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POLICY DEPARTMENT A
ECONOMIC AND SCIENTIFIC POLICY

Economic and Monetary Affairs

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Newborn Infants

WORKSHOP

EN

2013

Newborn Infants

EUROPEAN PARLIAMENT

DIRECTORATE GENERAL FOR INTERNAL POLICIES

POLICY DEPARTMENT A: ECONOMIC AND SCIENTIFIC POLICY

WORKSHOP

Newborn Infants

Brussels, 24 April 2013

PROCEEDINGS

Abstract

This report summarises the presentations and discussions at the Workshop on "Newborn Infants", held at the European Parliament in Brussels, on Wednesday 24 April 2013. The aim of the workshop was to discuss the challenges related to neonatal mortality and morbidity as well as preterm births, which continue to pose serious concerns for public health and healthcare in Europe. Half a million babies are born prematurely in the EU every year and these infants are at higher risk of developing health problems later in life.

The workshop was hosted by MEP Ms Glenis WILLMOTT (S&D, UK) and MEP Mr Alojz PETERLE (EPP, SL), Co-chairs of the Health Working Group within the ENVI Committee, and MEP Ms Angelika NIEBLER (EPP, DE), Member of the ITRE Committee.

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CONTENTS

LIST OF ABBREVIATIONS

BPD	Bronchopulmonary Dysplasia
DALY	Disability-Adjusted Life Year
DEHP	Di(2-ethylhexyl)phthalate
DG SANCO	Directorate General for Health and Consumers
EC	European Commission
EFCNI	European Foundation for the Care of Newborn Infants
ENVI	Committee on Environment, Public Health and Food Safety
EP	European Parliament
ESN	European Society for Neonatology
EU	European Union
IQ	Intelligence Quotient
MEP	Member of the European Parliament
NICU	Neonatal Intensive Care Unit
PCB	Polychlorinated Biphenyl
WHO	World Health Organization

EXECUTIVE SUMMARY

On 24 April 2013, the Committee on Environment, Public Health and Food Safety (ENVI) of the European Parliament held a workshop on “Newborn Infants”. The workshop was hosted by Mr Alojz PETERLE (MEP) and Ms Glenis WILLMOTT (MEP), Co-chairs of the Health Working Group within the ENVI Committee, and Angelika NIEBLER (MEP), Member of the ITRE Committee.

In his opening statement, Mr Peterle highlighted that half a million babies are born prematurely in Europe every year. These infants are at higher risk of developing health problems, including learning and behavioural disabilities, infections, chronic respiratory and cardiovascular diseases and diabetes. Mr Peterle thus stressed the need to identify the necessary policy changes at the EU level to improve maternal and newborn health, as well as to address inequalities across Member States in this area.

Ms Isabel de LA MATA, Principal Advisor for Public Health at the European Commission DG Health and Consumers, then explained the main developments in European policies related to newborn infants. In particular, she mentioned that the European Commission is promoting an integrated approach to public health with a focus on vulnerable groups, including newborns. In this respect, the Social Investment Package adopted in February 2013 is a step in the right direction as it includes measures to promote investments in healthcare and childcare. In Ms de La Mata’s words, “A healthy start in life is necessary to ensure healthy ageing”.

The first part of the workshop provided an overview of the main issues related to healthcare during pregnancy. Dr Gunta LAZDANE, Programme Manager for Sexual and Reproductive Health at the WHO Regional Office for Europe, started her presentation by explaining the key challenges in maternal and newborn health for Europe. In particular, she highlighted that significant improvements have been achieved in the WHO European region, with maternal mortality decreasing in most countries over the last twenty years. However, these improvements have been uneven and unequal across the region and the lifetime risk of maternal health is much higher in some countries compared to others. Growing inequality is therefore one of the main challenges, especially in times of economic crisis. Among the preventable risk factors for preterm birth, Dr Lazdane mentioned obesity, smoking, alcohol, stress and non-communicable diseases. In particular, she emphasised that the smoking bans introduced in several EU Member States have cut premature births significantly and should thus be extended.

After that, Prof. Dr Bo JACOBSSON, Director of the Perinatal Research Laboratory at the Sahlgrenska University Hospital in Sweden, focused on the importance of pregnancy as a “window of opportunity” to promote healthy ageing from the early days of foetal life. He likened the foetal programming during pregnancy to how tree rings are shaped during the life of a tree. For example, prenatal metabolic programming affects the possibility of being overweight and foetal malnutrition increases the risk of diabetes. Therefore, interventions for a healthy life should start before and during pregnancy, e.g. by promoting physical activity and healthy nutrition. Prof. Dr Jacobsson concluded his presentation by calling for further research on the unknowns of pregnancy and for more efforts to educate the public, patients and professionals about the relation between pregnancy and adult health.

Ms Silke MADER, Chairwoman of the European Foundation for the Care of Newborn Infants, concluded the first part of the workshop by introducing the voice of patients. Starting from her personal experience as a mother who gave birth to premature twins, Ms Mader highlighted that parents of preterm babies should be better supported and involved through information, education and guidance as well as through longer maternity and parental leave. She lamented that, at the moment, there is a lack of harmonised standards of care across the EU as well as of national policies and programmes adapted to the needs of preterm babies and their parents. Along with improved standards of care in hospitals, Ms Mader advocated a family-centred care approach that should integrate medical treatment and psychological and social support, especially in the transition from the neonatal intensive care unit to home.

The second part of the workshop focused on the relation between newborn health and chronic diseases. In his presentation, Prof. Dr Mats BLENNOW, Professor of Neonatology at the Karolinska Institute in Stockholm, emphasised that the quality of newborn and family care makes a difference to the health and well-being of Europe's current and future generations. Premature birth is an endemic disease comparable to other major diseases: it accounts for 3.1% of the global burden of disease and 7.1% of all births in Europe. Nowadays, most babies survive even after being born extremely preterm (i.e. three months or more too early). However, they need special attention both at birth and further on in life. To improve their condition, Prof. Dr Blennow encouraged the development of European standards for treatment and care as well as of common training curricula throughout Europe.

In the last presentation, Prof. Dr Neil MARLOW, Professor of Neonatal Medicine at the UCL Institute for Women´s Health in the UK, highlighted the importance of post-neonatal continuing care as a way to prevent chronic diseases. He explained that the most important risks associated with preterm birth include cerebral palsy, learning disability, behavioural problems, psychiatric disorders, respiratory disease and cardiovascular outcomes. These conditions have wide implications for adult life and may result in poor health, reduced social integration and reduced educational attainment. Optimal perinatal and post-neonatal continuing care is therefore critical in preventing chronic diseases and promoting healthy ageing. Prevention is equally important to help reduce the impact of prematurity on the global burden of disease and should focus on optimising the parent-infant interaction, ensuring careful on-going assessment and diagnosing chronic diseases at an early stage. In conclusion, Prof. Dr Marlow stressed that, after reducing their mortality rates, the next challenge for Europe is to improve the quality of life for preterm babies.

1. LEGAL AND POLICY BACKGROUND

The World Health Organization defines a newborn infant as a child who is less than 28 days old[1]. During this period, the infant is extremely vulnerable and at highest risk of dying. Although the vast majority of newborn deaths take place in developing countries[2], it is worth noting that neonatal deaths represent half of the deaths for under-five year old children even in the European Region[3,4]. The main causes for this are premature birth, low birth weight, infections, asphyxia, birth trauma and congenital abnormalities.

Prematurity, which occurs when a baby is born before 37 weeks of gestation, is the single, major and often preventable cause associated with infant morbidity and mortality in both developed and developing countries[5]. In particular, half a million babies are born prematurely in Europe every year. Whilst neonatal mortality is steadily decreasing in the EU, the number of babies suffering complications is increasing, as more preterm infants survive. Compared to their full-term counterparts, preterm infants grow with a higher risk of developing health problems, including learning and behavioural disabilities, infections, chronic respiratory and cardiovascular diseases and diabetes. The burden of prematurity in Europe is therefore considerably high, both in terms of personal impact on babies and their families, but also in terms of wider cost implications for public health, healthcare systems, the economy and society as a whole.

Premature infants require specialist care to improve their chances of survival and to lay the foundations for a healthy life. However, at the moment, there is a large disparity between Member States in the quality of care provided to preterm and newborn infants. In most EU countries, maternal and newborn health is not considered as a public health priority, despite its obvious connection with longer term health outcomes and healthy ageing. As a result, neonatal and preterm infant health rank low on the policy agendas of EU Member States, with only few countries having implemented targeted policies[6].

In accordance with Article 168 of the Treaty on the Functioning of the European Union (TFEU)[7], the EU is striving to attain a higher level of health protection through all European policies and activities. However, defining national health policies remains an exclusive competence belonging to Member States and, therefore, EU action is only complementary in the area of maternal and newborn health. Nevertheless, the EU has an important role to play in supporting research and in promoting a coordinated approach to reduce inequalities and to ensure high standards of health and healthcare across Member States.

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1 World Health Organization's website on Infant, Newborn: http://www.who.int/topics/infant_newborn/en/
2 WHO Fact sheet N. 333, May 2012. Available at: http://www.who.int/mediacentre/factsheets/fs333/en/index.html:
3 WHO, Progress towards Millennium Development Goals 4, 5 and 6 in the WHO European Region: 2011 Update. Available at: http://www.euro.who.int/__data/assets/pdf_file/0008/163088/03_MDG-report_17Apr2012.pdf
4 The European Region of the WHO is wider than the EU-27 Member States and includes 53 countries. The list of countries in the WHO European Region can be found at : http://www.euro.who.int/en/where-we-work
5 EFCNI, Too little, too late? Why Europe should do more for preterm infants, EU Benchmarking Report 2009/2010. Available at: http://www.efcni.org/?id=1571
6 Ibid.
7 Consolidated version of the Treaty on the Functioning of the European Union, OJ C 326, 26.10.2012, p. 47–390.

In addition, the EU is directly responsible for policies in a number of areas that have an important impact on maternal and newborn health. For example, the EU is regulating health determinants, such as tobacco, nutrition, and environment and health issues, such as air quality and chemicals. In particular, the on-going discussions on the Tobacco Directive[8] are relevant in the context of maternal and newborn health as the link between smoking and prematurity is well-established[9].

In addition, recent EU initiatives also promote larger investment in the social sector, including children's health care. In this context, the "Social Investment Package"[10], adopted by the European Commission in February 2013, encourages Member States to prioritise social investment and to ensure that social protection systems respond to people's needs at critical moments during their lives. As part of the package, the Commission published a Staff Working Document on "Investing in Health"[11], which outlines the main reasons for investing in health systems and reducing health inequalities, especially in times of economic crisis. The package also includes a Commission Recommendation on "Investing in children"[12], which promotes a holistic approach to children's education, rights and health. In particular, the Commission recommends that EU Member States should "improve the responsiveness of health systems to address the needs of disadvantaged children and to ensure that all children can make full use of their universal right to health care, including through disease prevention and health promotion as well as access to quality health services"[13].

To mark the urgency of tackling maternal and neonatal health, a number of MEPs have established a specific Interest Group on Maternal and Neonatal Health within the European Parliament[14]. The Group, chaired by Ms Angelika NIEBLER (MEP) and Dr Peter LIESE (MEP), aims to promote an open dialogue to help ensure the best possible start in life for all babies born in Europe. In particular, this is to be achieved by promoting the EU recognition of preterm birth as a growing threat to the health and wellbeing of Europe's citizens, by highlighting the importance of prevention measures before and during pregnancy, as well as by raising awareness of the major risks and impacts associated with infant prematurity in Europe.

