Irish Neonatal Health Alliance (INHA)
Pre-budget Submission 2022

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About the Irish Neonatal Health Alliance (INHA)

The Irish Neonatal Health Alliance (www.inha.ie) is a registered charity (CHY 21984, RCN-20100100). Our mission is to partner with, educate and empower families, healthcare professionals, educators, political decision makers and industry stakeholders on issues relating to the neonatal field.

This document outlines our concerns in relation to baby loss and premature birth and our asks of the Government for Budget 2022.

Facts and Figures

Each year, in Ireland, 4,500 babies are born too small, too soon and too sick - that is one baby every 116 minutes.

Baby loss is also not uncommon. The latest figures available from the National Perinatal Epidemiology Centre are from 2017 and they show that in Ireland 381 babies died. Stillbirths accounted for 235 (61.7%), early neonatal death accounted for 111 (29.1%) and late neonatal deaths accounted for 35 (9.2%). Baby deaths from multiple births accounted for 12.4% of all baby deaths (Source: https://www.ucc.ie/en/media/research/nationalperinatalepidemiologycentre/NPECPerinatalMortalityinIrelandAnnualReport2017.pdf).

Department of Social Protection

1. The Cost of Baby Loss

The death of a baby is something that parents are often completely emotionally and financially unprepared for. Many bereaved parents must rely on the generosity of friends and family or must take out a bank loan to pay for their baby's burial or cremation and funeral. In the darkest moment of a bereaved parent's life, they should not have to endure the financial burden of meeting funeral costs.

The Costs Involved

These costs can involve buying a new grave, burial in a family plot or burial in the angel's plot. Some maternity hospitals provide bereaved parents with a coffin for a baby to be taken home in and buried, others do not when the parents are holding a private burial from their own home or funeral home.

If parents choose to cremate their baby's body, they can choose between the six crematoria on the island of Ireland. Three of the crematoria charge no fee to cremate a baby and three charge between 160 euro and 330 euro (Source: www.aftering.com/crematoria-in-ireland/). The above fees may not include the cost of an urn, courier to return to baby's ashes in an urn, chapel service or burial of the urn. Other additional costs can include a funeral director, the grave digger, flowers and venues and refreshments at gatherings after the funeral.

Kildare County Council Sets Best Practice

We would like to commend Kildare County Council for introducing a policy to waiver the fee for a single burial plot where a baby under 18 months old will be buried. If parents choose to purchase a family plot for their baby, the plot fee will be equally reduced. Alternatively, if parents choose to bury their baby in an "angels" plot, the council will also waive the fee.

Best Practices in Other Countries

United Kingdom

In Wales and England, bereaved parents no longer must pay for the funeral costs for their child after Labour MP Carolyn Harris set up a campaign after she needed a loan to pay for her eight-year-old son's funeral. The Welsh Government has establishment of a Children's Funeral Fund, which will waive the costs of burials and cremations for the families of children who die each year in Wales. The Welsh Government made £1.5m available to support local authorities and other providers of cemeteries and crematoriums (Source: www.bbc.com/news/uk-wales-42096445). This funding will also be available to all other providers of cemeteries and crematoria in Wales who agree not to charge on the same basis.

In addition, throughout the UK, the Coop Funeral Franchcise, provides funeral services free of charge up to the age of 18 years old (Source: https://www.co-operativefuneralcare.co.uk/arranging-a-funeral/funeral-choices/childrens-funerals/).

The free services provided are:

- *All Funeral Director services to cover all aspects of the funeral arrangement, including the completion of all documentation and liaison with all third parties and appropriate advice, support, and guidance.*
- *Choice of coffin.*
- *Suitable vehicle for the parents and their child.*
- *Personnel to conduct the funeral.*
- *Use of the funeral home for service where available.*

Poland

In Poland, parents can apply for a funeral grant of €933 if their baby has died. To obtain this grant, bereaved parents need to present documents confirming the costs of burial and the right to obtain benefits (Source: https://www.blizejprawa.pl/prawo-rodzinne/prawa-rodzicow-po-poronieniu/).

Norway

Bereaved parents in Norway can get up to €2458.71 towards the costs of their child's funeral from the State when a child is under 18 years old. There is no lower limit age of the child.

Our Asks

1. A Children's Burial Fund should be established by the Department of Social Protection, so that all local authorities can feel that they are in a position to put in place a similar policy to that of Kildare County Council and claim back the cost of the waiver.

2. Changes to Maternity Leave and Paternity Leave

The Maternity Protection Acts 1994-2004 provide for up to 26 weeks paid maternity leave, and a further 16 weeks' unpaid leave for women whose pregnancy has been confirmed by a medical practitioner after the 24th week of pregnancy.

