

Issue 3 January 2008

"He matenga ohorere, he wairua uiui, wairua mutunga-kore"

"O eternal spirit -the grief of an untimely death — we will not stop the pursuit and endeavours to seek answers"

(Not a literal translation)

Chairpersons Message

Since our last newsletter we have been busy on a number of fronts.

Firstly, it has been satisfying to see the initial efforts to collect data coming to fruition and in 2008 we hope to release our Annual Report with data collected from the second six months of 2006 for perinatal deaths. As this newsletter goes to print we are busy looking at the tables and writing sections for the report. The purpose of this data is to report on the perinatal deaths with detailed information about the causes of death with a view to improving our care of pregnant women in the future. Our hope is to decrease the numbers of perinatal deaths in the future and now we know how many there are then we can use this as a benchmark. We are also completing the data collection for 2007. So thank you for your help in that endeavour.

Secondly we have continued to monitor maternal deaths and hope to have a short report to the Minister of Health for deaths that occurred in 2006 once the details have all been completed. This is a much longer process than for perinatal deaths and we only become aware of some deaths sometimes months and even years later.

Thirdly we have established a neonatal encephalopathy working group following a workshop with the aim of reducing perinatal morbidity and mortality. This group is currently working on processes of how to identify babies with neonatal encephalopathy (both babies who die and survivors).

Finally we have held a work shop on perinatal pathology services in New Zealand with a view to improving access to post-mortem services across the country.

In 2008 we will be busy report writing, holding meetings, conducting workshops and continuing to raise the profile of perinatal and maternal mortality and morbidity across the health sector. Thank you for all that you do for the PMMRC and we look forward to working with you in the future.

Cindy Farquhar



2007 PMMRC Annual report

The first PMMRC annual report was presented to the Minister of Health in August 2007. The full report can be found in the PMMRC website www.pmmrc.health.govt.nz this contains the following recommendations:-

The PMMRC recommends that the Minister:

1. notes that the PMMRC has established a national perinatal database and DHB system of perinatal death data collection
2. notes the importance of accurate, robust, timely clinical data on all pregnancies and recommends the establishment of a national perinatal database so that perinatal death rates can be calculated and comparisons can be made between babies that die and those that survive the perinatal period
3. requires DHBs to ensure that all providers of maternity services provide support to parents, families and whānau who have experienced perinatal or maternal loss including providing access

to information, counselling and clinical follow up

4. requires the Ministry of Health to develop and improve the provision of perinatal pathology services for accessibility, training and appropriateness to ensure quality and equitable services across the country
5. approves the establishment of a neonatal encephalopathy working group as included in the PMMRC 2007/2008 work plan
6. notes that there are significant challenges to auditing and reviewing perinatal mortality and morbidity given the current, limited information systems available
7. requires health professionals to recommend a post-mortem examination following a maternal death when a coronial investigation is not undertaken.

Maternal Mortality Review

The PMMRC review of maternal deaths commenced as of the 1 January 2006. The aim of this review is to identify preventable causes of maternal mortality and make recommendations to reduce the risk of death in the future.

If you are aware of a maternal death please advise the PMMRC Local Coordinator or the National Coordinator who will advise you of what is required.

It is a legal requirement that all maternal deaths are reported to the Coroner. The PMMRC has made the recommendation that health professionals recommend a post-mortem examination following a maternal death when a coronial investigation is not undertaken.

Perinatal Post-Mortem Examination

The perinatal post-mortem (aka autopsy) remains the gold standard investigation in the diagnostic evaluation of the causes of perinatal death.

Information gained from an autopsy can assist in the understanding of events surrounding the death and inform the Lead Maternity Carer LMC and parents with regard to future pregnancy planning. A cause of death may help the parents to come to terms with the loss as well as alleviate feelings of guilt.

A report by the Working Party of the Royal College of Pathologists recommended that we should aim for a 75% perinatal autopsy rate. The perinatal autopsy rate varies greatly between centres and the rate reflects, in part, the availability of a perinatal pathologist, the ethnic makeup of the population and the confidence that the midwifery and obstetric staff have in the service – that the report will be of value and that the baby will be returned to the family in good condition.

