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The situation and the challenges with regard to preterm birth in Europe – Why reducing the incidence of preterm birth matters and the main components needed to successfully address the challenges

By Professor Dominique Haumont, Professor Luc Zimmermann and Silke Mader, European Foundation for the Care of Newborn Infants

SUMMARY

Every family hopes to have a healthy newborn baby. Much progress in ensuring healthier pregnancies and pregnancy outcomes has been made over the past decades, but still, pregnancy and childbirth involve many risks. Maternal and infant mortality and morbidity, birth defects, low birth weight and preterm birth continue to be serious problems for our societies – this is the case throughout the world, and Europe is no exception.

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One baby in ten is born prematurely each year, i.e. about 500,000 babies in Europe alone and the number of preterm babies continues to rise. Preterm birth poses a serious, underestimated threat to the health and wellbeing of Europe's future population and places a burden on healthcare systems, many of which are already struggling to cope with demand.

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Preterm infants have a greater risk of developing short- and long-term health complications and families affected by preterm birth experience enormous physical, emotional and financial challenges. The rates of mortality and morbidity vary greatly depending on where babies are born and the socio economic status of the individual family.

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Although preterm infants represent Europe's largest child patient group, the health of newborn infants and especially preterm infants still remains absent from Europe's health policy agendas. Only very few countries have targeted neonatal policies and programmes to guarantee high-quality healthcare and social support to the children and their families.

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Preterm birth – what is it?

Preterm birth is defined by the World Health Organisation (WHO) as all births before 37 completed weeks of pregnancy (Table 1). It is the single major cause of infant mortality and morbidity in both developed and developing countries and has long-term adverse consequences for health.

Severity of preterm birth	Gestational weeks
Extremely preterm	Less than 28 weeks
Very preterm	28 – 31 weeks
Moderately preterm	32 – 33 weeks
Late preterm	34 – 36 weeks