When a baby is stillborn and dies after 24th week of pregnancy or is over 500g, the mother is entitled to take her full maternity leave. Paternity leave is also available to a parent when a stillborn baby dies any time after the 24th week of pregnancy or weighs over 500g.

However, if a baby is born showing no signs of life and has a birthweight of less than 500g and a gestational age at delivery less than 24 weeks, alarmingly the baby's parents are not entitled to any leave and the decision to grant leave is at the employer's discretion. This situation is unacceptable, and the Government needs to review and remedy this situation as a matter of urgency.

Our Asks

- The Department of Social Protection needs to make maternity leave available for mothers whose baby is born showing no signs of life and is delivered before 24th week of pregnancy or weighs under 500g.

- The Department of Social Protection needs to make paternity leave available to a parent whose baby is born showing no signs of life and is delivered before the 24th week of pregnancy or weighs under 500g.

Department of Health

1. Funding for Breast Pumps

Preterm babies face many challenges because of their early delivery. Morbidity and mortality of sick and preterm babies can only be reduced if their specific medical and nutritional needs are met. Exclusive breastfeeding is associated with a significant decrease in infant mortality rates and has positive psychological benefits for mother and child. The World Health Organisation (WHO), the United Nation's International Children's Emergency Fund (UNICEF), the European Milk Bank Association (EMBA) and the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) recommend exclusive breastfeeding - until six months of age and continuing to two years or beyond - as the optimal way of feeding infants. Scientific evidence demonstrates that human milk (either mother's own milk or donated milk) has many health benefits for preterm, sick, and low-birth-weight babies, including lower incidence rates of necrotizing enterocolitis (NEC), a severe multifactorial disorder of preterm born babies. The medical benefits of breast milk are manifold:

- it decreases intestinal disease/necrotising enterocolitis by 6-7 times,
- it reduces later hypertension by 34%,
- it decreases late-onset sepsis by 20%,
- it reduces chronic lung disease/bronchopulmonary dysplasia by 22% and
- it decreases vision disease/retinopathy of prematurity by 40-45%.

Alarmingly, the families of pre-term and sick babies do not have adequate and unlimited access to lactation support or hospital grade breast pumps. The 19 maternity hospitals do not have specifically assigned Neonatal Lactation Consultants, who can support mothers of preterm and sick babies to initiate expressing and achieve optimal supply and mothers must queue to avail of hospital pumps when they are visiting their babies in the Neonatal Intensive Care Unit. Consequently, the development of preterm infants is being compromised by the limited access to internationally recommended nutrition support of breast milk.

Our Ask

- Funding needs to be provided to ensure that every tertiary has a dedicated neonatal dietitian; that level 1 and level 2 neonatal units have access to dietitian services; that every parent with a baby in the Neonatal Intensive Care Unit has unlimited access to a hospital grade breast pump for as long as is required.

2. Availability of Dedicated Allied Health Professionals

The HSE Model of Care for Neonatal Services in Ireland sections 8.2 – 8.8 outline the vital role that Allied Health Professionals play in the development of preterm infants.

Our Asks

- Funding must be allocated to ensure that every Tertiary Neonatal Intensive Care Unit must have dedicated physiotherapists, occupational therapists, speech and language

therapists, dietitians, clinical psychologists, social workers, and neonatal pharmacists.
- Level 2 and Level 1 neonatal units must also have access to these services in the tertiary unit that they are grouped with.

3. Emotional supports

Emotional Support for Parents who Experience Pre-term Birth

The INHA recognises the enormous impact that preterm birth has on families - physically, emotionally, psychologically, and financially. Parents often experience an emotional crisis when their newborn baby is admitted to the Neonatal Intensive Care Units after their delivery. Parents are mostly at risk of anxiety, depression, acute stress disorder and post-traumatic stress disorder. Postpartum depression is a common experience in mothers of preterm babies. Babies who are premature are also more likely to have poorer cognitive and developmental functioning and this can be hard for a parent to cope with.

Currently, the 19 Irish Neonatal Intensive Care Units do not have designated emotional supports to help parents whose babies in the Neonatal Intensive Care Unit and these families connect with the INHA in search of assistance. Many of our families go on to receive counselling following their neonatal unit experience as they battle the emotional and psychological fallout from the preterm birth. The Irish neonatal system does not recognise the importance of parental mental well-being which can have devastating consequences for both babies and their families.

Emotional Support for Bereaved Parents in the Community

In its policy document "Specialist Perinatal Mental Health Services: Model of Care for Ireland" the HSE recognises that the death of a baby is a possible trigger for a need for mental health supports for bereaved parents (Source https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf).

