The Irish Neonatal Health Alliance – empowerment, education, partnership

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Over 15 million babies are born too early, too sick and too small in the world every year. One million of these babies die. In Ireland over 4,500 babies are born prematurely annually; that's one baby every 116 minutes. Preterm birth is an unexpected event for the majority of families and its impact on both the family and infant can last a lifetime. It forces families to re-evaluate their expectations and hopes for their children, disempowers parents of their parenting role and its sequelae can have far reaching consequences.

The Irish Neonatal Health Alliance (INHA) is an Irish charity founded by parents of premature infants who, following their personal journeys with premature birth, recognised the need for those in the neonatal field to work together to reduce the incidence of preterm birth, standardise care practices and improve outcomes for infants and their families.

Fast forward to 2018 and the INHA's remit has penetrated every aspect of the 'neonatal space' both in Ireland and internationally. INHA's vision is to support and empower families affected by prematurity by advocating increased awareness, improved pre-conceptual, antenatal and postnatal education, equitable and standardised neonatal care and improved long-term care for both the premature baby and the family.

Its objective, through consultation with global networks of prematurity groups, healthcare professionals, educators, researchers, political decision-makers and industry stakeholders, is to foster the exchange of information, provide education to healthcare professionals and families and with one collective voice, to provide the platform for a coordinated and integrated programme of collaborative support in the field of neonatal care in Ireland.

The pillars that comprise the vision of the organisation include:

- family support
- advocacy
- awareness
- education
- research.

Family support

Since the very early days of the charity, infants and their families have been at the heart of the INHA's work. Its family support structure includes peer-to-peer support, a private online parenting forum moderated by volunteers and members of the INHA Medical Advisory Panel and a comprehensive website that provides education and guidance for families by tracking the journey from pre-conception to the early childhood years.

Advocacy

Advocating for change in an environment where multidisciplinary collaboration had not been the norm has been a challenging task for the organisation but the successes include producing Ireland's inaugural Neonatal Benchmarking Report, which mapped the Irish neonatal landscape and highlighted five areas that required immediate attention in order to improve the care delivered; securing funding to extend the neonatal transport service from a nine-to-five service to 24 hours; producing Ireland's first Model of Care For Neonatal Services; drafting the National Children's Healthcare Charter and, with a petition of over 56,000 signatures, changing the law governing maternity leave to include additional leave for mothers of premature babies. Such efforts have seen the INHA awarded the Irish Healthcare Award for Best Medical Conference in 2012 and Best Premature Baby Patient Organisation in 2017.

A patient advocacy organization set up in December 2013 to facilitate a platform for partnership for the stakeholders in the field of preterm birth in Ireland.

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Opportunities exist to improve outcomes in many areas.

Parents should have the resources and tools necessary to become competent primary caregivers for their premature child.

To increase awareness, identify key target audiences and leverage existing data and research.

The INHA's vision for supporting and empowering families affected by prematurity.

One of the many benefits of the collaborative stakeholder platform has been the availability of skilled expert patient representatives to work alongside care providers on healthcare executive steering groups, thus ensuring that the patient perspective is at the heart of all healthcare decisions. Examples include the national medicines transport programme, primary eye care services review group and the therapeutic hypothermia e-register steering group.

Internationally the organisation has contributed towards the Call To Action For Newborn Health document (www.efcni.org); is currently working with over 220 European neonatal healthcare professionals to deliver the Standards of Care For Newborn Health in November 2018 (www.newborn-health-standards.org); and has published in the *Lancet, Journal of Obstetrics and Gynaecology, Archives of Disease in Childhood,* and *PLOS.*

Awareness

Lack of public awareness of the causes and long-term consequences of preterm birth was one of the five areas identified in the 2010 benchmarking report and the organisation leverages

The INHA was founded by parents who recognised the need to improve outcomes for their preterm babies.

the media on world prematurity day (17 November) to address this shortcoming. Each year, with the support of corporate funding, the INHA hosts a neonatal medical symposium in Dublin, with national and international speakers shining a light on specific topics: family-centred care, bonding and attachment, discharge, childhood development, etc.

In tandem with this, the wider community is targeted, with famous Irish landmarks illuminated in purple light (the international colour of prematurity) on world prematurity day.

The many community-based projects initiated by the organisation reach an audience where awareness on the topic is quite low. The Angel Gowns project sees donated wedding dresses converted into angel gowns for infants that pass away. The Incubator Cover and the Knit for NICUs projects have proven very successful with all items being donated to the 19 neonatal units in Ireland on 17 November each year.

Education

Another area of concern highlighted in the 2010 benchmarking report was neonatal education and to this end the INHA provides guest lectures in third-level (higher education) institutions, presents at medical conferences and hospital study days, delivers healthcare professional workshops on target topics (eg neonatal feeding challenges, developmental care, sensory processing disorder, etc) and funds education for healthcare professionals. As service users, families are a valuable source of feedback and education for everyone working with neonates and the INHA network prides itself on harnessing this resource and channelling it to improve outcomes.

Research

Since 2013 the patient and public involvement (PPI) role in research has become a crucial component and two of the large research institutes in Ireland (the Irish Centre for Fetal and Neonatal Translational Research in Cork and the Health Research Board Mother and Baby Clinical Trials Network) have partnered with the INHA on numerous projects. As the INHA also has representation on the boards of the European Foundation for the Care Of Newborn Infants (EFCNI, www.efcni.org) and the Newborn Individualised Developmental Care and Assessment Programme (NIDCAP, www.nidcap.org), it also holds the PPI role on many international research projects. A full list of all PPI roles can be seen on the INHA LinkedIn page (https://ie.linkedin.com/in/irish-neonatal-health-alliance).

Patients now have the ability to guide research priorities and make a real life difference to the lives of people living with the sequelae of preterm birth.

Prevention and screening

A more challenging recommendation highlighted in the benchmarking report was the implementation of a prevention and screening programme to help identify at-risk pregnancies and deliver better antenatal care. This is a difficult area to address; the causes of many preterm births are not well understood. Ongoing research is revealing more about premature births, especially those that arise as a result of a pregnancy-related medical condition or from a maternal medical condition. However, given the diversity of circumstances that can result in a preterm birth, a widespread global commitment to further research is required.

One of the unique aspects of the INHA charity is the 100% voluntary nature of the organisation. From the humble beginnings of a small group of volunteer parents whose initial reason for founding the organisation was to seek support to help them navigate their journeys with their preterm infants, this organisation has established the platform that facilitates a diverse range of national and international stakeholders to work collaboratively to reduce the incidence of preterm birth, empower parents, standardise care and improve outcomes.