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[8] Proposal for a DIRECTIVE OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL on the approximation of the laws, regulations and administrative provisions of the Member States concerning the manufacture, presentation and sale of tobacco and related products /* COM/2012/0788 final - 2012/0366 (COD) */

[9] Michael G Gravett, Craig E Rubens, Toni M Nunes and the GAPPS Review Group, Global report on preterm birth and stillbirth: discovery science, BMC Pregnancy and Childbirth 2010, 10(Suppl 1):S2.

[10] COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS Towards Social Investment for Growth and Cohesion – including implementing the European Social Fund 2014-2020 /* COM/2013/083 final.

[11] Commission Staff Working Document, Investing in Health, 20 February 2013: http://ec.europa.eu/health/strategy/docs/swd_investing_in_health.pdf

[12] Commission Recommendation "Investing in children: breaking the cycle of disadvantage", 20 February 2013: http://ec.europa.eu/social/BlobServlet?docId=9762&langId=en

[13] Ibid., page 7.

[14] Interest Group on Maternal and Neonatal Health in the European Parliament: http://www.efcni.org/index.php?id=1884

2. PROCEEDINGS OF THE WORKSHOP

2.1 Introduction

2.1.1 Welcome and opening – Alojz PETERLE (MEP)

Mr Alojz PETERLE, Member of the European Parliament Environment, Public Health and Food Safety (ENVI) Committee and Co-chair of the Health Working Group, welcomed the audience and the speakers to the workshop. As a way of introduction, he highlighted that Europe faces major challenges on maternal and newborn health as quality of care varies considerably between Member States. Mr Peterle stressed that 10% of the EU population is born preterm and is suffering from related long-term health consequences. The dramatic health inequalities of these infants and their families have to be urgently addressed both in Europe and globally. Preterm babies are at much higher risk of developing problems compared to their full-term counterparts. The earlier the babies are born, the more severe the complications are, which include learning and behavioural disabilities, infections, chronic respiratory and cardiovascular diseases and diabetes.

Before giving the floor to the European Commission representative, Mr Peterle reminded the audience that the main objective of the workshop was to provide an overview of the state of newborns' health in Europe and to identify the policy changes that are needed to improve the situation.

2.1.2 The development of European policies in the field of Newborn Infants, Ms Isabel de La Mata (EC)

Ms Isabel de LA MATA, Principal Adviser for Public Health. DG SANCO, EC

Ms de LA MATA started her presentation by emphasising that the European Commission takes an integrated approach to health, whilst paying particular attention to different vulnerable groups in the population, including to children and infants. In this respect, the Commission has been assessing the situation of newborns' health and perinatal mortality and has issued several reports on this matter.

In particular, Ms de La Mata welcomed the publication of the so-called "Social Investment Package"[15] in February 2013, which aims to prioritise social investment by performing active inclusion strategies and a more efficient use of social budgets. As part of the package, the Commission published a Staff Working Document on "Investing in Health"[16], which outlines the main reasons for investing in health systems and reducing health inequalities, especially in times of economic crisis. The package also includes a Commission Recommendation on "Investing in children"[17], which provides a holistic approach to children's education, rights and health.

[15] Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions: Towards Social Investment for Growth and Cohesion – including implementing the European Social Fund 2014-2020 /* COM/2013/083 final.

[16] Commission Staff Working Document, Investing in Health, 20 February 2013: http://ec.europa.eu/health/strategy/docs/swd_investing_in_health.pdf

[17] Commission Recommendation "Investing in children: breaking the cycle of disadvantage", 20 February 2013: http://ec.europa.eu/social/BlobServlet?docId=9762&langId=en

In Ms de La Mata's views, a good start in life is essential for healthy ageing, which begins during – and even before - pregnancy. The special vulnerability of infants who are born preterm should therefore be addressed. In particular, nowadays, an increasing number of preterm children survive and require specific follow-up in their first year of life. In conclusion to her presentation, Ms de La Mata highlighted that, in times of economic crisis, inequalities in health and in access to healthcare are growing and vulnerable groups, including newborns, are suffering the most. However, policy-makers should not let the economic crisis affect the health of the European population.

2.2 Part 1: Healthcare during pregnancy

2.2.1 Challenges in maternal and newborn health for Europe, Dr Gunta Lazdane (WHO Europe)

Dr Gunta LAZDANE, MD, Ph.D., Programme Manager, Sexual and Reproductive Health, Division of Noncommunicable Diseases and Life-Course, WHO Regional Office for Europe

At the beginning of her presentation, Dr LAZDANE reminded the audience that the European Region of the WHO is wider than the EU-27 Member States and includes 53 countries[18]. She then highlighted that, although significant improvements on maternal and newborn health have been made in the region as a whole, these remain uneven and unequal.

To illustrate her point, Dr Ladzane showed a graph indicating that maternal mortality has decreased in the WHO European Region over the past two decades and that the financial crisis has influenced maternal morbidity and mortality rates. Another graph illustrated that significant inequalities exist in the Region. For example, the lifetime risk of maternal death is 1 in 20,300 births in Italy, 1 in 14,100 in Sweden, 1 in 2000 in Latvia and 1 in 430 in Tajikistan. Looking at these figures, Dr Ladzane wondered why, with the current technology and knowledge, the situation is still so unequal.

She then showed another graph indicating that there is a trend for mothers in Europe to be increasingly older when they give birth. Mother's age is one of the risk factors for prematurity and may play a role in increasing perinatal death, for example in France. Figures were also presented for rates of preterm birth in Europe. Although the average preterm birth rate per 100 live births is 10%, the figure ranges from 5.5% in Finland to 15% in Cyprus, showing again important inequalities across the Region.

In the second part of her presentation, Dr Ladzane presented an overview of the preventable risk factors for preterm birth. First of all, she mentioned low and high body mass and referred to overweight and obesity. This factor is particularly relevant as the total data for the EU show that more than 50% of adults (in some countries even 70%) are pre-obese or obese. Preventable risks also include smoking and alcohol. In particular, increasing evidence shows that smoking is indirectly linked to prematurity. In Dr Ladzane's views, the good news is that after the smoking bans introduced in several EU countries in 2007 and 2010, the premature birth rate dropped by around 3%, according to a study conducted in Belgium. Similar results have also been reported in the UK. However, only few countries in the EU have enacted smoking bans so far. Other preventable risks are genitourinary infections, HIV, stress and violence, as well as noncommunicable diseases, including cardiovascular diseases and diabetes.

[18] The list of countries in the WHO European Region can be found at: http://www.euro.who.int/en/where-we-work

After providing an overview of the risk factors, Dr Ladzane highlighted that growing inequality is one of the biggest social, economic and political challenges. However, such inequities are not inevitable. She mentioned that there are global guidelines that could be applied to the European context on how to prevent preterm birth, manage preterm labour and take care of the premature baby, including education, preconception, pregnancy and antenatal care. Finally, Dr Ladzane concluded her presentation by stressing the need to translate the health policy agenda for the upcoming years into more concrete research and prevention efforts for maternal and newborn health.

2.2.2 Healthy aging starts before birth, Prof. Dr Bo Jacobsson (Sweden, Norway)

Prof. Dr Bo JACOBSSON, Director of the Perinatal Research Laboratory at Sahlgrenska University Hospital, Sweden and Department of Genes and Environment, Institute of Epidemiology, Norwegian Institute of Public Health, Norway

Prof. Dr Jacobsson's highlighted that his presentation would focus on the importance of pregnancy as a "window of opportunity" to shape healthy adult and old-age life and to prevent health devastating problems, such as diabetes or obesity. In this respect, he emphasised that, during pregnancy, the foetus is already exposed to the outside world, which affects its development. Therefore, it is crucial to promote healthy pregnancies.

During the last decade, more insight has been gained on foetal programming, i.e. on the idea that interventions during the development of the foetus in the womb (and even before pregnancy) can shape the adult life. For example, it is important to discuss interventions like smoking cessation, use of folic acid etc. during prenatal counselling.

To illustrate his point, Prof. Dr Jacobsson likened the foetal programming during pregnancy to how tree rings are shaped during the life of a tree. In the same way, what happens during pregnancy sets the background for obesity, respiratory disease, cardiovascular disease etc. For instance, prenatal metabolic programming, along with more traditional factors such as unhealthy diet, low physical activity and genetic predisposition, affects the possibility of developing obesity later in life. Other examples of the impact of foetal programming are Type II diabetes, which depends to some extent on foetal malnutrition, and brain development, which is affected by the relation between genetics and nutrition during pregnancy.

Prof. Dr Jacobsson went on to explain that the consequences of foetal programming can also be inherited by following generations. In particular, the phenotype results from the expression of an organism's genes and the influence of environmental factors, as well as the influence of epigenetics. The latter refers to the mechanisms that can change gene expression (for example, genes can be turned on and off by exposure to certain chemicals). As a result of genetic or external factors, the phenotype therefore shapes what will happen later in life, and this can be inherited both by the baby and by the future baby's baby.

Prof. Dr Jacobsson then re-emphasised his main message that what happens during pregnancy may affect health outcomes later in life and that interventions are possible both before pregnancy and in early pregnancy. He highlighted that today most pregnancy controls during antenatal care programmes take place in late pregnancy. However, the major efforts should be made in early pregnancy to select the risk groups and focus the prevention efforts accordingly.

In his last slide, Prof. Dr Jacobsson showed that whereas neonatology has been extremely successful in decreasing neonatal mortality and morbidity, there has been little progress on reducing the incidence of preterm delivery. In his view, this has to do with the fact that a basic understanding of pregnancy and delivery is still missing. Major research efforts should therefore be targeted at pregnancy-related issues, which could represent the most economical way to ensure a healthy start in life. In conclusion to his presentation, Prof. Dr Jacobsson also highlighted the need to educate the public, patients and professionals about the relation between pregnancy and adult health. Better and harmonised cross-country education and training should also be promoted.

2.2.3 The voice of patients - Impact of newborn diseases and prematurity on families, Ms Silke Mader (EFCNI)

Ms Silke MADER, Chairwoman of the European Foundation for the Care of Newborn Infants, Germany

As a mother of a preterm infant and as the founder and chairwoman of the European Foundation for the Care of Newborn Infants (EFCNI)[19], Ms Silke MADER brought a patient's and a parent's perspective into the discussion. She explained that the EFCNI focuses on research and care, but also represents the voice of parents of preterm babies across Europe. With 9 million preterm (and ex preterm) infants and 18 million parents, she stated that this is the largest patients' community in Europe and worldwide.

At the beginning of her presentation, Ms Mader emphasised that the involvement of parents is essential and can be achieved by providing more information during pregnancy or easier access to their newborn babies. However, enormous differences exist in Europe in the way parents are involved. She lamented a lack of adapted national policies and programmes, for example of extended maternity or parental leave for parents of preterm infants who need longer-term care and therapies. In addition, she mentioned that standards of care for parents to stay close to their babies are missing, as well as harmonised standards for research.

Ms Mader then showed a graph providing an overview of preterm birth rates, which are steadily increasing. As premature babies have a much bigger chance to survive nowadays compared to the past, it is estimated that in 2040 around a billion people will be affected by the issue of prematurity. Despite the magnitude of the problem, information and guidance for parents or parents-to-be on the potential risks linked to prematurity are still missing. Improvements in education and training of specialised professionals in the delivery areas would also be needed.

Drawing from her personal experience, Ms Mader highlighted that giving birth to a preterm baby represents a sudden and unexpected change of plans for parents, who are often left without the needed information and support. She then showed pictures of how the situation of care and services for preterm babies changes depending on the country. In her opinion, the optimum situation is for the parents to have single rooms like in Sweden, with an opportunity to be close to the baby and to be involved in the baby's treatment and care. In other countries, no policy exists to provide convenient spaces or family-centred care services for parents.

