

**Submission  
No 16**

**INQUIRY INTO CURRENT AND FUTURE PROVISION OF  
HEALTH SERVICES IN THE SOUTH-WEST SYDNEY  
GROWTH REGION**

**Organisation:** Miracle Babies Foundation

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## **Miracle Babies Foundation submission to Upper House Inquiry into health service needs in the South-West Sydney Growth Region**

Every year in Australia more than 48,000 newborn babies require the help of a Neonatal Intensive Care Unit (NICU) or Special Care Nursery (SCN). More than 27,000 of these babies are born premature and up to 1,000 babies lose their fight for life.

The experience of having a baby born premature or critically ill can be traumatic and life changing. The right support is vital to ensure a healthy long-term outcome for the entire family. Miracle Babies Foundation is Australia's leading organisation that supports premature and sick newborns, their families and the hospitals that care for them.

Over the last 15 years we have developed a robust understanding of the health needs for families in the South-West Sydney region, this also being the locality where our organisation was founded.

Current and future needs include:

- Capacity for parent organisations and groups to be better recognised and available in health care settings. This will include ensuring there is adequate space for parent organisations to be present in hospitals where the parent need is. Helping parents and carers of premature or sick newborns find a place where they can share their experiences with another person who has been in a similar situation is vital to improving their wellbeing in and out of hospital.
- Health services should be informed of the European Foundation for the Care of Newborn Infants (EFCNI) '[European Standards of Care for Newborn Health project](#)'. This alignment will help support the rights of the child from the beginning of life by serving as a reference for the development and implementation of binding standards and guidelines on a national and international level.
- Family Integrated Care (FICARE) including parent accommodation – FICARE allows parents and family members to be the primary carers of their baby during their hospital stay. The care is provided in partnership with doctors and nurses. For this to be possible, hospitals need to have the everyday amenities available at home. These include kitchen areas, accommodation and rest/quiet rooms, childcare facilities, bathroom amenities, parking permits and transport assistance. These facilities must be close to or within the Neonatal Unit.
- Access to a Donor Breast Milk Bank – Provisions to allow better access for newborns and information for parents around accessing, utilising and donating to the Breast Milk Bank.
- Parents voice in research - Having parent and consumer input into research relating to their common experiences is crucial in developing best practice approaches. Hospitals need to be more transparent and active with research opportunities and information for parents.

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### **CONTACTS:**

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