

IRISH PREMATURE BABIES

Information about Prematurity & Irish Premature Babies CHY19532

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What prematurity means – Definition and Statistics.

Premature birth is defined by the World Health Organisation (WHO) as a birth that occurs at less than 37 weeks gestation. Recent research (1) has shown that prematurity is an important factor in neonatal mortality and can possibly have much longer-term consequences, in terms of the health of children born early. Babies born prematurely have higher rates of cerebral palsy, sensory deficits, learning disabilities and respiratory illnesses compared with children born at term. Low birth weight is seen as an indicator for potential health issues throughout life and can have consequences for all of the baby's life.

The causes of premature births are still not clearly understood with approximately half (45 – 50%) of all premature births occurring spontaneously, without any known cause. Of the rest, about 30% are caused by PROM – premature rupture of membranes, and another 15 to 20% are because of medical issues arising with the mother or the baby. Premature births are a great threat to both mother and baby and it is an area that requires further extensive research.

In Ireland statistics on births and prematurity are collected by the Central Statistics Office (CSO) and by the ESRI through the National Perinatal Reporting System (NPRS) which is part of the Health Research and Information Division (HRID) at the Economic and Social Research Institute (ESRI). The NPRS publish an annual report on all births nationally. The latest report published in June 2011 is for 2009 and this gives the following information relating to premature births in Ireland. (2)

There were 76,021 births in 2009, of these

- 6. % were preterm (less than 37 weeks gestation)
- 5. % of live births were low birth weight (less than 2,500 grams)

3412 singleton births were premature and 1128 multiple births were premature. If these figures are taken to represent the general situation this means that over 4,540 families are faced with the birth of a premature baby in Ireland each year.

What happens when premature babies are born?

When a baby is born prematurely they will generally be taken immediately or very soon after birth to a Neonatal Intensive Care Unit (NICU) or Special Care Baby Unit (SCBU). Then, depending on the baby's gestation, birth weight or how sick they are, the baby can face days, weeks or months in hospitals. Babies can undergo life-saving procedures; some will have to spend periods of time being ventilated (machines that perform the breathing process) or on assisted breathing machines (BiPAP and CPAP). Immature digestive systems can result in feeding complications and many children are tube-fed as their suck reflex has not developed and they have to learn how to feed by either a bottle or breast. Many



premature babies have apnoeic episodes (stop breathing) and bradycardia (decreased heart rate). They can also suffer from brain bleeds, bowel infections (some can be fatal), anaemia, heart problems (PDA), infection, hernias, fluid accumulation on the brain, cerebral palsy, vision problems, hearing problems, development difficulties, and learning disabilities.

When the baby is well enough they will be discharged from hospital and allowed to go home. Some babies need to go home with specialised monitors or equipment. Many premature babies will need extensive follow up hospital appointments in the months and sometimes years following their discharge and will need to be referred for different therapies and clinics. Having a premature baby can be life changing for many parents.

What is Irish Premature Babies?

Irish Premature Babies is a charity CHY19532 comprised of parents who have all had a preterm baby or babies. Ireland in 2009 had very little that represented or promoted the welfare of parents of premature babies, but this has now changed. Irish Premature Babies is the only organisation in Ireland that supports the families of premature babies. We promote the welfare of families with premature children and support the work of the NICU's and SCBU's.

Why and how Irish Premature Babies was established?

Allison Molloy had her first premature baby in 2006. When she had her second premature baby in 2009, she found that there was still not enough readily available information or support for parents when they have a premature baby in Ireland. So Allison decided to address these issues and other problems faced by parents to make life a little easier for families throughout the country. In December 2009, she founded a group which she called Irish Premature Babies. Within a few weeks of its formation Irish Premature Babies had a number of dedicated parents who had come on board and kindly volunteered their valuable time and effort to further grow and develop the organisation. Without the dedication and support of all of our volunteers the organisation would never have grown into the charity that it is now. Irish Premature Babies has now a bountiful mixture of people volunteering in the charity from doctors, nurses, teachers to stay at home mums.

How Irish Premature Babies helps families of premature babies in Ireland.

- 10 Regional branches throughout Ireland.
- 13 Hospital representatives each liaising between the charity , the parents in the NICUs/SCBUs and the medical professionals.
- Buddy system support network for parents



- Bosom buddy support network for parents expressing and breastfeeding
- 24 Hour helpline
- Free discount card scheme for families
- Meet and Greet sessions for families throughout Ireland
- Information leaflets and booklets
- Free parent workshops
- Advocacy and policy making
- Exhibition days
- Access to professional lactation services
- Emergency accommodation for families
- Emergency funding for families in need.
- Fundraising to buy Specialist equipment for the NICU's and SCBU's around Ireland.

Current project:

When a child is born prematurely, they often face very long hospital stays due to the complications associated with premature birth. During this time parents are forced to stay in private accommodation if they can afford to (which many cannot during this difficult economic time). Others are forced to sleep on floors, stay in cars or stay separated from their baby. Having a premature baby is a stressful and traumatic event, the added complication of where to sleep at night is a burden families don't need.

Over the last number of years, 2750 babies have been transferred by the NNTP (National Neonatal Transport Programme) from around Ireland to Dublin for treatment and specialised care to give them a fighting chance to survive, but parents have nowhere to stay.

There is no financial help or support to parents for accommodation, except emergency funding IPB can provide. The average expense for parent with a baby in an NICU in Dublin is €618.50 per week, for a three month period it is €7422.00.



Parents need to be close to their babies and vice versa. The early weeks and months are a sensitive period when mother and baby need to be together. Separation of mothers and new-borns is a physical deprivation and an emotional trial. Mothers of premature babies are at higher risk of PTSD, up to 50% and separation from the baby further adds to this problem.

We need an end to this injustice for parents of premature babies. The right to stay with a premature baby is taken from parents if they cannot afford to pay for private temporary accommodation. If you have a sick baby in Temple Street hospital or Crumlin hospital both in Dublin, they both have ample accommodation to keep parents and their babies together.

Funding will go towards the following:

- Towards the purchase of a building central to the three Dublin Maternity hospitals. The accommodation will facilitate parents from all over Ireland whose babies are transferred to one of the three Dublin Maternity hospitals. The maternity hospitals are very eager to find a solution to this predicament faced by parents.
- Many premature babies require surgical / clinical follow up care in Dublin, and our proposed building can also provide accommodation for these parents.
- One room will be allocated to facilitate professional services such as counselling, lactational support and NICU discharge support for babies who go home on oxygen or tube feeding.
- We currently collaborate with professional organisations to deliver professional services to parents. We work with "Nurture -Post Natal Depression Support Services, The Lactation association of Ireland, an Bord Altranais registered NICU nurses and midwives. We will continue to develop our associations with these bodies.
- An additional room will be allocated as a parent's room allowing mothers and fathers to relax and meet other parents. Parents need a haven away from the Intensive Care Units.

Our Teams in the Charity

Pr & Communications Team.

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Allison Molloy (BA (Hons) H.DIPED, DIP Counselling) - **Chairperson and Founder**

References

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(2) Perinatal Statistics Report, 2009, Health Research and Information Division, ESRI June 2011, ISBN 978-0-7070-0317-7

(3) Effectiveness of a parent "buddy" program for mothers of very preterm infants in a neonatal intensive care unit by Michele Preyde & Frida Ardal (Mount Sinai Hospital, Toronto)

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