There has been a widespread decline in autopsy rates for a variety of reasons that include improved diagnostic imaging techniques. In tertiary centres in New Zealand, the perinatal autopsy rate (in autopsies performed by family consent) is far higher than adult autopsies (by family consent). A perinatal death is the loss of an expected life and many parents want the death explained and want to know if it will happen again. The LMC may also want to know if they missed anything and how can such an outcome be avoided next time.

The low autopsy rate from some centres may reflect a reluctance to request autopsy or a failure to understand the reason for the request. There are many reasons put forward for such reluctance that may include personal aversion to the procedure or concern that it will further burden the distressed parents. It is of course hard for the LMC to initiate the discussion around post-mortem examination. It is hard for the parents to absorb such information as well dealing with the unexpected fetal death – and be expected to make a decision.

Following the diagnosis of intra uterine death many women require induction and the clinical person who is often closest to the parents during this traumatic time for an extended period is a midwife – who may or may not be the LMC. The importance of the midwives participation in gaining consent for autopsy cannot be overemphasised. The same applies to neonatal nurses in postnatal deaths. It is generally recommended that an experienced clinician undertake request for autopsy – but the family will often look to the midwife for guidance in this often difficult decision.

The optimum time for the performance of a perinatal autopsy is as soon as is possible and convenient to both the parents and pathologist. This means that the discussion around the autopsy should ideally be raised before the baby is born. The parents do not have to make a decision immediately and should have the opportunity to discuss the issue amongst themselves. They may prefer to delay the decision until after the birth. The Working Party report stated that it is the right of every parent to be given the opportunity make an informed decision with regard to a post mortem examination on their child. It is also their right to decline. The LMC needs to be mindful that when the parents return for their debriefing that they may have a lot of questions. If there has been a post-mortem examination the discussion will centre around that report. If there has been no post-mortem examination either of the baby or placenta then in the absence of any definitive clinical reason for the baby to die – there will be no further information that the LMC can impart to the parents.

The adverse publicity generated from the inquiries into autopsy practices both in New Zealand and overseas are thought to have made a major impact on clinicians willingness to seek consent and parents acceptance of the procedure. Clinician reluctance to seek consent due to the burden placed on the family may be misplaced as a recent survey of parents indicated that over 80% would

agree to a post-mortem examination if asked. It should be stated though that the survey was not conducted when parents were acutely bereaved – but rather in retrospect. Clinicians should discuss the value of an autopsy with the parents in all cases of a perinatal death and seek consent for the procedure. Seeking of parental consent is best done by an experienced clinician who has a rapport and understanding with the parents.

The placenta is an integral part of the post-mortem examination and should always accompany the baby when an autopsy is to be performed.

If the parents do not wish for the baby to have an autopsy examination – they may consent to examination of the placenta and this may provide useful information.

Placental examination by a perinatal/paediatric pathologist should be performed for all high risk neonates including the following:

- infants admitted to neonatal intensive care
- infants failing to respond to resuscitation;
- spontaneous preterm labour and birth
- planned delivery for fetal compromise including growth restriction
- severe cardiorespiratory depression at birth including resuscitated stillborn babies
- signs consistent with congenital infection
- severe growth restriction;
- hydropic infants
- suspected severe anaemia
- suspected or known major congenital abnormalities
- other circumstances where a liveborn infant dies shortly after birth in the delivery room.

The placenta can be returned to the family, when requested after histological examination.

Amended from Perinatal Society of Australia and New Zealand Perinatal Mortality Audit Guideline; Section 4: Perinatal post-mortem examination

Jane Zuccollo Perinatal Pathologist and Member of PMMRC

The PMMRC is currently completing work on an information pamphlet for Parents and Whanau on post mortems.

International Stillbirth Alliance ISA conference 2007 Birmingham, UK

I was fortunate in being able to attend the ISA conference in Birmingham through funding from my 2006 Vodafone World of Difference award. The ISA is an international non-profit coalition of organisations dedicated to understanding the causes and prevention of stillbirth. They work to raise awareness, educate and facilitate research into stillbirth prevention.

