (AFE). Cara - a survivor of AFE – and A/Professor Nolan McDonnell (AMOSS Investigator) give poignant perspectives on the impact of this condition on family, community and clinicians as well, of course, as the women who experience this often catastrophic event. Nolan is the lead author of an upcoming AMOSS paper on AFE (in press) which we look forward to circulating in the early new year. Thank you to Cara for her generosity in sharing her story.

**Staff moves**

I thank Nasrin Javid for all her work as project co-ordinator of the AMOSS study especially in the smooth transition of the project from UNSW to UTS in 2014. She provided thoughtful guidance and leadership in co-ordinating multiple studies on breast cancer, vasa praevia and massive obstetric haemorrhage. I am sure those of you who have worked with Nasrin will have appreciated her warm collegiality, clinical expertise and professionalism. She is leaving us to pursue her doctorate on a full-time basis and we wish her all the best. We welcome Kirisha Thana who has proved a terrific addition to the AMOSS team with her administrative support.

**Partnerships**

The collaboration that underpins AMOSS continues. A research partnership with Dr Shilpanjali Jesudason of Royal Adelaide Hospital and her team of investigators will commence next year to study chronic kidney disease in pregnancy, using the AMOSS system. Work with our counterpart UKOSS (UK Obstetric Surveillance Systems) continues, with upcoming studies comparing super obesity and vasa praevia in progress. We look forward to working with RHD Australia as they build resources on RHD in pregnancy for midwives and other clinicians.

Of course, among the most important partnerships are those with our participating AMOSS sites that have contributed data over the years. We are currently working on a series of changes to our web data collection, including benchmark reports to feed back to sites.

We look forward to 2016 as we disseminate and publish more findings from the AMOSS system. Surveillance continues on AFE, and planned new studies include cardiovascular disease and cancer in pregnancy in addition to chronic kidney disease. We will continue to use AMOSS resources and research to engage with stakeholders, raise awareness and participate in conversations around clinical guidelines and care, with the overarching aim of improving maternal and perinatal outcomes for women with severe and rare conditions in pregnancy.

On behalf of the AMOSS Investigators and project team, I wish you and your family and friends a safe and restful break, and all the best for 2016.

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**Professor Elizabeth Sullivan**

Principal Investigator AMOSS, Professor of Public Health, Faculty of Health and Assistant Deputy Vice-Chancellor (Research), University of Technology Sydney

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**Rheumatic heart disease in pregnancy news**

**NSW:** Rheumatic fever and rheumatic heart disease are now notifiable diseases - see the [NSW Health website](http://www.health.nsw.gov.au).  
**Qld:** RHD Australia & RHD Queensland in partnership with Heart Foundation (Qld) and AMOSS RHD in Pregnancy study are holding a two day workshop on the prevention of acute rheumatic fever and impact of rheumatic heart disease. All health professionals are invited to attend. Brisbane Convention and Exhibition Centre 22 – 23 March 2016. More info/register [here](http://www.health.qld.gov.au).
Can you talk a bit about your early recovery, how it was for you and your family

I think we all handled it differently. Medically, I was told my recovery would take months, but I couldn’t believe that - honestly, the attention felt too over the top. There was one midwife (who has walked along with Cara since the AFE occurred) – I would say to her “I love you all and you’re great – but – really?! I don’t need your time”.

I was told I’d be in hospital for three months, but got to a point where I felt mentally I was worse off than there I would be at home. I was allowed out only because I agreed to have a fulltime carer (Cara’s husband). He was thrown into the deep end! Paul was grateful to have the extended medical team around … for him it was an assurance that they had everything covered. For me, I wanted them at arm's length and was determined to do things my way. In hindsight, I’m grateful they were so persistent... I had no idea of the complexity of it all.

When we got home, I couldn’t lift James, so I'd pull him onto the couch from the pram on a blanket with my hands/feet. It was important I could do things for him, that I got skin on skin contact – I couldn’t do it any other way. My Child Health nurse was amazing. “Ok this is not quite normal”, she’d said. “How can we do things safely that works for you all?”. And we’d sort it out. I had good people that gave sensible advice: that helped me move through the doubt I had about being a mother.

And as time went on?

