



# **Irish Premature Babies Information Leaflet for Parents**

Irish Premature Babies  
(CHY19532)



*'Trying to make a big difference to each tiny life'*

## Who we are:

According to figures from the ESRI (Economic and Social Research Institute) and the CSO (Central Statistics Office), over 4,500 babies are born preterm in Ireland every year. One in 16 women will deliver a preterm baby in Ireland and every 116 minutes a baby is born too soon in this country.

Established in 2009 by founder Allison Molloy Fegan, Irish Premature Babies is a charity focused on supporting and helping the families of preterm babies in Ireland. We are the only national charity in Ireland that works directly with families of premature babies. Another major role of Irish Premature Babies is to fundraise and buy equipment for all the Neonatal Units around Ireland.

As a volunteer led charity all funding goes towards our charities objectives. We ensure families of premature babies receive the assistance they need and we purchase life saving equipment for NICU's. The charity is run by a board of directors and is supported by a parent advisory board and volunteers.

## Our main objectives:

- To promote a better support system for parents of premature babies in Ireland.
- To liaise with other bodies in helping parents to access professional services.
- Highlight the difficulties facing parents while in the NICU and in the months/years following discharge.
- Provide information that is important and relevant to parents and their preterm baby.
- Support the work of the medical professionals in the NICU's/SCBU's
- Create networks for parents to link in with other parents.
- Put the topic of prematurity on the Irish health system agenda.

## We can help:

### Social Interaction:

We are currently setting up regional branches of the charity. One of the functions of these branches will be run "meet & greet" sessions for parents to in their own locality. They serve to alleviate the isolation and loneliness often felt by parents of preterm babies. We organise days out focused on the babies and children who were premature and hold these in Dublin, Cork and Galway. They are family days out and a great way to meet new parents and IPB volunteers. We host awareness exhibitions around the country and attend numerous public exhibitions/shows. Our website has a forum where parents can connect with each other. Our Facebook page "Irish Premature Babies" has over 43,000 people following this page is busy, informative and interactive.

### Breastfeeding & Expressing:

We operate a breast pump rental scheme for preterm mothers in financial difficulty. We rent breast pumps for one month only, so we can support as many mothers as possible. We charge a highly reduced fee. We have a breastfeeding "bosom buddy" system set up. We know that mums can find expressing and breastfeeding challenging. We offer help and support to mums from our trained "bosom" buddies who have expressed or breastfed their own premature babies. We also liaise with professional lactation specialists who have experience with dealing with premature babies and we can help support mothers with the transition from bottle to breast. When hiring a breast pump from Medicare, remember to quote our charity and you will get a discount. For any information relating to breastfeeding please contact our co-ordinator at [breastfeeding@irishprematurebabies.com](mailto:breastfeeding@irishprematurebabies.com).

### Hardship fund:

We provide discounted hospital grade breast pumps for mothers. We provide clothing packages for parents who are struggling financially. We get donations of baby accessories and distribute them to parents in need. The funding for our hardship fund is limited but we help families with counselling, breast pump rental, emergency accommodation and travel expenses. We have helped with therapy assessment for older prems, helped parents with medical costs and funeral costs. The funding is only for families who are struggling and are in severe difficulty. An application can be obtained by emailing one of our directors at [info@irishprematurebabies.com](mailto:info@irishprematurebabies.com).