[19] For more information, see the EFCNI's website: http://www.efcni.org/

Parents of preterm babies should be supported through information, education and guidance, which would help relieve the stress for the family and, eventually, for the baby. In addition, better newborn nutrition is needed, ideally with breastfeeding but also with safe and proved alternatives. In this context, Ms Mader stressed that medications or formula are usually not tested on newborn infants and that more research is necessary in this area. She then advocated a family-centred approach integrating medical treatment with psychological and social support for families. This approach is essential to ensure a healthy start in life. Support is also needed for discharge management and to face the long-term challenges for the children and their parents.

Ms Mader concluded her presentation by highlighting that it is possible to change and succeed in Europe. For example, a successful campaign was carried out in Serbia, resulting in major improvements in a hospital in Belgrade. This campaign, "Battle for the Babies", involved parents, experts and caregivers, government, media and industry. In Ms Mader's own words "every baby has the right to a healthy start in life". For this, she called for the promotion of standards of care for maternal and newborn health, the inclusion of maternal and newborn health in all national policy agendas and programmes, and the setting up of a platform at the EU and national levels to ensure that both targets are met.

2.3 Part 2: Newborn health – Preventing chronic diseases

2.3.1 The quality of newborn *and family* care makes a difference to the health and well-being of Europe's future population, Prof. Dr Mats Blennow (Sweden)

Prof. Dr Mats BLENNOW, Professor of Neonatology, President of the European Society of Neonotology, Karolinska Institute Stockholm, Sweden

At the beginning of his presentation, Prof. Dr Blennow stated that he would focus on the size of the issue of prematurity and the problems faced by newborns and their families. He emphasised that newborn infants are not small adults and thus need specific treatment. In addition, babies should be considered as part of a bigger context, starting from their families. Reiterating Ms Mader's point, he stressed that standards of care have to be harmonised across the EU.

To explain the magnitude of the problem, Prof. Dr Blennow quoted an article from The Lancet[20] to highlight that the Disability Adjusted Life Years (DALYs)[21] lost as a result of prematurity account for 3.1% of the total burden of disease. In comparison, cardiovascular disease accounts for 11.8%, injuries for 11.2%, all cancer for 7.6% and HIV/AIDS for 3.3%. He also mentioned that half a million children are born premature in Europe every year, i.e. 7.1% of all births.

Afterwards, Prof. Dr Blennow clarified that being premature means being born before 37 weeks of gestation. Extremely preterm babies are born more than 3 months before the expected delivery date, and usually face a hospitalisation period of 2-4 months as they need medical support through respirators, intravenous nutrition, antibiotics etc. For the care, these babies are very much dependent on their families and the medical team.

[20] Lancet 2012; 380: 2224–60. Available at : http://press.thelancet.com/GBDpaper7.pdf

[21] DALYs for a disease or health condition are calculated as the sum of the Years of Life Lost (YLL) due to premature mortality in the population and the Years Lost due to Disability (YLD) for incident cases of the health condition.

Not too long ago, before 1950, only 1 in 6 children survived preterm birth. Today, as shown in a Swedish national study[22] between 2004 and 2007, 80% of all babies born before 27 weeks of gestation are alive at 1 year of age and beyond. From these figures, Prof. Dr Blennow concluded that nowadays 9 million children and teenagers were born preterm and 18 million parents have been affected by prematurity.

In Prof. Dr Blennow's view, newborns should not be treated as small adults and all the medications and equipment in the nursery would have to be adapted to their needs or specifically designed for them. In particular, newborns' organs are developed, but not mature enough. Therefore, for example, much of the brain development of a preterm baby happens in the neonatal intensive care units (NICUs). In addition, the metabolism of nutrition and medications are different from those for an adult. However, as mentioned by Ms Mader, most drugs are never tested on newborn babies.

In this context, the role of the family in the NICUs is essential, as the closeness of parents have been shown to improve health outcomes and even reduce mortality of newborn babies. Therefore, parents should have unlimited access to the NICUs to encourage early parental participation in the daily care of their babies. For the same reason, extended parental leave should be granted. An example from Sweden of a modern NICU incubator for family-centred care shows that it is possible to implement these changes in practice.

Prof. Dr Blennow re-emphasised that there are large differences in Europe, in particular on mortality rates at different gestations and for extreme prematurity. Differences also exist on the number of units that are not sufficiently equipped to provide appropriate levels of care for preterm babies. To overcome these inequities, Prof. Dr Blennow highlighted that European standards for the treatment and care of preterm infants, as well as harmonised guidelines for neonatal education have to be introduced. However, he also mentioned that the implementation of these guidelines needs to be appropriately followed up because, at the moment, two-third of EU Member States is not integrating in their national system the European Curriculum and Syllabus for Training in Neonatology[23] promoted by the European Society for Neonatology (ESN).

In conclusion to his presentation, Prof. Dr Blennow stressed that prematurity is an endemic disease in numbers comparable to other major diseases, both globally and in Europe. It is true that today even extremely premature babies do survive, but they need special attention further on in life. Finally, Prof. Dr Blennow advocated once again the introduction of harmonised standards for treatment and care and common training curricula throughout Europe.

2.3.2 Postneonatal continuing care and health needs to prevent chronic diseases later in life, Prof. Dr Neil Marlow (UK)

Prof. Dr Neil MARLOW, Professor of Neonatology, UCL Institute for Woman´s Health, UK

Prof. Dr Marlow started his presentation by stating that the neonatal period is a real opportunity for intervening and preventing adversity. In his view, improving healthcare conditions around the time of birth would lead to better health outcomes later in life.

[22] JAMA 2009, 301 (21): 225-2233.
[23] For more information, see: http://esn.espr.info/training-esn/national-programmes

To illustrate that the health outcomes are much worse at lower gestational age, Prof. Dr Marlow showed a graph of general Intelligence Quotient (IQ) in relation to gestational age from week 42 to week 23 of gestation. The relationship is weak down to week 32. However, below that, there is a dramatic fall in the mean IQ for survivors. A second graph indicates that the proportion of survivors that require special education is directly related to the general IQ curve, i.e. the earlier the babies are born, the more likely they are to need special education later in life. Therefore, he concluded that all preterm babies are not equal in relation to long term outcomes: those born extremely premature are at higher risk of developing impairments.

Data from two national studies carried out in the UK in 1995 and 2006[24] show that perinatal outcomes are improving overall, with a reduction in the number of deaths and an increase in the number of babies showing no disability for each gestational week from 22 to 25 weeks. Despite the increase in the children surviving without disability, Prof. Dr Marlow noted that the proportion of children who are still developing major problems as they grow up remain remarkably consistent.

Prof. Dr Marlow then provided an overview of the main risks associated with preterm birth, i.e. cerebral palsy, learning disability, behaviour problems that may translate into psychiatric disorders, respiratory disease and cardiovascular outcomes. These have combined effects on the population in the form of reduced educational attainment and social integration, and of poor adult health.

Implications for adult life of being born preterm can be seen, for example, on an accelerated decline in the lung function. In particular, preterm babies are at higher risk of developing a chronic lung disease called Bronchopulmonary Dysplasia (BPD) and, as a consequence, to suffer from a 30% reduction in the lung function. Prof. Dr Marlow emphasised that long term disability could be prevented if the lung function was protected and improved from the neonatal stage.

As regards the cardiovascular function of children, one of the EPICure studies[25] shows that preterm babies born at 26 weeks and under have a higher chance to develop aortic pressure augmentation. This is likely to translate in more prevalent cardiovascular disease later in life. In addition, Prof. Dr Marlow explained that up to 23% of extremely preterm survivors are likely to develop psychiatric problems. Hence, mental health is becoming an increasingly worrying issue.

To sum up, in Prof. Dr Marlow's views, preterm birth amplifies the effects of what is known as the developmental origin of adult disease. Therefore, good perinatal and aftercare is crucial to ensure better health outcomes as young adults as well as healthy ageing.

A key aspect in this context is prevention. Knowing that the baby will be at a higher risk of disability, the parent-infant interaction has to be optimised to lead to the best environment for the baby's development. In addition, Prof. Dr Marlow emphasised the need for careful assessment and early diagnoses, to pick up potential impairment and intervene at an early stage to prevent long term effects. Home support programmes are also fundamental once the baby is discharged home with his family, as well as outpatient assessment and follow up to prevent the early signs of impairments developing into fully-fledged problems.

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[24] Moore et al, British Medical Journal (BMJ) 2012

[25] EPICure studies are population based studies of survival and later health status in extremely premature infants. For more information, see: http://www.epicure.ac.uk/

With 77 million the Disability Adjusted Life Years (DALYs)[26] lost worldwide due to prematurity, Prof. Dr Marlow concluded that it is essential to invest in prevention and that the EU should be more active in this area. Optimising perinatal and aftercare is critical to preventing chronic disease. Also, it is crucial to develop preventative strategies in early pregnancy, in the perinatal and in the post natal period to minimise childhood and adult disease. The goal should be to show improvements in the quality of outcome and of life for preterm babies in the same way as mortality rates have improved over the past decades. In Prof. Marlow's final words, this is a unique opportunity for the EU to improve the quality of life of the EU population for the years to come.

2.3.3 Question time

Mr PETERLE thanked the speakers for all the valuable information provided and highlighted that "those who know more should do more". He then opened the floor for question. First of all, he asked the European Commission to address the experts' call for harmonised standards and guidelines.

Ms de LA MATA emphasised that harmonisation is very difficult, but in some cases it is feasible. For example, she referred to the standards for cancer screening. Training remains a national competence and it is not possible to intervene at the EU level. However, European doctors' associations (e.g. the Standing Committee of European Doctors) could be approached to apply voluntary but common standards across the EU.

Although it is not possible for the EU to impose standards in this area, Mr Peterle stressed that more could be done, for example through complementary measures.

Prof. Luc ZIMMERMANN, President of the European Society for Paediatric Research[27], asked a question to Prof. Dr Jacobsson on how research efforts on pregnancy could be improved. Prof. Dr JACOBSSON answered that financing is the main issue. He also highlighted that the EU should undertake a major effort to promote a pregnancy-related research agenda to understand both the basic mechanisms of human pregnancy and the functioning of foetal programming.

Dr LAZDANE then took the floor to emphasise that, for the past five years, sexual and reproductive health, as well as maternal and newborn health, have never been on the agenda of the health research board of the WHO Regional Office for Europe. This means that Member States have never suggested making it a priority like other important issues, such as mental health or healthy ageing. Policy makers should therefore be made aware of the importance of conducting research in this area.

Ms Dorota SIENKIEWICZ from the European Public Health Alliance[28] mentioned that the discussion on children's health should be broadened to include economic and financial issues in order to understand the funding priorities for research and innovation. In her view, this is about how much we value our future generations and how we prioritise action.

Prof. Dr MARLOW highlighted that, at the moment, research is mainly focusing on the end result, e.g. on diseases, as well as on the early identification of problems during childhood. However, he stressed that it would be possible to prevent many of the disease processes in the first place by focusing on pregnancy.

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[26] See footnote 21.
[27] For more information, see : http://www.espr.info/
[28] For more information, see : http://www.epha.org/

A representative from Health Care Without Harm[29] then made a comment on the specific vulnerability of children to hazardous chemicals during critical perinatal periods. In this respect, she stressed that some hospitals have already started to phase out certain substances, such as polychlorinated biphenyl (PCBs). In particular, France has introduced a ban on a specific chemical (Di(2-ethylhexyl)phthalate or DEHP) in medical tubing. However, despite the existing information on the hazardous effects of these chemicals, she lamented that the Commission's current proposal for a revision of the medical devices Directive[30] only requests the labelling of some of these devices, without promoting safer alternatives. In her view, the ENVI Committee has an opportunity to strengthen the Commission's proposal to widen the use of medical devices without hazardous chemicals.