Table 1 Definition of preterm birth

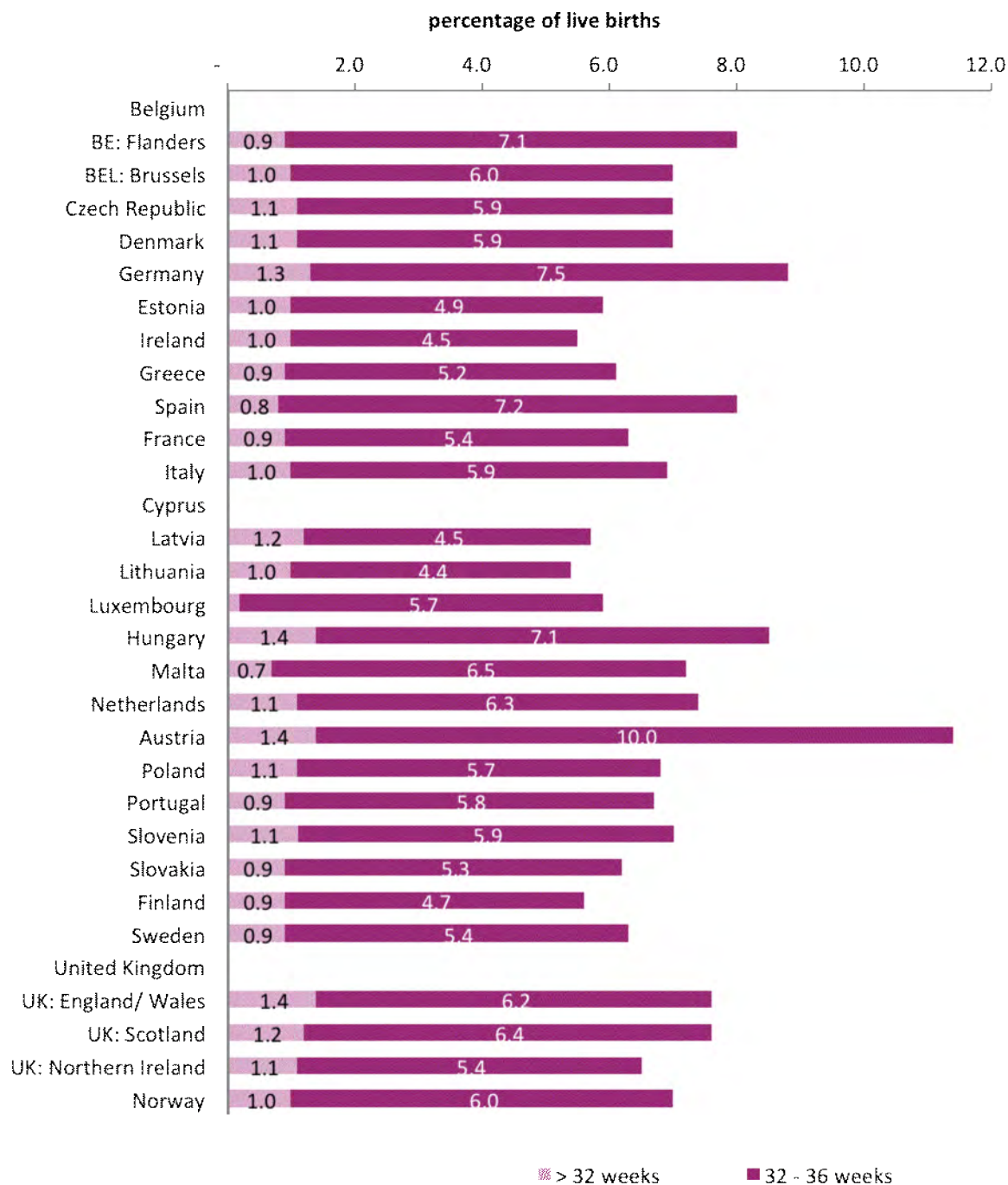
Preterm birth – alarming numbers

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Approximately 5 million children are born every year in the EU, of which about 500,000 are preterm (born before 37 weeks of pregnancy) or experience complications requiring intensive or special care in the neonatal¹ period, i.e. 10% of all births.

According to data from national registers and the 2008 European Perinatal Health Report, the prevalence rate of preterm birth in the EU ranges from 5.5% (Ireland) to 11.4% (Austria) and inconsistencies in data suggest that these figures are still considered to underestimate the current rate of preterm birth. Available data also provides evidence of an increasing number of preterm infants across Europe in the last ten years, a trend which is only expected to rise.



Source: Euro-Peristat Report 2008
Page 13, Figure 7.10

Table 2 Percentage of live births with a gestational age of less than 32 weeks and between 32–36 weeks

What are the Causes of Preterm Birth and can Preterm Birth be prevented?

Little is known about the causes of preterm birth. In about half of all cases of preterm birth, the exact cause of the early delivery still remains unknown. Nonetheless, some of the risk factors associated with preterm birth are listed in Table 3.

Lifestyle factors	Medical Conditions	Demographic factors
Smoking	Infections (urinary tract/ vaginal)	Aged under 17 or over 35
Alcohol consumption	High blood pressure	Low socioeconomic status
Drug use	Diabetes	Ethnicity
High stress levels and long working hours	Clotting disorders	
Late or no prenatal care	Underweight/ obesity	
Lack of social support	Multiple pregnancy	
	Having experienced a preterm birth before	
	Increased number of pregnancy interventions ⁱⁱ	
	Uterine or cervical abnormalities	

Table 3 Risk Factors for Preterm Birth

Once a woman is pregnant, most of the interventions only delay the birth, turning early preterm birth into a late preterm birth, or enhance foetal maturity. Some solutions are known to prevent preterm birth but these are clustered in the preconception period or in-between pregnancies

Why does Preterm Birth matter?

Preterm birth is now the second leading cause of death in children under 5 years of age and the single most important cause of death in the critical first month of life

Preterm birth is now the second leading cause of death in children under 5 years of age and the single most important cause of death in the critical first month of life. Preterm infants represent Europe's largest child patient group and preterm birth is a major cause of infant mortality and morbidity in the EU and worldwide.

This means that not only does Europe have a huge influx of vulnerable newborns to care for each year but also the number of preterm born people suffering from health problems is steadily increasing

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As these infants grow up, they do so with a higher risk of developing both short-term health complications and long-term chronic diseases and non-communicable diseases that will have an impact throughout their lives: The earlier the baby is born, the less developed his/her organs will be, and the higher the risk of medical complications later in life. These include, but are not limited to:

- learning and motor disabilities
- cerebral palsy
- sensory deficits
- respiratory illnesses (including asthma and RSV-bronchiolitis)
- diabetes
- cardiovascular problems
- allergies

Prematurity has a huge personal impact on the child and his/her family. Some of the intangible costs associated with caring for preterm infants include the emotional and physical energy required to care for the infant and the risk of isolation and restricted social contact that ensues. In addition, there are also wider cost implications for public health, the healthcare and social welfare system (including direct and indirect costs), the economy and for society.