### Advocacy:

In 2014, Irish Premature Babies produced the report called “The national report on prematurity **“Preterm birth: An insight into the social, economic and psychological encumbrance on families in Ireland 2014”** is part one of a longitudinal study into the long term effects of prematurity on both the baby and the family of the preterm baby. There will be three stages in this report, beginning when the neonate is born up right up to eighteen years of age until they reach adulthood. This report will give a unique perspective into both the short and long term experiences of parents. The report will also highlight the epidemiology associated with preterm birth and follows over 600 families. In conjunction with the RCPI Faculty of Paediatrics and EFCNI launched Ireland’s inaugural Benchmarking Report “Positive Steps for Prematurity” in November 2011. This report has now been included in a pan European report “Too Little Too Late”. The charity also contributed towards the EU White Paper “Caring for Tomorrow” which was presented to the EU Parliament. We also work with a number of other agencies and charities such as IPPOSI which is Irish Platform for Patients’ Organisations, Children’s rights in Ireland, ALCI (Association of Lactation consultants Ireland), Healthy Newborn Network, Save the Children, and Children’s right International Network. We have worked with the HSE on the National Paediatric Charter for 2013 and with the Institute of Public Health and the breastfeeding implementation committee on the 5 year strategic plan for breastfeeding in Ireland.

### Research:

The Charity is also involved with fellow premature baby charities Bliss from the UK and Tiny Life in Northern Ireland in a research programme. The Preterm Birth study is part of a wider research programme called “Improving quality of care and outcome at very preterm birth”. The Social Research Science Unit at the Institute of London is working with the James Lind Alliance and our charities to identify uncertainties in treatments and outcomes for preterm birth and to prioritise them in the future. The charity has just recently invested in new IT hardware and software that will allow parents to register their premature baby at birth. With the help of parents, we can monitor each baby’s progress up to 18 years of age. For research, statistical and lobbying purposes this data will be of huge benefit. Irish Premature Babies understands the importance of keeping abreast of all the latest research published on prematurity. Further information can be found on our website.

### Supporting the NICU/SCBU's around Ireland:

To date we have helped raise and donate over €200,000 to the Intensive Care Units across the country. We buy all sorts of equipment from incubators to MR10 monitors. We also have a nationwide team of knitters who knit hats, cardigans and blankets for premature babies. These items are donated to the various NICU’s. In December 2013 we began a new initiative of refurbishing parent’s rooms. We renovated three parents’ rooms in Our Lady’s Children’s Hospital Crumlin to create a “home from home” environment. We have seen the benefits of these rooms and intend to continue this programme, focusing on a different hospital each year.



### Annual IPB Family Membership:

The charity are now running a membership scheme. The membership runs annually and families are asked to contribute €25.00 per annum. Each family will be issued with a unique card. Families will be eligible to attend all our workshops for free, to attend all our days out for free, will get a copy of our newsletter to your house and will be able to use our discount scheme.

### Workshops:

We run workshops for parents and families of premature babies.

#### Some of our workshops include:

- Paediatric First Aid for parents and grandparents (in Dublin and Cork)
- Expressing and breastfeeding premature babies
- Sensory processing issues ( Dublin and Cork)
- Dealing with the emotional side of having a preterm baby
- Art Therapy

### Discounts:

We provide Discount Schemes for families of premature children that are free to all families. To avail of the scheme download and complete the application form on our website and return the form to Irish Premature Babies. A discount card with a list of all the businesses we have secured discounts from will be posted to you. The scheme offers a wide range of discounts. Full details are on the website. To get your IPB annual membership please go to our website, click the membership link and enter your details. You can pay with paypal or card.

### Information:

We provide a comprehensive information guide that parents will find relevant from birth on our website. You can find information on rights and entitlements including details of claiming tax refunds, how to defer your maternity leave, where to purchase premature baby clothing and where to access counselling services. We run a newsletter called “**Early Addition**”, you can sign up for the newsletter on our website (previous versions are available on our website). We have produced booklets on “**Rights & Entitlements**”, “**Weaning a Preterm Baby**” and general information leaflets. We have compiled a unique book called “**Tiny Footprints**” which gives an account of 80 families who have had a preterm birth in Ireland. As a charity, Irish Premature Babies works tirelessly to spread the word about preterm birth and as such we provide information packs for schools and undergraduates who are study the area of preterm birth.

## How to contact us:

Website: [www.irishprematurebabies.com](http://www.irishprematurebabies.com)  
Address: Carmichael House, North Brunswick Street, Dublin 7  
Twitter: [irishprems](https://twitter.com/irishprems)  
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