Further on, a representative from Special Foods from The Netherlands raised the fact that nutrition is very important, both for the mother and for the preterm infant. Research in this field needs to be stimulated and supported by the Commission.

Prof. Dr Jacobsson agreed with this point and highlighted that indeed nutrition is extremely important. For example, recent research shows that sugar sweetened beverages during pregnancy increase the risk for spontaneous preterm delivery.

Prof. Dr Blennow added that the optimal way to feed babies in the NICUs has not been found yet. Research institutes and industry are working hard to find the best solutions, whether it is by expressed breast milk or formula, which needs to be adapted to the gestational age.

A representative from the International Federation for Spina Bifida and Hydrocephalus[31] emphasised that nutrition is crucial. In particular, it is known that the status of folic acid of the mother is fundamental to prevent neural tube defects and other birth defects. Yet, very little has been done in Europe over the past 20-25 years to reduce the incidence of neural tube defects. The second point he wanted to make is that data are crucial. If data on incidence are not properly collected and measured, there is little incentive for policy makers to act.

On the issue of data availability, Prof. Dr Marlow commented that, for many years, registers for congenital abnormalities had existed in Europe. However, they have now been disbanded because they are considered as a luxury. In fact, such registers are necessary to understand the prevalence of these conditions and ensure prevention and treatment. It is also crucial to analyse what causes congenital abnormalities as well as the association with environmental hazards and genetic risks.

Ms Annemie DRIESKENS, President of the Confederation of Family Organisations in the European Union (COFACE)[32], took the floor to highlight the importance of investing in longer maternity leave, education and nutrition, but focusing more on issues that are already on the European agenda, such as environmental pollution and air quality. In her view, the special vulnerability of newborn infants should be linked to the on-going debate in this area.

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[29] For more information, see : http://www.noharm.org/

[30] Proposal for a REGULATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL on medical devices, and amending Directive 2001/83/EC, Regulation (EC) No 178/2002 and Regulation (EC) No 1223/2009/* COM/2012/0542 final - 2012/0266 (COD) */

[31] For more information, see: http://www.ifglobal.org/en/

[32] For more information, see: http://www.coface-eu.org/en/

Ms Jana HAINSWORTH, Secretary General of Eurochild[33], stressed that it is important to put the rights of children and their families at the forefront as well as to see the whole picture, without looking at these issues solely through the medical lenses. The emotional health that derives from the direct contact of children with their families is crucial. In her opinion, the fundamental point is to reorientatate investments, with a greater focus on education, training and the empowerment of parents.

Ms MADER recalled that the key success factor of the "Battle for the Babies" campaign in Serbia was the cooperation among different national stakeholders. Partnerships between professionals, patients and policy-makers are therefore crucial in this respect. In addition, countries have to learn from each other's successes, and best practices should be identified and applied in each Member State.

Commenting on the need to integrate health and environment considerations, Dr Ladzane mentioned that the World Health Assembly has decided to adopt a life course approach linking public health with social determinants of health, the gender dimension and health and environment. She then highlighted that only five countries have official smoke-free public places according to the international definition, i.e. Ireland, the United Kingdom, Spain, Hungary and Bulgaria. Considering the proven link between smoking and premature births, comprehensive smoking bans should be enacted in all other countries as well.

Ms Helen BREWER from the European Critical Care Foundation[34] drew the attention of the audience on the decision-making process that parents have to go through when they are confronted with premature births and she called for more support to be provided to parents in terms of information and counselling.

In this respect, Prof. Dr MARLOW highlighted that several countries have enacted policies for preterm babies, but parents' opinion is hardly ever sought. For example, across the EU, only two Member States actually involve parents in the decision as to whether or not to resuscitate babies at birth, whereas in most countries doctors are making this decision without consulting the parents.
Afterwards, Mr Peterle gave the floor to Dr Peter LIESE (MEP) who proposed the issue of newborn babies as a subject for the workshop.

After thanking all the experts for their valuable contribution, Dr Liese emphasised the need to focus on the issues that are already on the agenda of the European Parliament to support families and children who are prematurely born or that are at risk of prematurity. For example, he mentioned the upcoming discussion in the ENVI Committee on the Tobacco Directive[35] as a key opportunity to highlight the link between smoking and prematurity. He mentioned that the European Commission has already included in the proposal the importance of considering the risks not only for the smoker, but also for children. In conclusion, Dr Liese promised to stress this point even further by tabling amendments on the proposal that would make the link between smoking and prematurity even more visible.

[33] For more information, see: http://www.coface-eu.org/en/
[34] For more information, see: http://euroccf.org/
[35] Proposal for a DIRECTIVE OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL on the approximation of the laws, regulations and administrative provisions of the Member States concerning the manufacture, presentation and sale of tobacco and related products /* COM/2012/0788 final - 2012/0366 (COD) */

2.3.4 Conclusions

In his concluding remarks, Mr PETERLE stressed that public health inequalities within the EU should be overcome as EU citizens have the right to be treated equally when it comes to access to care. Moreover, policy-makers at the European and national levels should work together on the development of harmonised standards, education and training curricula and should keep the issue of newborn infants high on the political agenda, even when discussing other related topics. Finally, Mr Peterle emphasised that, even if health systems are in trouble due to the economic crisis, investments in prevention should be ensured, as this would ultimately reduce the costs for treatment.

ANNEX 1: PROGRAMME

WORKSHOP
Newborn Infants

Wednesday, 24 April 2013 from 13.00 to 14.45
European Parliament, Room A5E-2, Brussels

Organised by the Policy Department A - Economy & Science
for the Committee on the Environment, Public Health and Food Safety (ENVI)

AGENDA

13.00 - 13.05
Welcome and opening by Co-chairs of the Health Working Group, Glenis WILLMOTT and Alojz PETERLE (MEPs, ENVI Committee), and Angelika NIEBLER (MEP, ITRE Committee).

13.05 - 13.10
The development of European policies in the field of Newborn Infants.
DG SANCO, EC

Part 1

Healthcare during pregnancy

13.10 - 13.20
Challenges in maternal and newborn health for Europe
Dr Gunta Lazdane, MD, PhD, Programme Manager, Sexual and Reproductive Health, Division of Noncommunicable Diseases and Life-Course, WHO Regional Office for Europe

13.20 - 13.30
Healthy aging starts before birth
Prof. Dr Bo Jacobsson, Director of the Perinatal Research Laboratory at Sahlgrenska University Hospital, Sweden and Department of Genes and Environment, Institute of Epidemiology, Norwegian Institute of Public Health, Norway

13.30 - 13.40
The voice of patients – Impact of newborn diseases and prematurity on families

Ms Silke Mader, Chairwoman of the European Foundation for the Care of Newborn Infants, Germany

13.40 - 13.50
Question Time

Part 2

Newborn health – preventing chronic diseases

13.50 - 14.00
The quality of newborn *and family* care makes a difference to the health and well-being of Europe's future population
Prof. Dr Mats Blennow**,** Professor of Neonatology, President of the European Society of Neonotology, Karolinska Institute Stockholm, Sweden

14.00 - 14.10
Postneonatal continuing care and health needs to prevent chronic diseases later in life
Prof. Dr Neil Marlow, Professor of Neonatology, UCL Institute for Woman´s Health, UK

14.10 - 14.40
Question Time

14.40 - 14.45
Conclusions

14.45 Closing

ANNEX 2: SHORT BIOGRAPHIES OF EXPERTS

Ms Isabel de la Mata

Isabel de la Mata was born in Bilbao (Spain). She graduated in Medicine at the University of Basque Country in 1983 and holds post-graduate degrees from the University of Leuven and Paris VI. She is specialist in Preventive Medicine and Public Health.

She worked at the Ministry of Health of Spain and at the Regional Departments of Health in the Basque Country and in Madrid. She has an experience working with International Organisations, such as the WHO, Pan American Health Organisation and Inter-American Development Bank.

From 2004 until February 2008 she worked at the Permanent Representation of Spain to the EU. Since 1 March 2008 she works as Principal Adviser for Public Health at Directorate SANCO – Health & Consumers.

Dr Gunta Lazdane

Gunta Lazdane is an obstetrician and gynaecologist, Ph.D. and a Professor, Head of University Department in Riga Stradins University, Latvia. Since 2003 she has been working in the WHO Regional Office for Europe as the Programme Manager, Sexual and Reproductive Health including Maternal and Neonatal Health in the Division of Noncommunicable Diseases and Health Promotion. She is assisting 53 WHO Member States in the European Region with the aim of improving sexual and reproductive health of population.

Dr Lazdane has participated in many European and global conferences and congresses including International Conference on Population and Development in Cairo in 1994.

She is the Chief Editor of the European Magazine for Sexual and Reproductive Health Entre Nous and the member of several Editorial Boards of peer review journals in the area of sexual and reproductive health.

Prof. Dr Bo Jacobsson

Bo Jacobsson received his Medical Degree at Sahlgrenska Academy in Gothenburg, Sweden in 1991. He then specialised in Obstetrics and Maternal/Fetal Medicine and got his Ph.D at Gothenburg University, Sweden in 2003. After receiving his Ph.D he carried out his post-doctoral research training at Aarhus University in Denmark.

He has been a Guest Professor at Rikshospitalet, Oslo Norway and is presently the director of the Perinatal Research Laboratory at Sahlgrenska University Hospital in Gothenburg, Sweden, where he also does his clinical obstetrical practice. He is also the head of Fetal Medicine at Sahlgrenska University Hospital in Gothenburg, Sweden and a senior research at Norwegian Institute of Public Health.

Dr. Jacobsson's laboratory is studying basic and applied aspects of the mechanisms of preterm delivery. Another area that has attracted his interest is the genetic components of the timing of delivery and also the interplay between genes and the environment. One of his main interest for the moment is the possibility to prevent preterm delivery by intervention with dietary products, e.g. probiotics. At his lab, he is training researchers from different parts of Europe and Africa.

Ms Silke Mader

Silke Mader is the Chairwoman of the Executive Board and co-founder of EFCNI. 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 faced the non-existence of any kind of support, 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.

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 take on the role of chair on the Executive Board of EFCNI.

Silke Mader is co-editor of the EFCNI Benchmarking Report “Too little, Too Late? Why Europe Should do more for Preterm Infants”, “Caring for Tomorrow” – the EFCNI White Paper on Maternal and Newborn Health and Aftercare Services” and technical editor of the “Born too Soon” Global Action Report on Preterm Birth”.

Prof. Dr Mats Blennow

Mats Blennow is a medical doctor specialised in the care of newborn infants (neonatology). He holds a position that combines academic research (40% professorship in perinatal neuroscience) and clinical work (60% senior consultant) at the Karolinska Institutet and University Hospital in Stockholm, Sweden.

After finishing his M.D. in 1980, he specialised in pediatrics (1992) and in neonatology (1995). He defended his Ph.D. at the Karolinska Institutet in 1995.

Blennow holds several commissions of trust within the field of newborn medicine. Amongst these, he is president for the European Society for Neonatology, the organisation representing neonatology within the Union of European Medical Specialities. He is also the acting chair for the scientific committee for the largest pediatric scientific meeting, EAPS, to be held in Barcelona in 2014.

Blennow has published 60 peer-reviewed scientific articles in major international journals. In addition he has published book-chapters, teaching materials and national and european guidelines on various aspects of care of the newborn infant.

Prof. Dr Neil Marlow

Neil Marlow is Professor of Neonatal Medicine, University College London. He was Professor of Neonatal Medicine in the University of Nottingham from 1998-2008.