The HSE's National Standards in Bereavement Standards following Pregnancy Loss or Perinatal Death also says that level two bereavement care will be of benefit to some bereaved parents so that they have an opportunity to talk about what they have gone through (Source: file:///C:/Users/conno/Desktop/INHA%20Work/Nat%20Std%20in%20Bereavement%20Care/national-standards-for-bereavement-care-following-pregnancy-loss-and-perinatal-death.pdf).

In the Department of Health's "Consultation on the development of a National Maternity Strategy" several respondents said that they would like to see greater access to counselling services and follow up supports and it was noted that "no funding is available to provide counselling to those who suffer stillbirth" (Source: https://assets.gov.ie/18838/eb7036e9223445449fd15e647723b6c2.pdf).

In addition, the National Maternity Strategy 2016-2026 makes a commitment that "all couples who experience pregnancy loss should be supported psychologically by hospital staff and have access to bereavement counselling either in a hospital or primary care setting" (Source: https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf).

Standard 1.8 in HIQA's National Standards for Safer Better Maternity Services states that "Maternity service providers ensure additional supports are in place for women and families who experience

bereavement or pregnancy complications and that "If you experience pregnancy loss, perinatal death or pregnancy complications you receive the care and emotional support you need from the time this becomes known (Source: https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf).

It is obvious that parents who experience loss of their baby may require specialist emotional support triggered by intense grief and the trauma of their experience. However, despite the Government policy commitments outlined above this support continues to be unavailable or inaccessible for many. Bereaved parents whose baby has died are falling through the gaps between policy and funding and are being overlooked.

Many bereaved parents need to seek additional supports such as counselling outside of the support that they receive from family and friends as parental grief can bring about particular challenges. Some bereaved parents seek organised supports from baby loss organisations which may involve professional counselling but many of these organisations, operate on a voluntary basis and do not receive State funding and struggle to provide such supports.

The Government needs to take action to ensure that all parents who experience loss of their baby who want to avail of specialist emotional support can access it, at a time and place that is right for them, free of charge, wherever they live.

Best practice in the UK

The NHS England and NHS Improvement announced in April 2021 that more mental health support for expectant and bereaved mothers. Research carried out by SANDS UK, the leading stillbirth and neonatal death charity in the UK (www.sands.org.uk), alongside other pregnancy and baby loss charities in the UK, found that 60% of bereaved parents felt they needed specialist emotional support in the community, but were not able to access it on the NHS (Source: https://www.england.nhs.uk/2021/04/dedicated-mh-services/). Thousands of new, expectant mothers and bereaved mothers will now receive help and support for mental health problems through 26 new dedicated hubs which are being set up across the UK. This is part of the NHS Long Term Plan (Source: https://www.longtermplan.nhs.uk/) and it is planned that every area will have a hub by April 2024. It is estimated that it costs the NHS and social care sector £1.2 billion per year where women do not access high-quality perinatal mental health services.

Our Asks

- The Department of Health's policy on mental health needs a coherent plan for parents who experience pre-term birth and loss of their baby. A review of supports available to parents whose baby has died or who baby is pre-term is required. This review needs which are benchmarked against existing best practices and standards. This plan must include an assessment of the capacity of voluntary sector to provide sufficient counselling to meet needs of bereaved parents and parents who have experienced pre-term birth or loss of their baby in an appropriate and evidence-based way. Representative organisations, including the INHA, and bereaved parents and parents who experience pre-term birth must be involved in the research as key

stakeholders. This should be led by the Department of Health, as part of mental health policy and strategy.

- The Department of Health needs to follow the best practice in the UK, outlined above, by rolling out of mental health support services for expectant mothers, bereaved mothers and mother who experience pre-term birth through new dedicated hubs across the country.

4. Prevention of Baby Loss in a Multiple Pregnancy

Prevention of loss in a multiple pregnancy needs to be urgently addressed by the Irish Government. This is because the research shows a consistent association between baby loss and multiple pregnancy (Source: https://www.ucc.ie/en/media/research/nationalperinatalepidemiologycentre/NPECPerinatalMortalityinIrelandAnnualReport2017.pdf)

Shockingly, there are no consistent standards for multiple births across all 19 maternity units in Ireland with each hospital clinical governance board self-selecting which guidelines to use, such as:

- The NICE guidelines for twin and triplet pregnancy (NG137) and its quality standards [Source: https://www.nice.org.uk/guidance/ng137] or
- the HSE Clinical Practice Guideline: Management of Multiple Pregnancy [Source: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/clinical-practice-guideline-management-of-multiple-pregnancy.pdf].

Best Practice in the UK

NICE guidelines for twin and triplet pregnancy (NG137) and its quality standard (SQ46) were set up by the UK Government and are mentioned in its Health and Social Care Act 2012 to advise the Department of Health and Social Care (Source: https://www.legislation.gov.uk/ukpga/2012/7/part/8). The NHS Long Term Plan commitment to roll out the "Saving Babies Lives Care Bundle", recommends using NICE, across every maternity unit in England during 2020. The process for which NICE reviews evidence and develops their standards is published in association with the guidelines (Source: https://www.nice.org.uk/guidance/ng137/evidence).