Preterm Infants and their families have special needs

Babies and children fall into a special category when it comes to health issues and cannot simply be treated as "smaller adults". They are much more vulnerable, and need to be protected and provided with the best possible physical and social environment when brought into the world.

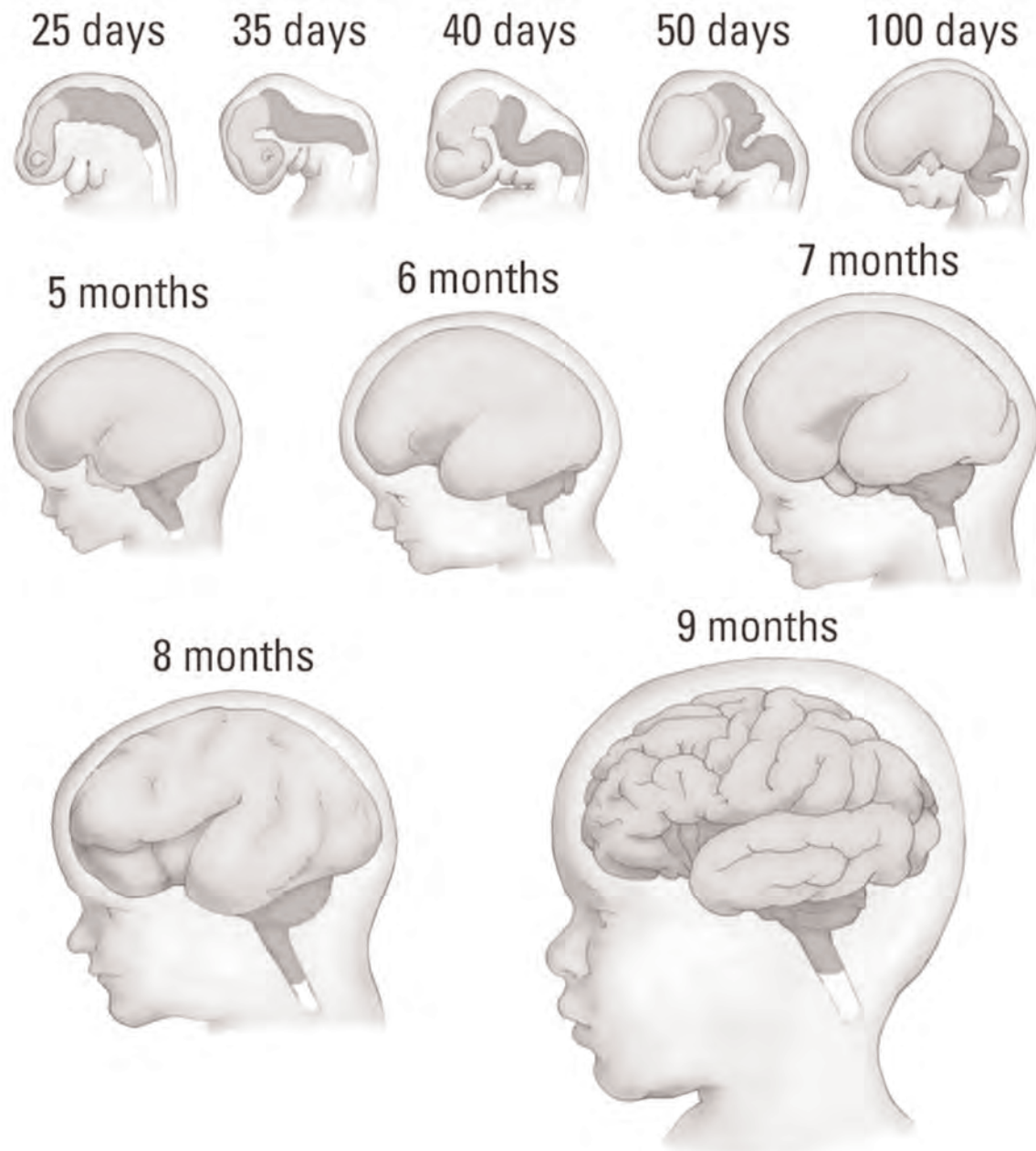
The introduction of neonatal intensive care in the 1960s resulted in substantial improvements in outcomes for preterm infants. But even though European countries provide high-quality neonatal care, the special needs of preterm infants are often neglected. In many countries, the topic of preterm children is still taboo, and as a result, families do not get the support they need.