About eighteen months after the AFE something clicked. It was like ‘Oh my god, this happened to me’. I did nearly die. And all of a sudden it was horrible. Like I’d woken up. Everything was really hard. I would ring my midwife and say: “Hey I don’t understand why – but this and this is happening and I’m not normal”. I became engulfed with fear. People were saying “You’ve survived an AFE!”. I felt like I was on display. And I thought they were saying – “…so what’s the problem? Why are you bitter that you’ve had a hysterectomy?” There’s a stigma to the mental health side – and hey, I was one of them. I understand more now. It’s really hard to put your hand up – it’s a control thing.

And I know it sounds silly looking back, but I was terrified of losing my baby James: that someone would step in and say “You’re just not cutting it. We need to take you home until you get your act together”. It was then that I asked for help.

What happened then?

I wanted to know what had happened, to understand it, so I asked to see my file. My midwife wasn’t keen on me just reading it, so we went through it together. And I saw what happened. That helped … it told me it was alright, I was allowed to be a bit wobbly! I got confirmation and surety … that it will be ok. Nobody’s judging you, nobody is going to take James. It was like a massive hug. We had the perfect people right through helping us.

It’s nearly ten years since you had the AFE. How is it now?

You know, I’m good. But then - a couple of weeks ago I had a medical procedure and had a full blown panic attack. Fortunately I’d had that doctor before - both he and the anaesthetist were fantastic. But as quick as a flick – I lost it – and that’s nearly ten years after the AFE.

You’ve been pretty active in the community of AFE survivors. What led you to that?

I was on a baby website and there was another woman who’d had an AFE – the first one I met. We swapped numbers and spent 2 1/2 hours talking. For the first time I felt...
AFE: THE CLINICIAN’S PERSPECTIVE

Clinical Associate Professor Nolan McDonnell
[AMOSS Investigator, Staff Specialist Department of Anaesthesia and Pain Medicine, King Edward Memorial Hospital for Women Perth WA]

It has been said that in life there are often a few events that define the path we end up taking. For me personally, my interest in amniotic fluid embolism (AFE) started towards the end of my anaesthetic training, with my wife heavily pregnant with our first child. After inserting a relatively uncomplicated epidural into a woman in labour, I was almost immediately called back to find her unconscious and with no pulse. Ultimately, after significant resuscitation efforts, the mother and her baby survived and she has now gone on to have a further child. However, this case which happened over a decade ago made me realise how little we know about AFE, how little teaching there was at the time about the specific resuscitation demands for pregnant women and the impact of catastrophic events such as this on - not only the woman concerned and her family - but also the staff involved.

A decade on from that how has our knowledge of AFE changed? Unfortunately, it is fair to say that there has been little progress in understanding this condition. What we do know is that it is currently the leading cause of direct maternal mortality in Australia and New Zealand with a higher prevalence than some other countries. What we don’t know is why. Is there something about our population which puts us more at risk of the condition? Is it over-diagnosed? We still do not know what triggers AFE and hence rely on case reports of the condition and registries such as AMOSS to further our knowledge. The good news is that the case fatality rate from AFE has decreased dramatically in recent times, with a mortality of approximately 20%. Any death of course is devastating, but these rates are a significant improvement on earlier mortality rates of up to 80-90%. There is no doubt that this is in part due to the greatly improved resuscitation teaching for all clinical staff as well as advances in critical care techniques.

What of the staff that are involved in situations such as this? The impact of critical events on the patient and their family/friends is usually profound and often long-lasting. Staff involved in the care of the women can also suffer significant psychological trauma. The patient and their family are the ‘first’ victims. The ‘second’ victims are members of the health care team involved in care, who can unrealistically blame themselves for events that may have unfolded and suffer from many features consistent with post traumatic stress disorder. (cont next column)

(normal story - The long-term impact of AFE – cont)

Her whole world was completely different to mine, but we were in the same space – and it was ok. All of a sudden it wasn’t scary to say how it felt, because there was another person that understood. And it made me think – if I feel like that and so does she, there’s probably others. I found the (USA) AFE forum and started the Australian branch. I’ve had an amazing network of support – I’ve been really lucky, and I try and put back a bit. A lot of women who’ve survived AFEs and their partners don’t have that. Sometimes the smallest support can make the biggest difference.

What could more support look like for women who’ve had an AFE?

