

## **Reducing Neonatal Encephalopathy in New Zealand**

### **The Neonatal Encephalopathy\* (NE) working group**

#### **Why was the NE working group established?**

The Perinatal and Maternal Mortality Review Committee (PMMRC)'s purpose is to review New Zealand's perinatal and maternal deaths, and report to the Minister of Health on how to reduce the numbers of preventable deaths. The PMMRC's role also includes developing strategic plans and methodologies to reduce perinatal morbidity. Neonatal encephalopathy (NE) was identified as an area where there may be the potential for improvement of services and outcomes for babies. In late 2007 the Neonatal Encephalopathy Working Group was established by the PMMRC and was charged with reviewing New Zealand data on NE.

#### **Why NE?**

Despite advances in obstetric and neonatal care, NE remains a major cause of brain injury in the full-term newborn infant. Of those infants affected by NE, 10-60% will die and at least 25% of those surviving will have long term neurological complications resulting in chronic handicapping conditions such as cerebral palsy, neuro-developmental delay or retardation, blindness, hearing deficits and epilepsy. Although there are a number of population studies looking at the prevalence of NE internationally, there is currently no local data available.

#### **What is the NE working group doing?**

To establish the true size of the problem of NE in New Zealand, the first priority of the group is to collect data on the prevalence in New Zealand in order to form a national data set. It is hoped that predictors and/or mediators of NE will also be identified, potentially allowing the development and implementation of effective preventative and remedial therapies with a view to reducing both the severity and occurrence of NE in New Zealand. In order to do this an observational audit will take place.

#### **What will the observational audit involve?**

The observational audit will include the following components:

- The inclusion of NE as one of the conditions on the Perinatal Surveillance Unit Reporting Card
- Completion of the *PMMRC Mother Rapid Reporting Form for a Baby Diagnosed with NE* by the Lead Maternity Carer.
- Completion of the *PMMRC Baby Rapid Reporting Form for Surviving Infant with Moderate to Severe Neonatal Encephalopathy* – by the attending paediatrician

This observational audit has been designed in consultation with the Paediatric Surveillance Unit (PSU), and has been approved under expedited review by the Multi-region Ethics Committee.

#### **What will this mean for me as a paediatrician?**

The PSU will ask you to identify any cases of NE in your unit. You will then receive the *PMMRC Baby Rapid Reporting Form for Surviving Infant with Moderate to Severe Neonatal Encephalopathy* to be

\* *Neonatal encephalopathy:*

*A clinically defined syndrome of disturbed neurological function within the first week of life in the term infant, manifested by difficulty in initiating and maintaining respiration, depression of tone and reflexes, subnormal level of consciousness and often seizures.*

completed and returned (details where to send it will be on the form). This form is just a few pages long and shouldn't take more than 20 minutes to complete.

**What will this mean for me as a Lead Maternity Carer (LMC)?**

As the LMC of a baby that has been identified as having NE, you will receive the *PMMRC Mother Rapid Reporting Form for a Baby Diagnosed with NE* to be completed and returned to the coordinator (details of where to send it will be on the form). This form is similar to the current PMMRC rapid reporting form and should also be quick and easy to complete.

**Will individuals be identified in the process?**

No. The information you provide will be de-identified and no individual infant or mother will be identified. Data will be stored in both paper and electronic form in a secure office. The investigators, as agents of the PMMRC, are under strict confidentiality obligations under Schedule 5 of the New Zealand Public Health and Disability Act. The penalty for disclosing personal information is a fine of up to \$10,000, and individuals are liable to professional disciplinary proceedings.

The members of the NE Working Group are the only people who will have access to raw data and/or clinical records during or after the study. Upon completion of the project, the raw data will be transferred to secure storage unit at the Ministry of Health, and will be the responsibility of the PMMRC.

**How will information from the audit be used?**

Data gathered in this audit will identify the number of newborn infants with moderate to severe NE in New Zealand, the distribution of these affected infants in terms of geographic location and the spread between level 2 and level 3 neonatal units. It will determine possible predictors of the condition and how these infants are managed. It is intended that this audit will identify areas for development and implementation of effective preventative and remedial therapies with a view to reducing both the severity and occurrence of NE.

**When will the observational audit start?**

The audit should be starting nationwide in January 2010, although there will be some piloting of the process in the end of 2009.

**Who is on the NE working group?**

The members of the NE working group are clinicians involved in the provision of perinatal care and representatives from associated areas.

The current members are:

- Dr Malcolm Battin – chairperson
- Dr Dawn Elder – Senior Lecturer in Paediatrics/ PMMRC representative
- Anja Hale – Neonatal Nurses College of Aotearoa
- Deborah Harris – Neonatal Nurse Practitioner/ PMMRC representative
- Vicki Masson – PMMRC National Coordinator
- Assoc Prof Lesley McCowan – Australasian College of Obstetrics and Gynaecology
- Tomasina Stacey – New Zealand College of Midwives
- Dr Tosh Stanley – Paediatrician (level III)
- Rachel Taylor – Accident Compensation Corporation
- Dr Alex Wallace – Paediatrician (level II)

Further information on the Perinatal and Maternal Mortality Review Committee and the Neonatal Encephalopathy Working group can be found on our website [www.PMMRC.health.govt.nz](http://www.PMMRC.health.govt.nz) .

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