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The fundamental difference between preterm infants and all other patient groups is that the preterm brain is in a very active stage of development. Although genetically geared, brain development is to a large extent influenced by sensory stimulation, which makes infants exceptionally receptive but also vulnerable, especially when born preterm. Consequently, the sensory environment may influence both short-term morbidity and long-term development in these infants. As such, bright light, high sound/noise levels are known to have a negative influence; but also e.g. positioning, handling and presence of parents (voice and skin-to-skin contact) play an important role.

In order to adjust the clinical care to the appropriate developmental stage of the individual infant's brain maturation, some caregiving models have evolved that focus on enhancing the competence of the caregivers (parents and clinical staff) to better meet the babies' needs and to make the environment more appropriate for the individual infant. These models, especially avoiding parent-infant separation, have proven to reduce the length of hospital stay and short-term morbidity, and to improve long-term development.

The uptake of family centred developmentally supportive care needs to be better known as does the implementation of evidence-based care procedures in European Neonatal Intensive Care Units (NICUs). This includes practical aspects such as the positioning of the infant, minimal handling, enhancing the infant's sleep organization, kangaroo careⁱⁱⁱ, supporting breastfeeding and pain relief, and, very importantly, individualized care for each infant with his/her family.



C.R. Reynolds, E. Fletcher-Janzen (eds.), *Handbook of Clinical Child Neuropsychology*, DOI 10.1007/978-0-387-78867-8_2, _ Springer Science_Business Media, LLC 2009; FIGURE 2. Prenatal development of the human brain showing a series of embryonic and fetal stages. (Adapted from Cowan, 1979; ©Springer Images) with kind permission of Springer Science and Business Media.

traditional neonatal care should be replaced by developmentally supportive "couplet care" allowing mothers and families to stay with their baby from birth to when the baby is discharged from the hospital

The parents of a preterm infant have to face physical, psychological, social, emotional and financial challenges: the pregnancy is interrupted at a point when they are not fully prepared to become parents. The fact that the fragile, immature baby has to be taken away from the parents, brought into the high-tech atmosphere of a Neonatal Intensive Care Unit (NICU), where the baby is placed in an incubator and attached to tubes and wires instead of being able to nestle in the parents' arms, is an overwhelming and catastrophic situation for a family. Parents are traumatised and experience a mixture of intense feelings from denial, resentment, deep grief, anxiety and hopelessness or depression to guilt, shame, and a sense of failure or anger. They constantly fear that their newborn might not survive and struggle with the insecurities of the situation. Breastfeeding under such circumstances becomes very difficult – if not impossible – and many parents struggle with the limitations to their parental roles. Therefore, traditional neonatal care should be replaced by developmentally supportive "couplet care" allowing mothers and families to stay with their baby from birth to when the baby is discharged from the hospital. The historical application of adult type intensive care in order to increase survival has been accompanied by a distressing hospital environment unadapted to the needs of the newborn baby. The next steps in neonatology should restore an appropriate environment for preterm infants and their families.



Hospital routine and family needs, e.g. care for siblings, work, travel and economic conditions, may also create difficulties for the parents in caring for their preterm baby in the hospital, and for them to develop the necessary parental confidence to be responsible for and handle their preterm infant on their own once the baby is discharged and the family is finally at home. They often feel isolated and misunderstood by those around them and even by their own partner. The risks of divorce, feelings of distance from the child and even rejection of the child, or maltreatment of the child are reported to be high amongst families with preterm infants.

Concerned parents need to be empowered and supported, also psychologically. They need better guidance on how to care for their preterm baby as well as how to obtain support. However, families need support not only during the hospital stay, but also during their first period back at home; post-discharge intervention programmes, systematic follow-up and good aftercare programmes report improved long-term cognitive and behavioural outcomes for preterm infants.