There were two 'tracks' at the conference - bereavement and scientific. In fact, sometimes it seemed as though there were two conferences running alongside each other. Each morning we held a joint session so each stream could hear what the other heard the previous day. I attended the bereavement track predominantly, joining in to listen to a few scientific discussions now and then. I was especially interested in the discussion on reaching a consensus on an international definition of stillbirth. This discussion started at the Yokohama conference in 2006 and I imagine it will continue to be on the agenda for a few years yet. The definitions are so varied, it seems almost impossible to think we could reach a standard international definition.

Highlights of the conference were numerous for me. There were a number of people from developing countries which provided a breadth and richness to the conference. Particularly poignant was a Nigerian obstetrician's personal story told to the whole conference, a lesbian

couple's presentation on being treated as individuals rather than as a family, a Muslim chaplain's presentation on supporting Muslim families, and a study on the impact of stillbirth on health professionals. I gave two presentations at the conference and was privileged to bring the story of Raja Enrique Gounder to an international audience. Raja was born in Lower Hutt in August 2006 and lived for 5 hours and 5 minutes. This was a presentation told in photos accompanied by music – it made quite an impact on those in the bereavement track that saw it. So much so, that I was asked to show it to the whole conference the following morning. Their story illustrated some of our practices in New Zealand that we take for granted – like taking baby home from the hospital and transporting baby ourselves. These are not common practices in other parts of the world and the conference attendees were interested in how we manage that side of perinatal death here in New Zealand. I also gave a presentation on the newly developed transportation guidelines for parents, hospitals and the police and emergency services. This presentation was also well received.

I enjoyed meeting so many people with whom I correspond by email regularly – in particular, the ISA Parent Advisory Committee of which I am a member. The next conference is in Oslo, Norway in 2008 and there is talk of the 2010 conference being held in Australia.



Vicki Culling, Sands NZ and Member of PMMRC

PMMRC Perinatal Rapid Reporting Forms

Data collection on perinatal death has been underway for 18 months. Following a perinatal death we ask that all LMCs and/or other involved clinicians enter information on the website www.pmmrc.otago.ac.nz. To ensure this process is as thorough and user friendly as possible we review and update the forms annually. The latest changes came into effect on the 1st January 2008.

Just a reminder of how this works. Each DHB has an individual Username and Password - your Local Coordinator will be able to assist you with this or you can contact the National Coordinator. The first time you use this site you will be given a registration identification number (REG ID) You should always use the same REG ID, if you forget this you are now able to send an email through the website and your RED ID will be sent to you, alternatively please contact the National Coordinator.

Both Mother and Baby Forms need to be completed. You may save a form and when you are able to complete the data access it again in the INCOMPLETE section under your unique registration identification number (REG ID). While we would prefer you to complete the forms on the website, paper forms are available for those who do not have access to the internet (or who only have a slow dial-up system). Please ensure you are using the December 2007 forms. These are available from your Local Coordinator or the National PMMRC Coordinator.

An information sheet is available on this website to give to family/whānau when you are completing the forms to give them information about what you are doing. Your PMMRC DHB Local Coordinator now has this information in leaflet form.

If you have any questions about data collecting following perinatal or maternal deaths please do not hesitate to contact your [Local Coordinator](#) or the National PMMRC Coordinator, [Vicki Masson](#)

Contact details

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Further Information

Upcoming Conferences

PSANZ 12th Annual Conference

The 12th Annual Conference- 20 - 23 April 2008, Gold Coast, Brisbane, Australia

International Stillbirth Alliance ISA

Conference Oslo Norway November 5-7, 2008

Recent Publications

PMMRC Annual Report 2007 can be found on the website www.pmmrc.health.govt.nz

Saving Mothers' Lives 2003-2005 - Reviewing maternal deaths to make motherhood safer 2003-2005 This Report on confidential enquiries into maternal deaths in the United Kingdom, 2003-2005 can now be accessed online at www.cemach.org.uk or on the PMMC website www.pmmrc.health.govt.nz

International Stillbirth Alliance ISA

Conference 2007 Birmingham, UK Newsletter and details of conference www.stillbirthalliance.org