He is the chief investigator of the EPICure Studies, two of the largest longitudinal studies of extremely preterm birth. Neil is immediate past President of the European Society for Pediatric Research. He was elected as a Fellow of the Academy of Medical Sciences in 2007 and awarded the honour of Honorary Life Friend by Bliss, the UK premature babies charity in recognition of his contribution to clinical care.

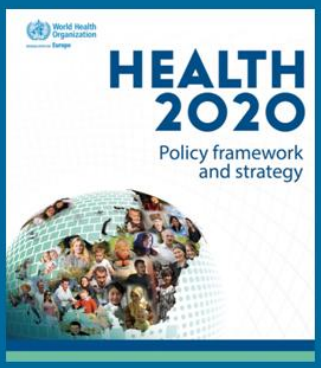
Neil's current research profile includes ongoing longitudinal population studies, several randomised trials of neonatal and antenatal intervention with childhood outcomes, biomarker discovery for preterm developmental problems and an investigation into parental experience of decision making and issues surrounding end of life decisions in neonatal care.

ANNEX 3: PRESENTATIONS

Presentation by Dr Gunta Lazdane

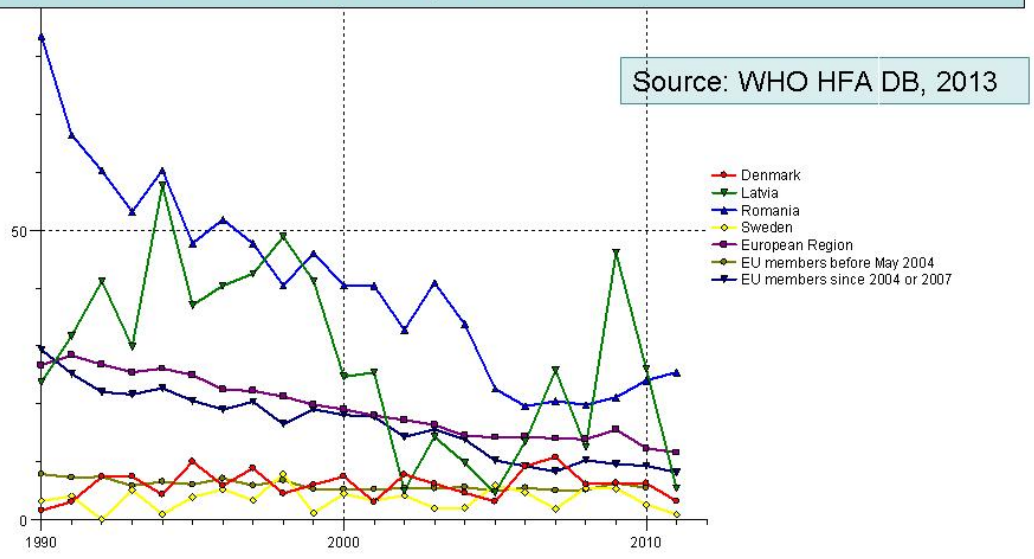
Challenges in maternal and newborn health for Europe

Dr Gunta Lazdane
Sexual and Reproductive Health Programme,
WHO Regional Director for Europe



World Health Organization
REGIONAL OFFICE FOR Europe

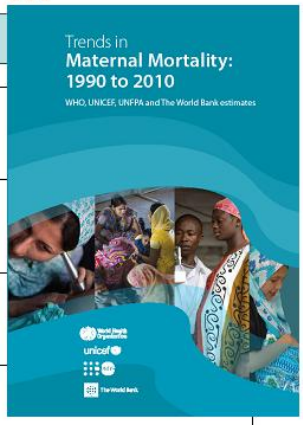
Maternal mortality WHO European Region and selected EU countries, 1990-2011



World Health Organization
REGIONAL OFFICE FOR Europe

Lifetime risk of maternal death 1 in …

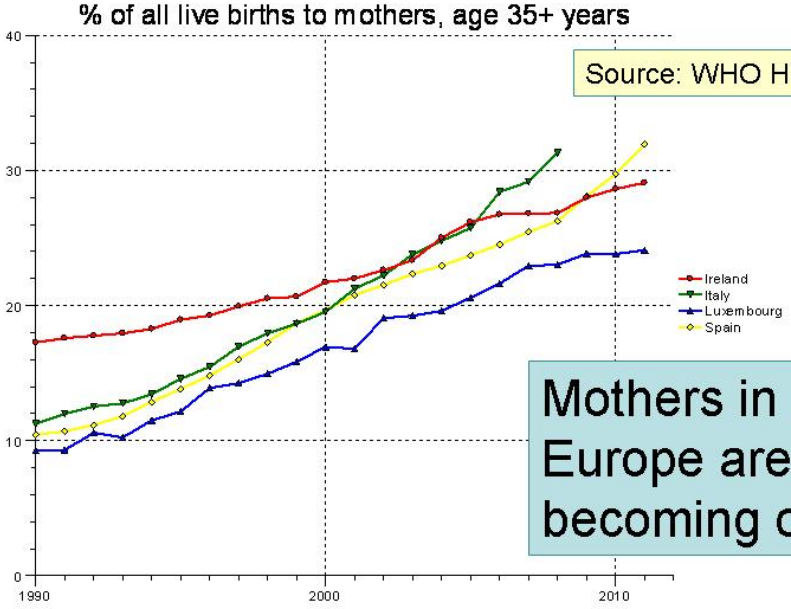
Source:



World Health Organization
REGIONAL OFFICE FOR Europe

% of all live births to mothers, age 35+ years

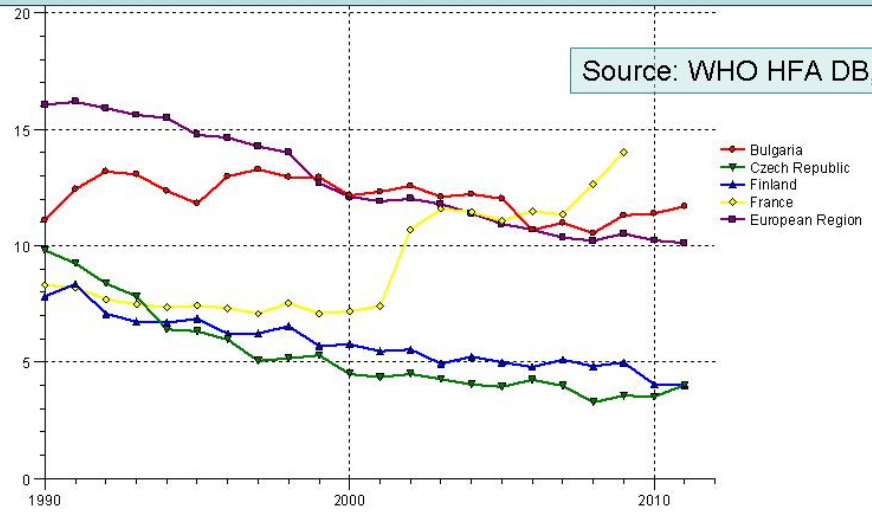
Source: WHO HFA DB, 2013



Mothers in Europe are becoming older!

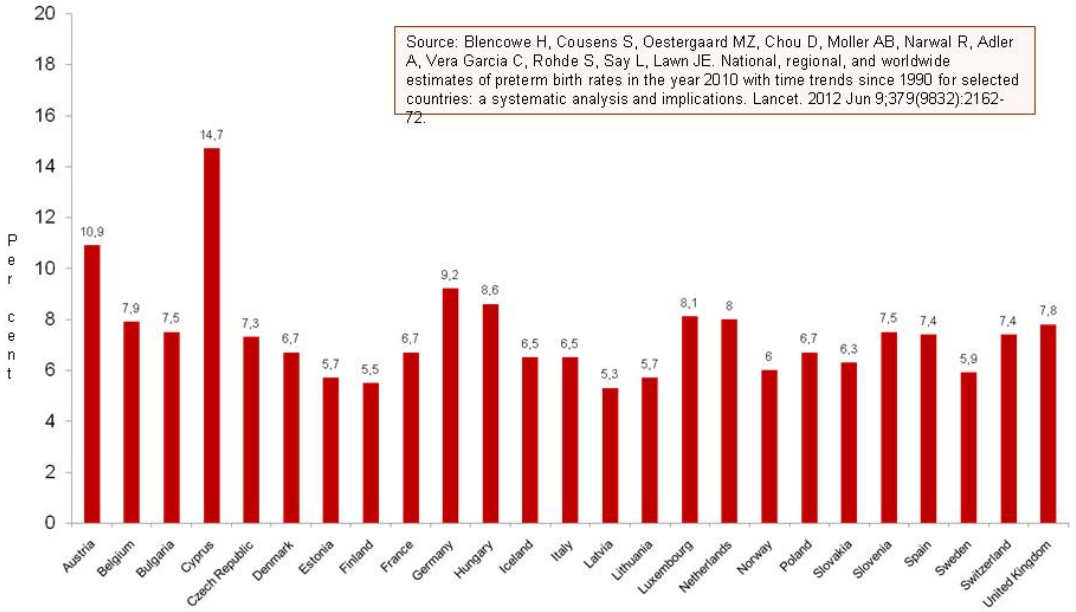
World Health Organization
REGIONAL OFFICE FOR Europe

Perinatal deaths per 1000 births in WHO European Region and selected EU countries, 1990-2011



World Health Organization
REGIONAL OFFICE FOR Europe

Preterm birth rate per 100 live births (%), 2010

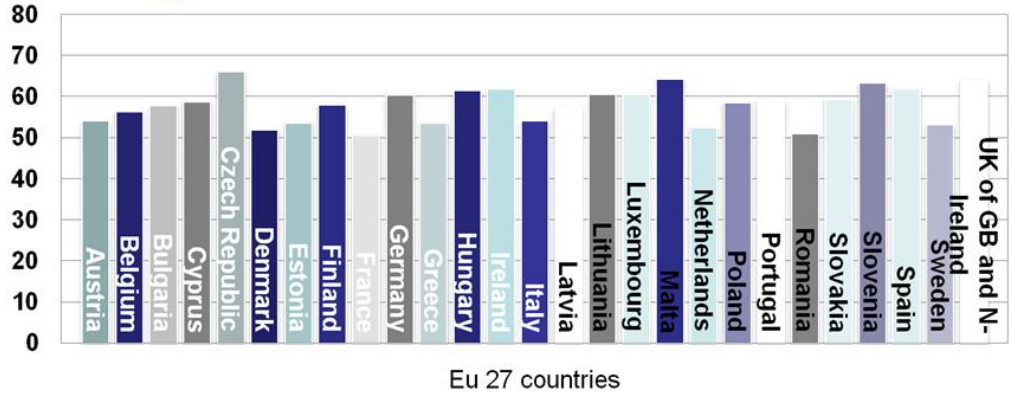


World Health Organization
REGIONAL OFFICE FOR Europe

Preventable risk factors for preterm birth

- Low and high BM

Overweight in adults 2008 (% pre-obesity and obesity)



Preventable risk factors for preterm birth

- Smoking and alcohol
- Genitourinary infections and HIV
- Stress, Violence
- Management of noncommunicable diseases

Smoking ban "cuts premature births"

After the smoking bans in 2007 and 2010, the premature birth rate dropped by around 3% each time

Hasselt University in Belgium, 2013

World Health Organization
REGIONAL OFFICE FOR Europe

Increasing attention to inequity

Photo: WHO/Djordje Novakovic

Growing inequality is one of the biggest social, economic and political challenges of our time. But it is not inevitable ……