Several attempts have been made to insist on principles of newborn care and the rights of newborn infants and their families. Nonetheless, the care of preterm or newborn infants in Europe does not always adhere to these important principles and recommendations and the special needs of the children and their families. In Table 4, parents and professionals tried to summarize and list the most important rights that could help improve and develop family-centred neonatal care, including short – and long-term outcomes for the individual child.

Table 4 Parents and Newborn Rights

1. The right to receive equal and early access to education

All (expecting) parents have the right to receive equal and early access to evidence-based adequate education. This must include comprehensive and adequate information and counselling/advice on pre-conception and maternal issues, sexual and reproductive health, healthy lifestyles, healthy pregnancy, delivery, newborn care and early parenthood.

2. The right to evidence-based high-quality treatment and care

All (expecting) parents and newborns have the right to evidence-based, high-quality treatment and care and a basis for active and healthy ageing. This includes equipment, use of medication, as well as education and training of healthcare providers.

3. The right to remain as a family unit

All families have the right to be considered as a unit. Each member, and the family as a whole, has to be approached with dignity, respecting their social, cultural, developmental, emotional and clinical needs as well as their rights to privacy.

4. The right to comprehensive and accurate information

All parents have the right to be provided with comprehensive and accurate information on available techniques and procedures of diagnosis and therapies, including risks in their own wording and language. Based on this information, parents have to be included in the decision-making process to perform a chosen diagnostic and/or therapy service.

5. The right to be actively involved in child care

All parents have the right to receive appropriate education and be actively involved in their baby's care- giving in an effective and sensitive manner.

6. The right to complain

All parents have the right to voice complaints and recommend changes without fear of negatively affecting or influencing a change in the quality of care of their child.

7. The right to receive support

All (expecting) parents and children born at risk have the right to psychological, social, and financial support and, if required, individual culturally-appropriate bereavement support.

8. The right to pregnancy-, maternity/paternity- and parental leave

All parents are entitled to pregnancy -, maternity/paternity- and parental leave. Families of preterm infants, with multiple births and infants with illnesses should be entitled to extended leave periods.

9. The right to family-centred care

All parents and newborns have the right to family-centred care and to stay together while the child receives healthcare.

10. The right to allow close family members contact with the newborn

All parents have the right to allow close family members (i.e. grandparents, siblings or close friends) to have contact with the newborn.

11. The right to receive information about support services and groups

All parents have the right to receive adequate information about the existence and services of parents' support groups and national parents' and patients' organisations.

12. The right to appropriate transfer and discharge procedures

All parents and newborns have a right to appropriate and individual transfer and discharge procedures.

13. The right to receive specialised aftercare services

All parents and newborns at high-risk have the right to receive evidence-based and experience-based, coordinated, specialised and appropriate follow-up and aftercare services.

14. The right to lifelong inclusion

All newborns with adverse neurological and motoric outcomes have the right to lifelong integration and/or inclusion as well as psychological, social and financial support.

Challenges for the EU and its Member States – What can be done?

It is not surprising that those countries with the highest rates of prematurity in Europe are among those without a targeted national policy for newborn health and preterm infants

Depending on where in the European Union a woman becomes pregnant or a baby is born, the level of care received will vary. Indeed, some care practices will fall far short of promoting and protecting the right to a healthy start in life.

To date, only a very small number of EU Member States have implemented targeted policies focused on newborn health and preterm infants. In most countries, the approach to newborn health policy is fragmented and uncoordinated. Newborn health, especially the huge challenge of prematurity, more often appears in the framework of other more general health and social programmes. Thus it remains a secondary priority for action. It is not surprising that those countries with the highest rates of prematurity in Europe are among those without a targeted national policy for newborn health and preterm infants.

Another concrete and very important example of the variation of policies is the immense discrepancies between Eastern and Western Europe. Several countries in the European Union still fail to report on whether they are adhering to WHO guidance; therefore, official data may underestimate the full scale of the problem.

There is a general lack of comprehensive data in the European countries measuring the real health economic impact of preterm birth. The feasibility of such cost assessment is also dependent on the availability of reliable and comparable data on morbidity linked to prematurity such as subsequent disabilities, disorders and chronic diseases, which is currently not provided.

