Australian Paediatric Surveillance Unit
STUDY PROTOCOL

Severe Neonatal Hyperbilirubinaemia OR Exchange Transfusion

COMMENCING April 2010

BACKGROUND

There is concern internationally that the number of babies affected by severe neonatal hyperbilirubinaemia may be increasing. Cases of cerebral palsy caused by severe jaundice have been reported with increasing frequency in Europe and North America.[1-4] There is a paucity currently of accurate severe hyperbilirubinaemia incidence data in Australia and it is of concern that unless this information is gathered urgently, an increasing number of Australian children and their families could be affected by athetoid cerebral palsy.

Extremely high circulating levels of unbound bilirubin in the newborn period can have detrimental effects on the developing brain. Kernicterus, or bilirubin encephalopathy may result from severe neonatal hyperbilirubinaemia and cause athetoid cerebral palsy, deafness and paralysis of ocular muscles in surviving infants.[1,5,6] Timely recognition and appropriate treatment of newborn babies with hyperbilirubinaemia prevents these sequelae and thus, cases of cerebral palsy due to hyperbilirubinaemia may be preventable.[7,8]

Reasons postulated for the re-emergence of kernicterus in an age of advanced neonatal care are multifactorial and include: early hospital discharge, inadequate community newborn surveillance and deficiencies in education programs concerning jaundice and its potential consequences among parents and care-providers.[8,9] On review of the root cause of 125 cases of kernicterus in the United States, Johnson et al found that health-system failings included: failure to recognise the significance of early jaundice, failure to institute appropriate monitoring and treatment in addition to inadequate post-discharge follow-up and lactation support.[10]

We aim to establish in Australia the current incidence of severe neonatal hyperbilirubinaemia and its sequelae including cerebral palsy and to document the underlying causes and associated clinical risk factors. It is anticipated that these data will inform the development of important future prevention strategies such as screening initiatives and education programs for parents, care-providers and health professionals. This study will also inform future improvements to the continuity and co-ordination of newborn care, particularly after hospital discharge. Ultimately, our study strives to inform risk reduction strategies for severe neonatal hyperbilirubinaemia and associated disabilities.

STUDY OBJECTIVES

The study aims to describe:

- The current incidence of severe neonatal hyperbilirubinaemia in Australia
- The associated diagnoses in affected infants and clinical risk factors
- The type and timing of treatment received
- The short-term* outcomes for each infant

*Long term sequelae including developmental outcome will be determined via a separate study

CASE DEFINITION

A newborn infant born **after 34 weeks** gestation and **up to 1 month post delivery** with severe hyperbilirubinaemia defined by:

- A **total** serum bilirubin ≥ 450µmol/L

OR

- needing an **exchange transfusion** for prevention or treatment of bilirubin encephalopathy

OR

- clinical and/or MRI imaging evidence consistent with bilirubin encephalopathy

REPORTING INSTRUCTIONS

Please report any neonate with severe hyperbilirubinaemia according to the case definition above.

INVESTIGATORS
Associate Professor Nick Evans, Head of Neonatology, Newborn Care, Royal Prince Alfred Hospital, Missenden Rd, Camperdown, NSW 2050

Dr Angela M^{c}Gillivray (Clinical Neonatology Fellow and study coordinator/contact person) Tel 0403 786 298

or email: angela.mcgillivray@sswahs.nsw.gov.au

Newborn Care, Royal Prince Alfred Hospital, Missenden Rd, Camperdown, NSW 2050

CO-INVESTIGATORS
Dr Philip Beeby (Senior Neonatologist) Newborn Care, RPAH, Camperdown, NSW
Prof Nadia Badawi, Macquarie Foundation Professor of Cerebral Palsy.
A/Prof Ross Haslam, Women's and Children's Hospital, Adelaide, SA
A/Prof Alison Kent, Canberra Hospital, ACT
Dr Andrew Watkins, Mercy Hospital, Melbourne
Dr Noel French, King Edward Maternity Hospital, Perth, WA
Dr Peter Gray, Mater Hospital, Brisbane, QLD
Dr Peter Dargaville, Royal Hobart Hospital, Tas

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