The Economist Special Edition October 13th 2012

World Health Organization
REGIONAL OFFICE FOR Europe

PREVENTION OF PRETERM BIRTH

- Preconception care package, including family planning (e.g., birth spacing and adolescent-friendly services), education and nutrition especially for girls, and STI prevention
- Antenatal care packages for all women, including screening for and management of STIs, high blood pressure and diabetes; behavior change for lifestyle risks; and targeted care of women at increased risk of preterm birth
- Provider education to promote appropriate induction and cesarean
- Policy support including smoking cessation and employment safeguards of pregnant women

MANAGEMENT OF PRETERM LABOR

- Tocolytics to slow down labor
- Antenatal corticosteroids
- Antibiotics for pPROM

CARE OF THE PREMATURE BABY

- Essential and extra newborn care, especially feeding support
- Neonatal resuscitation
- Kangaroo Mother Care
- Chlorhexidine cord care
- Management of premature babies with complications, especially respiratory distress syndrome and infection
- Comprehensive neonatal intensive care, where capacity allows

Source: **Born too soon, action report 2012**

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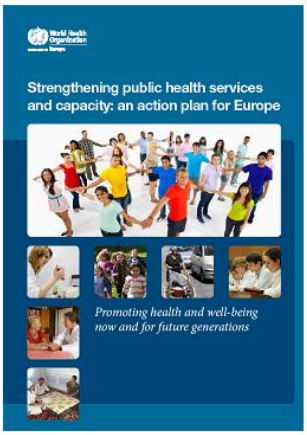
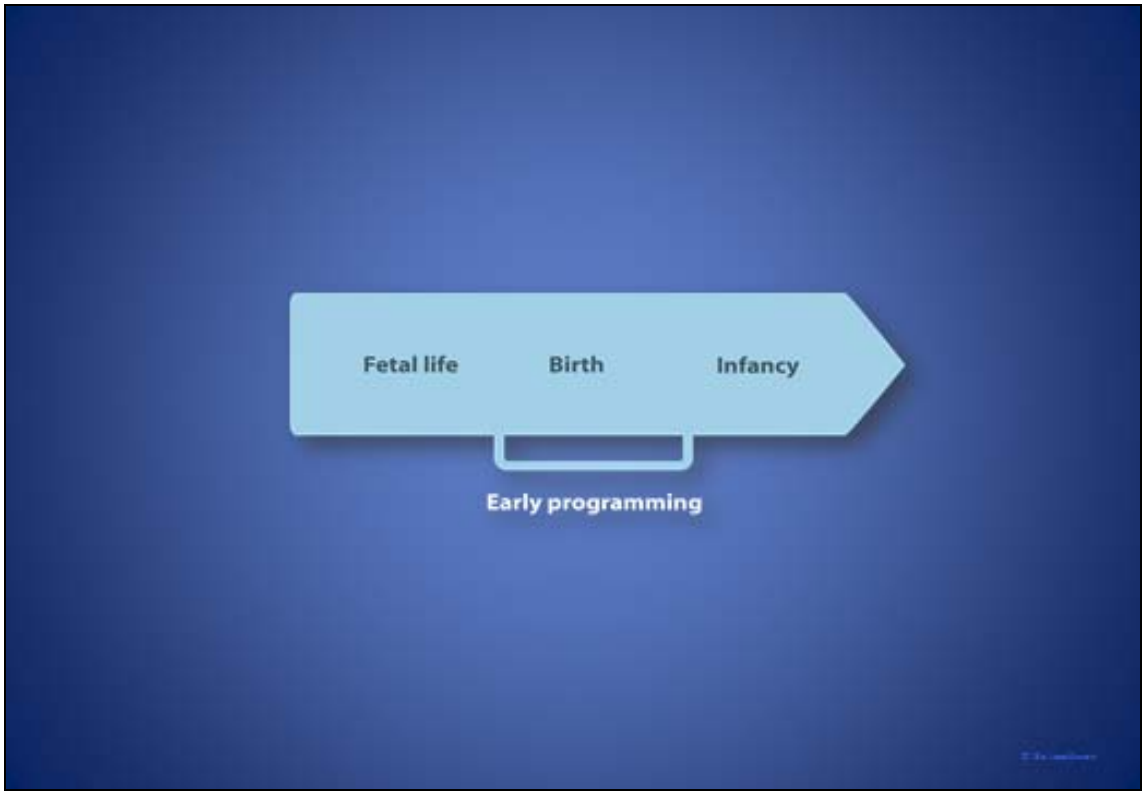
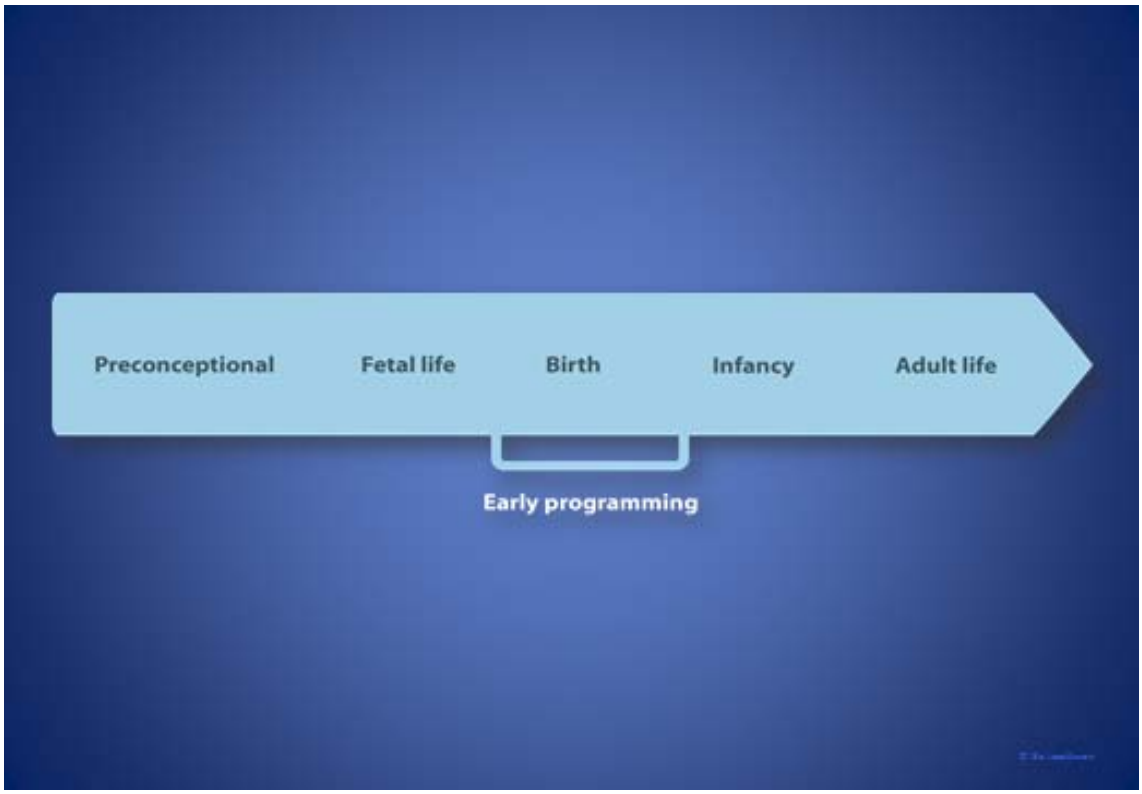


Thank you!

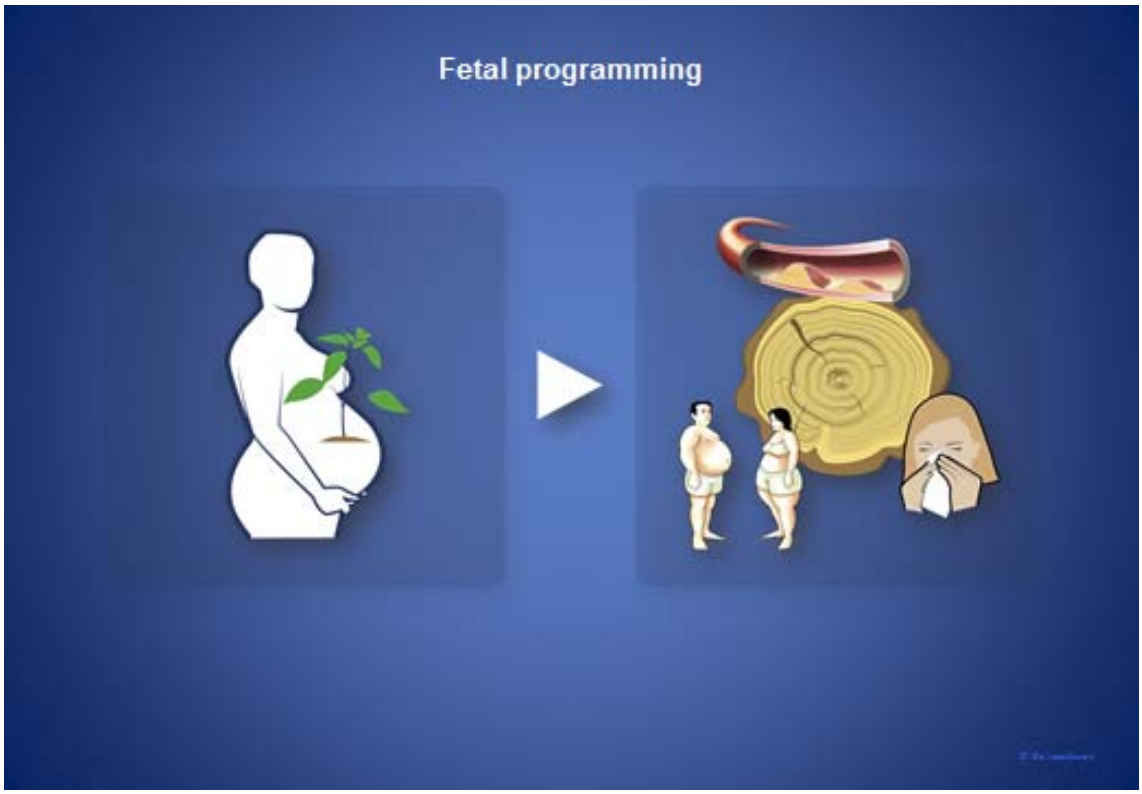
World Health Organization
REGIONAL OFFICE FOR Europe