It’s not just for AFE. There needs to be some sort of ongoing support for maternal conditions when it doesn’t go ok. Each case is different, and those who survive will recover in their own way, in their own time at their own level. I feel a referral to a GP that understands AFE (what an AFE is) is so important. You need their understanding as your base. It all comes back to having that one person that can be your 100% support and link you to a network of people to assist in your recovery. The emotional and mental side are as big, if not bigger sometimes, than the physical recovery.

And now?

And over time, I’ve got me back. I’m not just Cara who’s had an AFE and a medical miracle, so lucky, etc etc. I’m Cara who is a great Mum, wife, friend, volunteer etc again. Our family is taking every day as a miracle. We look at life differently, and make time to make memories.

Thanks and chocolates to ...

Sandy Nelson and Kayleen Jordan of (Gold Coast University Hospital) and Danielle Siwert (Liverpool Hospital Sydney), Elize Bolton (Mater Brisbane), Bernadette White (Mercy Hospital for Women Melbourne), Jo Borman and Boon Lim (Canberra Hospital), Kristen Rickard (Royal North Shore Hospital), Cath Jamieson (The Women’s Hospital Melbourne), Simon Kane (Lyell McEwin Hospital Adelaide), the Nepean midwives at Nepean Hospital (especially Sue Downward, Peta Armstrong and Juanita Taylor), for their ongoing support of AMOSS, particularly for their work with the massive obstetric haemorrhage study.

And thank you to all the participating New Zealand data collectors!

More information on AFE


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Thanks to the following participating AMOSS sites