NICE has been adopted in the UK as best practice in preference to seeking the advice of solely independent membership organisations of medical professionals. Its evidence is developed after extensive, documented review of the literature that has gone to public consultation so that representative organisations also have an opportunity to feed into the process.

The report called "NICE works" produced by the charity Twins Trust UK in 2020, demonstrates through its Maternity Engagement Project that increased adherence to the NICE Quality Standard on Multiple pregnancy (QS46) is linked to improved outcomes for women and their babies (Source: https://twinstrust.org/static/afcc44b3-776e-4341-

8a16e9bd990c3425/NICE-works-final-report.pdf). The report shows that in just two years after NICE QS46 was followed in 27 maternity units in the UK, there was a:

- *6% reduction in stillbirths*
- *18% reduction in neonatal deaths and*
- *23% reduction in neonatal admissions.*

It found that if all units followed NICE QS46 across the UK:

- *100 babies' lives could be saved every year,*
- *Neonatal admissions could be reduced by 1,308 and*
- *All of this could save the NHS £8million every year.*

All 27 maternity units who took part in the Maternity Engagement Project made changes to their antenatal care and these changes were a zero cost or a low cost.

Initial funding for the project from the UK Department for Health and Social Care was £400,000 over 3 years. This covered everything from recruitment costs to staff costs and the time needed to establish the processes, tools, and resources for maternity units to implement NICE QS46.

Systems Analysis Review

A Systems Analysis Review (2019) by the RCSI Group produced the following recommendations which align with NICE clinical guidelines:

i. Revise the Standard Management of Multiple Pregnancy Guidelines to include antenatal admission of women with multiple pregnancy for any reason.

ii. On completion, the policy must be circulated, and appropriate training and education given.

iii. Audits must be carried out at regular intervals to monitor if full compliance with this guideline has been achieved.

iv. All antenatal admissions whether admitted for obstetric or non-obstetric reasons should have a plan of care described for monitoring of fetal wellbeing.

v. The practice of recording Fetal Heart Heard (FHH) should be discontinued and instead the numbered rate of the fetal heart beats should be recorded to ensure identification of multiple fetal hearts.

vi. Method of auscultation (For example: Pinard: a handheld device for listening to fetal heart rate. Sonicaid: a handheld doppler for measuring fetal heart rate. CTG: Cardiotocograph or electronic fetal monitor for measuring fetal heart rate and uterine contractions in labour) should also be documented at every assessment of fetal heart.

vii. In the event of difficulty in fetal heart auscultation the documentation in the healthcare record must reflect assistance sought and the outcome recorded.

viii. Recommend to the Institute of Obstetricians and Gynaecologists to generate a guideline with respect to fetal wellbeing for antenatal monitoring to include admission for non-obstetric issues.

As the incidence of velamentous cord insertion is common in twins especially in MCDA twins where its prevalence is 1:9, Dublin District Coroner has also recommended that the placental cord insertion site must be checked and recorded at the time of the anomaly scan in all MCDA twins.

Our Asks

- The Department of Health must instruct that all 19 maternity units in Ireland use the revised HSE national clinical practice guideline for the management of multiple pregnancy rather than self-selecting which one to use and / or developing their own guidelines.
- The Department of Health needs to fund an initiative that will enable the 19 maternity units in Ireland to be audited and supported to implement the HSE national clinical practice guideline for the management of multiple births. It will cost considerably less than in the UK as learnings from the Twins Trust Maternity Engagement Project can be used, for example, the Twins Trust Care Pathway, that is endorsed by NICE, assists with the implementation of the NICE Quality Standard on Multiple Pregnancy (QS46). This resource is freely available and are an easy way to improve ante-natal care [Twins Trust (2020) Multiple Pregnancy - Care Pathway https://twinstrust.org/uploads/assets/510d7947-8a35-4272-bbd477be5e9ac834/Multiple-Pregnancy-Care-Pathway-for-Parents.pdf].
- Free online training is also already available through Twins Trust at: https://twinstrust.org/healthcare-professionals.html. Irish healthcare professionals can already log on to access free CPD videos covering antenatal and intrapartum best practice and resources from multiple specific study days. The Department of Health needs to provide €300,000 over 3 years initial funding for the initiative. This will cover recruitment costs for staff, staff costs and development of processes, tools, and resources. The Department should also provide €8,500 per maternity unit for an audit to be carried out with 6 audits being carried out in the first year, 6 in the second year and 7 in the third year.

More information

If you would like any further information on our concerns and asks outlined above, please contact:

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