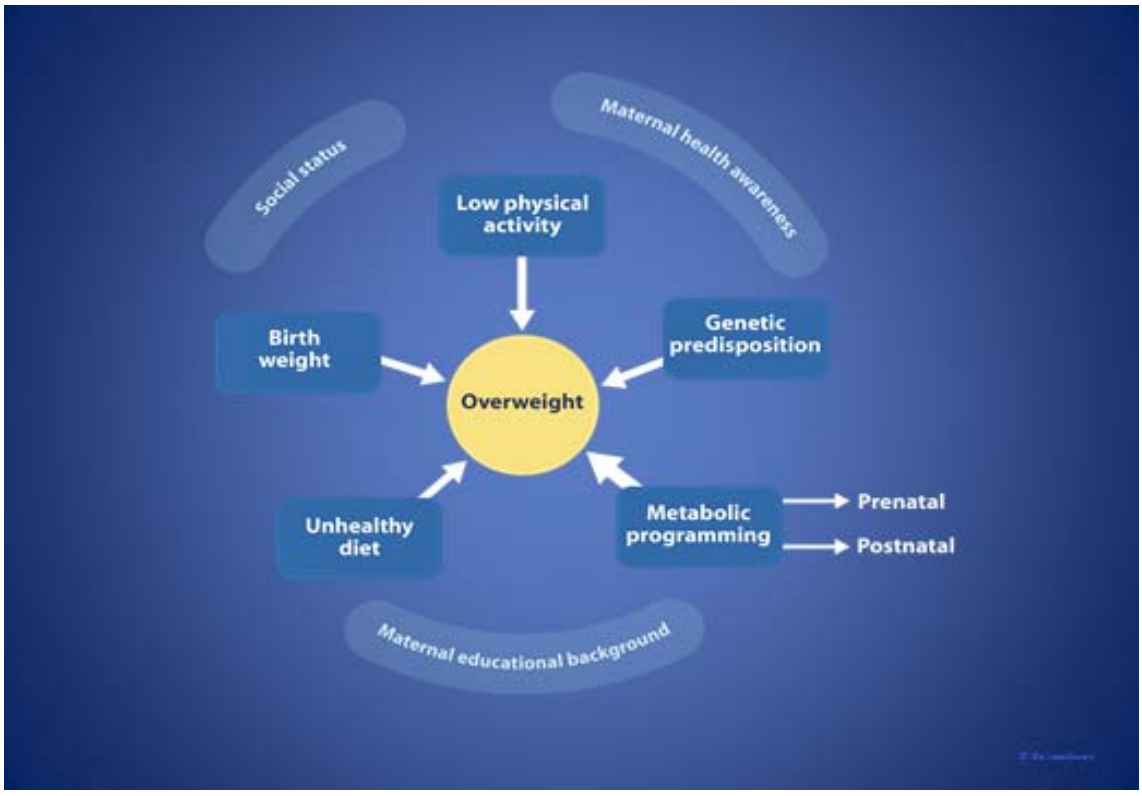
Presentation by Prof. Dr. Bo Jacobsson

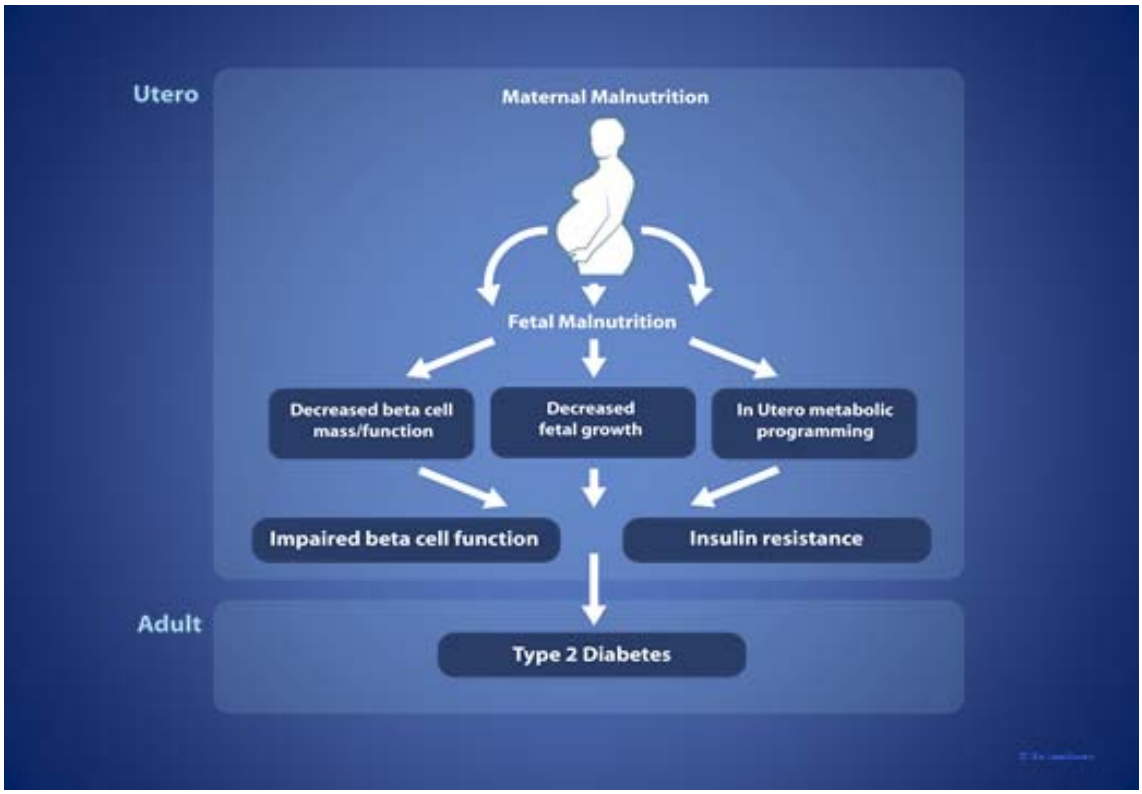


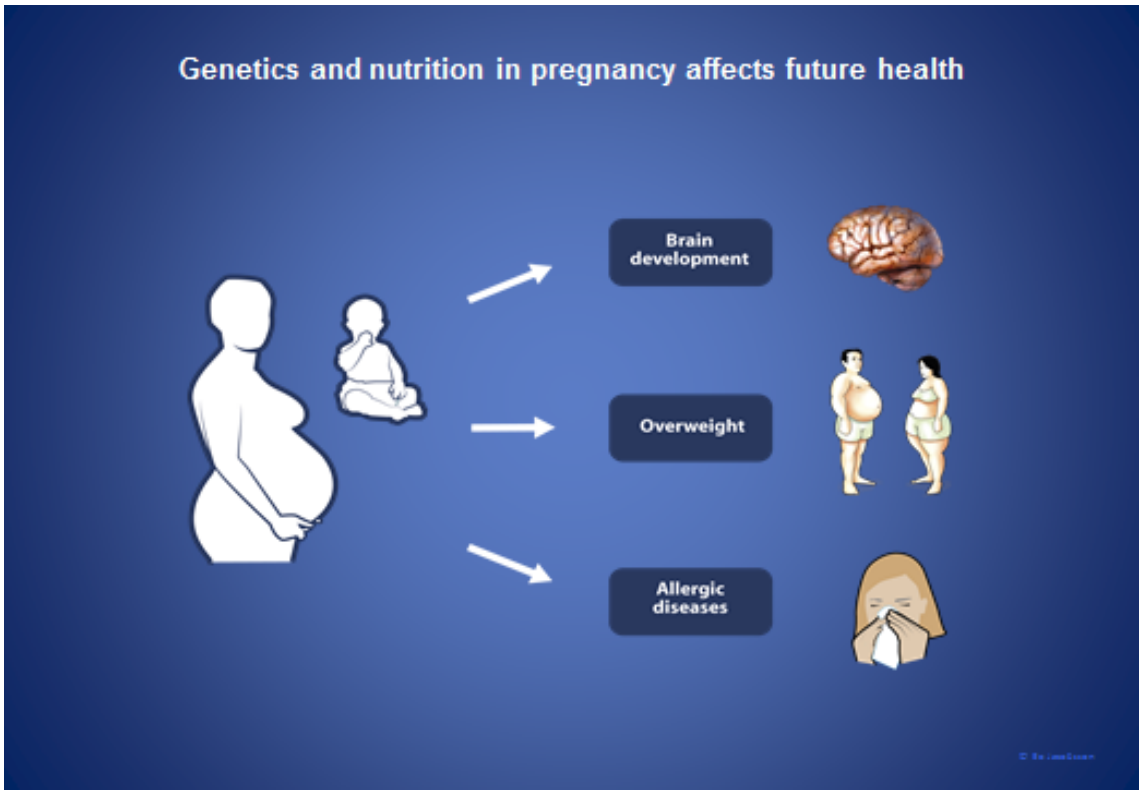

Preconceptional
Fetal life
Birth
Infancy
Adult life
Early programming

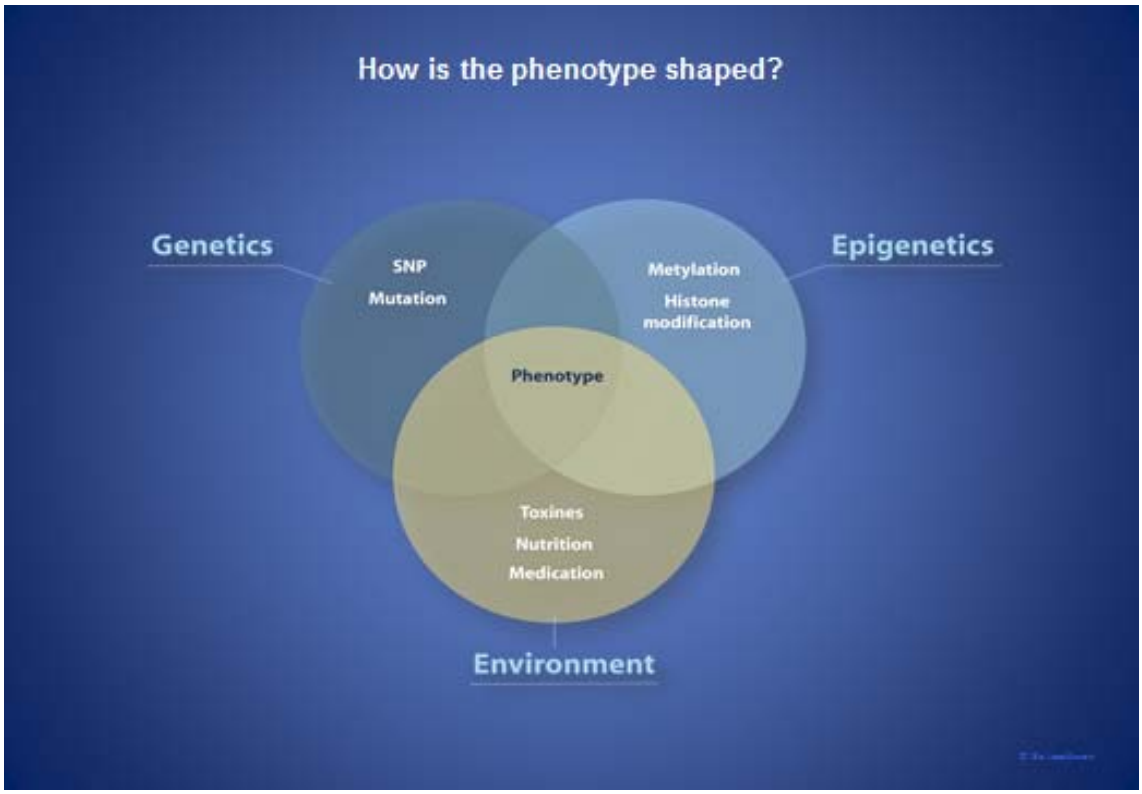

Intervention for a healthy life starts before and during pregnancy
Before Pregnancy
Pregnancy
Childhood
Adulthood
Old age