Where data is collected on prevalence and mortality and morbidity, these data collections are often voluntary and based on different parameters, indicators and definitions.

In view of the growing number of preterm infants, the risks and possible life-long consequences of preterm birth for the infant and their family, it is clear that prematurity poses a serious and growing threat to the competitiveness, health and well-being of Europe's future population and that immediate action is required both at EU and national political level, taking into account the following recommendations (Table 5).

Table 5 Recommendations to reduce the prevalence of preterm birth together with the associated morbidity and mortality.

Recognize the growing challenge of prematurity in Europe and its impact on infant morbidity and mortality;

Acknowledge the health and social inequalities linked to prematurity (the Lisbon Treaty) and mainstream maternal and neonatal health into patient-centred policies on health promotion, prevention, care and treatment of chronic diseases, by, amongst others:

- **Implementing targeted prematurity prevention programmes, including improved screening, health promotion and education measures targeted at healthcare professionals, future parents and the general public;**
- **Implement programmes and legislation to support mothers to stay with their preterm infants during and after discharge without a negative impact on their jobs;**
- **Improving neonatal health outcomes by increasing access to high-quality maternal and neonatal health services, including access to specialised healthcare professionals and transport services;**
- **Increasing access to specialised after-care with documented medical follow up, and long-term care, as a key component towards effective prevention, early diagnosis and adequate care of chronic diseases linked to preterm birth. This should also include psychological and social support for families with preterm infants in hospitals and following discharge as appropriate.**

Address the interconnection between prematurity, chronic / non-communicable diseases and health and social inequalities. These affect the access to high-quality prevention, treatment and long-term care of preterm infants. There is also a need to **recognise that poor health outcomes resulting from prematurity – which can be largely prevented or improved, may lead to greater inequalities in the longer term.**

Member States need to establish policies, procedures and guidelines or standards to ensure that all children and pregnant women have full access to healthcare, including health promotion and disease prevention services and to harmonize these in order to facilitate cross border healthcare.

Implement effective mechanisms to allow for comparable data gathering and analysis and sharing of successful practices and experiences across EU Member States. There is a lack of comprehensive data on prematurity prevalence, mortality, morbidity, long-term impairment, outcomes and costs. A common reproductive data registry with common definitions and measurement criteria would allow for comparative analysis, exchange of best practices and evidence-based policies.

Support coordinated research on maternal, neonatal and perinatal health, aimed at improving the prevention of prematurity and related possible resulting illnesses / health consequences, treatment and care as means to optimise health outcomes, prevent and reduce linked diseases, and improve the wellbeing and quality life of patients in the longer-term.

Preterm and ill newborns are children in need of special protection, but until now, little provision has been made for this particularly vulnerable group and their needs

Every child has the right to a safe start in life and to family care. Preterm and ill newborns are children in need of special protection, but until now, little provision has been made for this particularly vulnerable group and their needs. Infants in the Neonatal Intensive Care Unit (NICU) have no legal capacity or ability to decide on their own treatment or even their fate and are utterly reliant on adult representation for advocacy. We need to make the best possible decisions and to provide the best possible care for them to allow these children and their families the best possible start and outcomes in order for them to lead happy lives.



Close up of a baby sleeping

© D.Hurst / Alamy

Dominique Haumont

Professor Dominique Haumont has been the Head of the NICU at Saint-Pierre University Hospital at the Free University of Brussels since 1985. Her academic research has been focused on intravenous lipids, surfactant, DNA damage, oxidative stress and ethical decision making. She has been the president of the Belgian Society of Neonatology (2004–2007), the President of the College of Physicians for mother and newborn (section Neonatology) in Belgium since 2008. She is a member of several international scientific societies and is the President of the Educational Committee of EAPM (European Association of Perinatal Medicine). Besides her academic career Dr Haumont has always pioneered developmental family centered care and developed a Newborn Individualized Developmental Care and Assessment Programme (NIDCAP) training centre in Brussels.