Albany Regional Hospital, WA
Albury Wodonga Health, VIC
Alice Springs Hospital (APH), NT
Angus Hospital, VIC
Ararat Campus, VIC
Armadale Health Service, WA
Armidale Hospital, NSW
Ashford Hospital, SA
Atherton Tablelands Hospital, QLD
Attadale Private Hospital, WA
Auburn Hospital, NSW
Auckland City Hospital, NZ
Ayr Hospital, QLD
Baintaine 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
Bridgewater District Hospital, WA
Broken Hill Health Service, NSW
Broome District Hospital, WA
Bunbury Regional Hospital, WA
Burnside War Memorial Hospital, SA
Burnside Health Service, WA
Bundaberg Hospital, QLD
Bunbury Regional Hospital, WA
Bunbury District Hospital, WA
Burwood Hospital, NSW
Byron Bay DHB, NSW
Caloundra Hospital, QLD
Calvary Health Care, ACT
Calvary Health Care Canley Vale, NSW
Calvary Health Care, NSW
Calvary John James, ACT
Campbelltown Hospital, NSW
Canterbury Hospital, NSW
Canungra Hospital, QLD
Caraway Hospital, WA
Central Gippsland Health Service, VIC
Charleville Hospital, QLD
Chinchilla Hospital, QLD
Christchurch Women’s Hospital, NZ
Coft’s Harbour Base Hospital, NSW
Cohuna District Hospital, VIC
Cohunu Hospital, NSW
Cooma Hospital, NSW
Cootamundra Hospital, NSW
Cowra Health Service, NSW
Dalby Hospital, QLD
Dandenong Hospital, VIC
Darwin 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
Epsworth Freemasons Hospital, VIC
Esperance District Hospital, WA
Fairfield Hospital, NSW
Fingal Private Hospital, NSW
Fiona Stanley Hospital (Kalwaya), WA
Flinders Medical Centre, SA
Flinders Private Hospital, SA
Forbes Hospital, NSW
Frances Perry House, VIC
Frankston Hospital, VIC
Gaiters Private Hospital & Specialist Centre, WA
Gawler Health Service, SA
Geelong Health, WA
Geelong Hospital, Barwon Health, VIC
Geelong Hospital, VIC
Gippsland Southern Health Service, VIC
Gisborne Hospital, NZ
Gladstone Hospital, QLD
Gladstone Mater Hospital, QLD
Glen Innes Hospital, NSW
Glenunga 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, NSW
Griffith Base Hospital, NSW
Griffith Hospital, NSW
Gungahlin Hospital, ACT
Gympie Hospital, QLD
Hawke’s Bay Hospital, NZ
Hawkesbury District Health Service, NSW
Hedland Health Campus, WA
Hewer Bay Hospital, QLD
Hobart Private Hospital, TAS
Hornsby Ku-ring-gai Hospital, NSW
Hurstville Private Hospital, NSW
Hutt Valley Hospital, NZ
Inifadha Hospital, QLD
Inverell Health Service, NSW
Ipswich Hospital, QLD
Jessie McPherson Private Hospital, VIC
John Flynn Gold Coast Private Hospital, QLD
Jondalup Health Campus, WA
Kalgoorlie Regional Hospital, WA
Kapunda Hospital, SA
Kareena Private Hospital, NSW
Katarinaan 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
Kyrabiam District Health Service, VIC
Lalorobe Regional Hospital, VIC
Launceston General Hospital, TAS
Leeon Hospital, NSW
Lismore Base Hospital, NSW
Liverpool Hospital, NSW
Logan Hospital, QLD
Longwack Hospital, QLD
Lootan Hospital Complex, SA
Lyle McEwin Hospital, SA
Mackay Base Hospital, QLD
Macksville Hospital, NSW
Manning Base Hospital, NSW
Mansfield District Hospital, VIC
Maroebah Hospital, QLD
Margaret River District Hospital, WA
Maryborough-Ulladulla 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
Merry Hospital for Women, VIC
Mersey Community Hospital, TAS
Mildura Hospital, VIC
Mildura Base Hospital, VIC
Milkert & District Hospital, SA
Milton-Ulladulla Hospital, NSW
Mitcham Private Hospital, VIC
Monash Medical Centre, VIC
Monroe Hospital, NSW
Monuya District Hospital, NSW
Mount Barker and Districts 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 Base Hospital, NSW
Muswellbrook District Hospital, NSW
Nambour General, QLD
Narracort Hospital, SA
Narrabri Hospital, NSW
Narrandera Hospital, NSW
Narrangin Regional Hospital, WA
Nelson Hospital, NZ
Nepau Hospital, NSW
Nepean Private Hospital, NSW
Newcastle Private Hospital, NSW
Nor East 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 Wagaratta, 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
Parke 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
Reddfern Hospital, QLD
Redland Hospital, QLD
Riverland Regional Health Service, SA
Rockhampton General Hospital, QLD
Rockingahm General Hospital, WA
Roma Hospital, QLD
Rotoura 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, NSW
Royal Prince Alfred Hospital (RPAH), NSW
Ryde Hospital, NSW
Sandringham Hospital, VIC
Scot Memorial Hospital, NSW
Seymour District Memorial Hospital, VIC
Shoalhaven Memorial Hospital, NSW
Singleton District Hospital, NSW
South Coast District Hospital, SA
South Gippsland Hospital (Foster), VIC
South West Health Care (Campdenpark), VIC
South West Health Care (Warnambool), VIC
Southern Finders 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, WA
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 Bunburry, VIC
St John of God Health Care Subiaco, WA
St John of God Hospital Bendigo, VIC
St John of God Hospital Mildura, VIC
St John of God Mt Lawley Hospital, WA
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
Swin Hill District Hospital, VIC
Swan Kalumunda Health Service, WA
Sydney Adventist Hospital, NSW
Sydney Southwest Private Hospital, NSW
Tamworth Rural Referral Hospital, NSW
Tauranga Hospital, NZ
Tanunda Hospital, SA
Tarunaka Base Hospital, NZ
Tauranga Hospital, NZ
Temora District Hospital, NSW
The Bays Hospital Mornington, VIC
The Cabrerra Hospital, ACT
The Illawarra & 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
Towowooba Base Hospital, QLD
Townsville Hospital, QLD
Tumut Hospital, NSW
Wagga Wagga Base Hospital, NSW
Wakaru Hospital, NSW
Walker Health Services, VIC
Wararapa Hospital, NZ
Wairau Hospital, NZ
Waitakere Hospital, NZ
Wallanata DHE, WA
Wallaroo Hospital, SA
Warwick Hospital, QLD
Wellington Hospital, QLD
Werribee Mercy Hospital, VIC
West Gippsland Hospital, VIC
Western District Health Service (Hamilton), VIC
Westmead Hospital, NSW
Westmead Private Hospital, NSW
Whanganui Hospital, NZ
Whanganui Hospital, NZ
Whimnery 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