Luc J.I. Zimmermann

Professor Luc J.I. Zimmermann became an MD in 1984 at the Catholic University of Leuven, Belgium and did his residency in Paediatrics at the same university, at the University Hospital Gasthuisberg Leuven, Belgium (1984–1989). He trained as a Fellow in Neonatology at the Hospital for Sick Children and the University of Toronto Perinatal Fellowship Program in Toronto, Canada from 1989 to 1992. From 1992 to 2003 he was a staff Neonatologist at the Erasmus Medical Center – Sophia in Rotterdam, where he was Chief of the Division of Neonatology a.i. from 2000 to 2003. His PhD thesis (in 1995) was titled 'Regulation of CTP:phosphocholine cytidyltransferase in fetal type II cells'. In 2003 he became a staff neonatologist at the Academic Hospital Maastricht, in 2004 a Professor in Paediatrics and in 2005 Chief of the Division of Neonatology. In 2006 he became Chairman of the Department of Paediatrics and Director of the Residency Programme in Paediatrics, as well as Division leader at the GROW research institute (Oncology and Developmental Biology). He is the president of the European Society of Paediatric Research (ESPR).

Silke Mader

Silke Mader is the Chairwoman of the Executive Board and co-founder of EFCNI (the European Foundation for the Care of Newborn Infants). Her professional background lies in elementary educational theory, mainly focusing on the linguistic support of migrant children and remedial educational theory. In 1997, her twins were born in the 25th week of pregnancy, and were not given the appropriate care. Unfortunately, one of them died a few days after birth, leaving the parents and the sibling behind. During her time in hospital and afterwards, she was faced with the non-existence of support of any kind, the absence of public awareness and the lack of information and education for parents during pregnancy. She felt that no parents should ever undergo such an awful experience again. Therefore, in 1999, she decided to actively participate in the Munich-based local parent group, which she headed from 2001 on. Two years later, she became Chairwoman of the German umbrella organization "The preterm born child e. V.". Together with experts, Silke developed declarations, guidelines and information material for parents with preterm children. As the situation throughout Europe is distressingly similar and preterm children urgently need a voice not only within Europe but also worldwide, she decided to give up her job as a teacher and to take on the role of chair on the Executive Board of EFCNI.

About EFCNI

The European Foundation for the Care of Newborn Infants (EFCNI) is the first pan-European organisation to represent the interests of preterm and newborn infants and their families. It gathers together parents and medical professionals from different disciplines with the common goal of improving the long-term health of preterm and newborn children by ensuring the best possible prevention, treatment, care and support. www.efcni.org

For further information please take a look at:

- <http://www.who.int/en/>; <http://www.who.int/mediacentre/factsheets/fs363/en/>
- *International classification of diseases and related health problems*. 10th revision. Geneva: World Health Organization; 1992. <http://www.who.int/en/>
- EFCNI Benchmarking Report 2009/ 2010 "Too little Too late? Why Europe should do more for preterm Infants" – www.efcni.org
- Caring for Tomorrow – EFCNI White Paper on Maternal and Newborn Health and Aftercare – www.efcni.org
- Call to Action for Newborn Health – www.efcni.org
- March of Dimes, PMNCH, Save the Children, WHO. Born Too Soon: The Global Action Report on Preterm Birth. Eds Howson, C.P, Kinney, M.V, Lawn, J.E. World Health Organization. Geneva, 2012.
- Levin, A. (1999), Humane Neonatal Care Initiative. *Acta Paediatrica*, 88: 353–355. doi: 10.1111/j.1651-2227.1999.tb01118.x
- Europeristat Report 2008 – <http://www.europeristat.com/our-publications/european-perinatal-health-report.html>

Endnotes;

- ⁱ The World Health Organization defines the newborn period as the first 28 days of life. It represents the time of the greatest risk to the infant. Approximately 65% of all deaths that occur in the first year of life happen during this 4-week period.
- ⁱⁱ Pregnancy interventions such as assisted reproduction or provider-initiated preterm birth: medical induction or cesarean birth for obstetric indication, fetal indication but also cases without medical indication.
- ⁱⁱⁱ Kangaroo (mother) care is a way of holding babies skin-to-skin with a parent or family member. In kangaroo care, a baby is undressed down to the diaper and placed on a parent's bare chest. A blanket is placed over the baby to keep it warm. Kangaroo care can be done with any medically stable infant. It has been shown to have several benefits for preterm babies and their mothers. It helps babies breathe and sleep better, gain weight more quickly, and have more stable temperatures. Mothers who practice kangaroo care have better milk supplies and less depression.