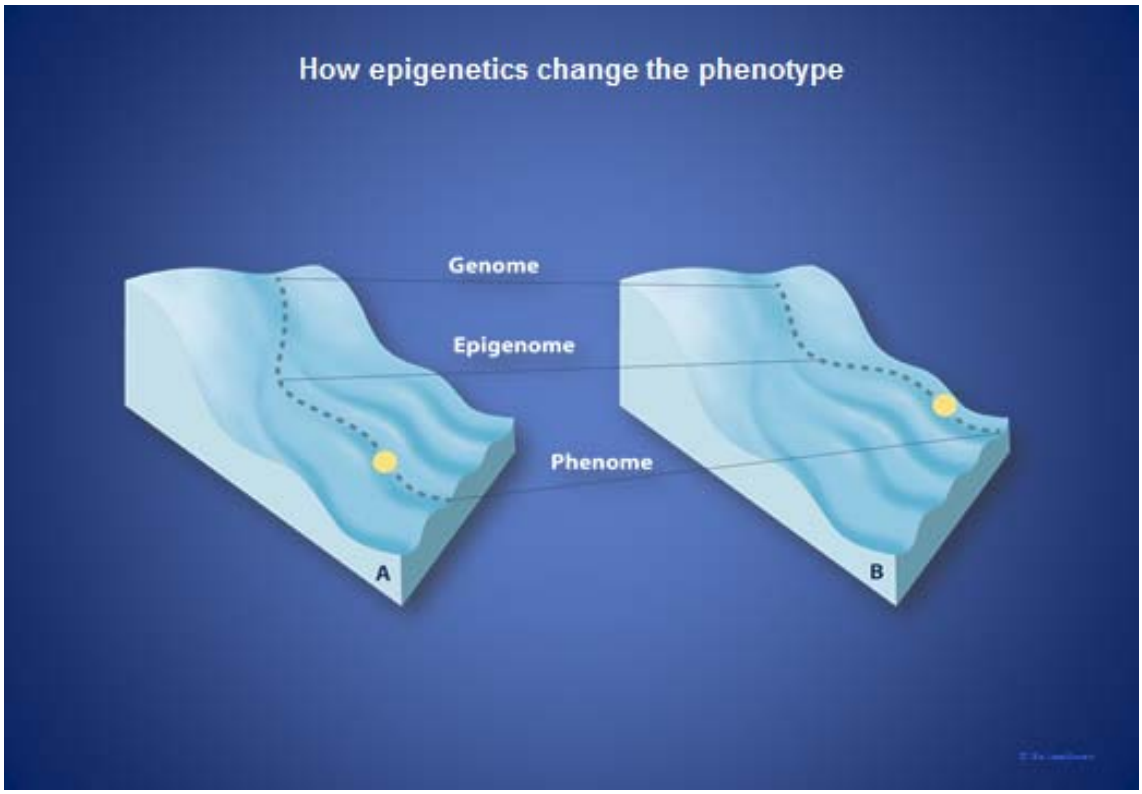

Fetal programming

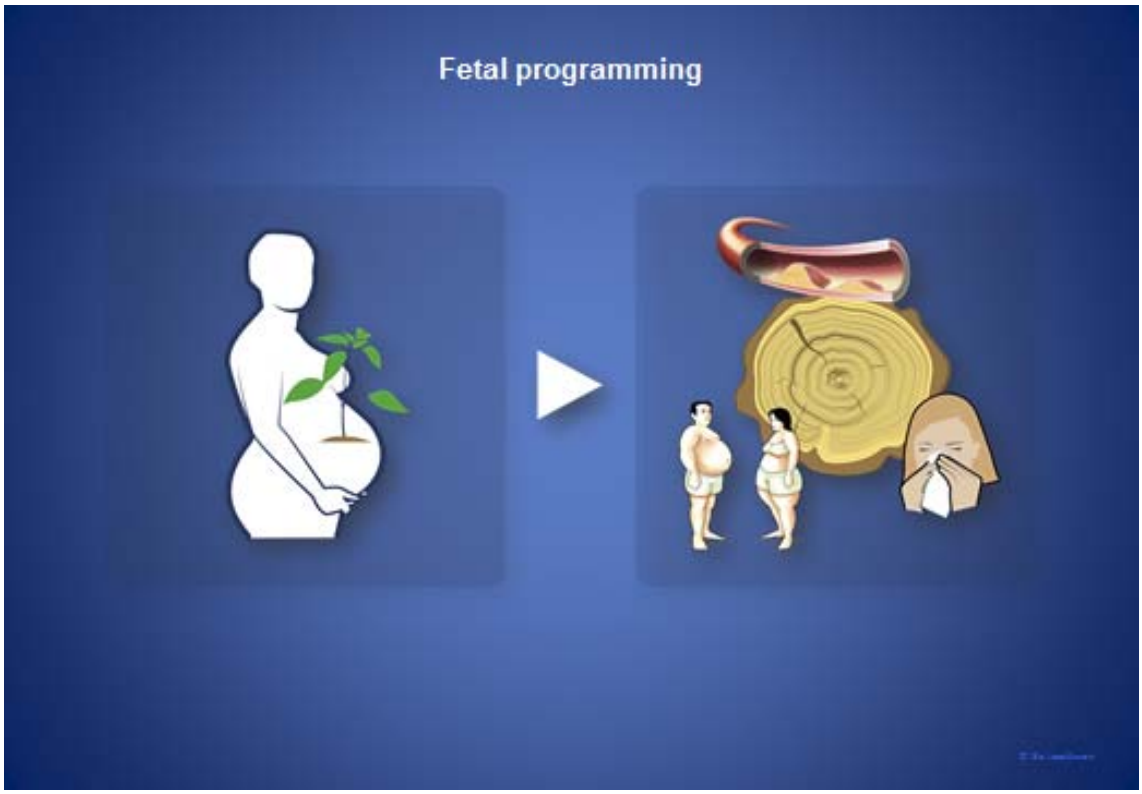

Social status
Maternal health awareness
Low physical activity
Birth weight
Genetic predisposition
Overweight
Unhealthy diet
Metabolic programming
Prenatal
Postnatal
Maternal educational background


Utero
Maternal Malnutrition
Fetal Malnutrition
Decreased beta cell mass/function
Decreased fetal growth
In Utero metabolic programming
Impaired beta cell function
Insulin resistance
Adult
Type 2 Diabetes

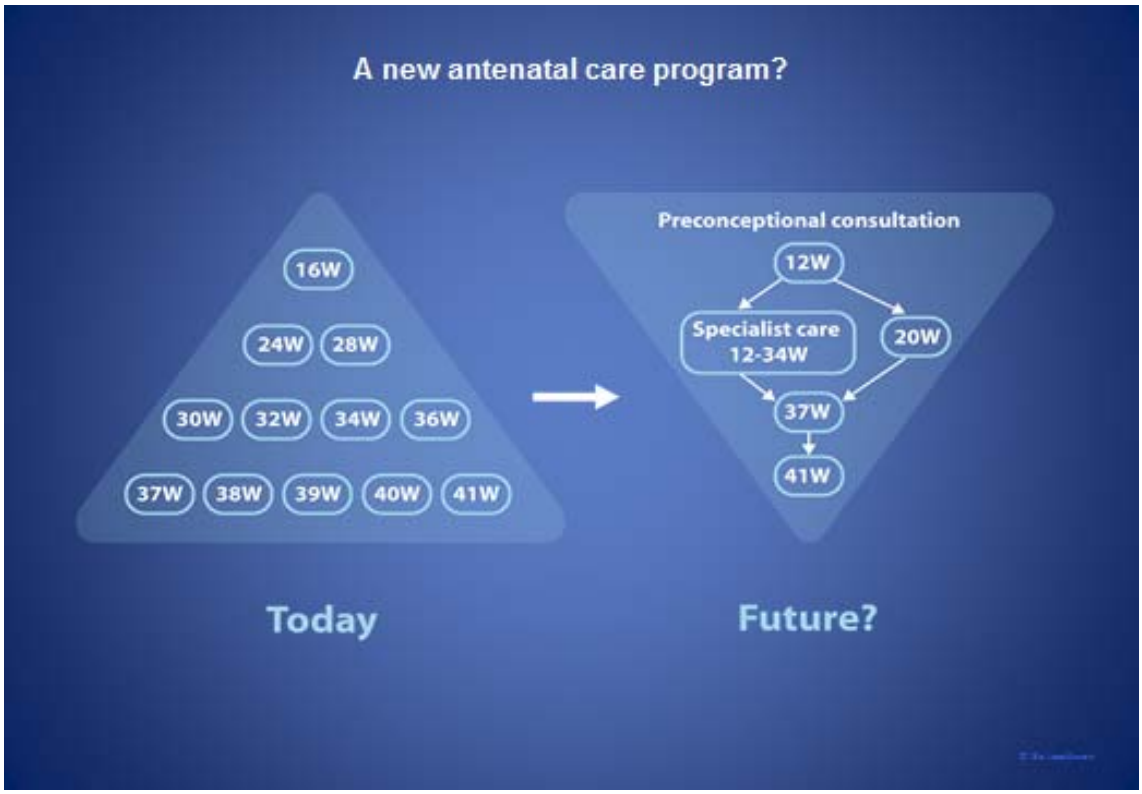

Genetics and nutrition in pregnancy affects future health
Brain development
Overweight
Allergic diseases

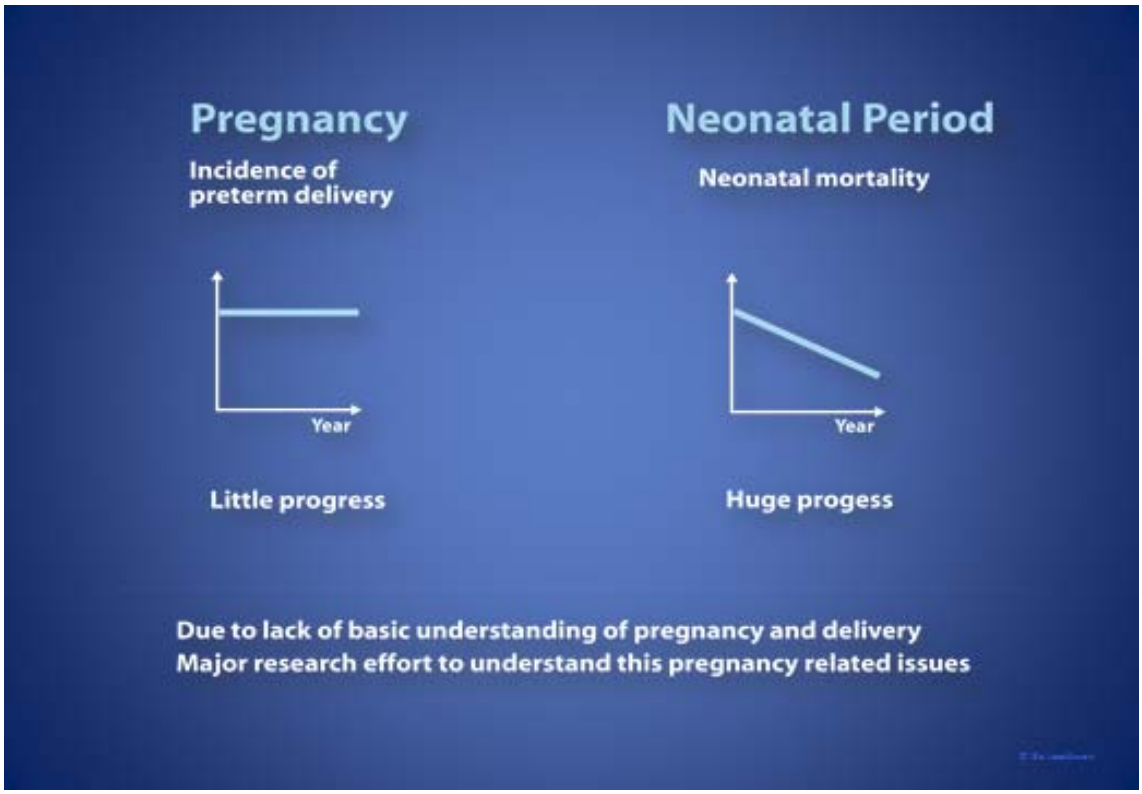

How is the phenotype shaped?
Genetics
SNP
Mutation
Metylation
Histone
modification
Epigenetics
Phenotype
Toxines
Nutrition
Medication
Environment


How epigenetics change the phenotype
Genome
Epigenome
Phenome
A
B


Fetal programming


Intervention for a healthy life starts before and during pregnancy
Before Pregnancy
Pregnancy
Childhood
Adulthood
Old age


A new antenatal care program?
16W
24W
28W
30W
32W
34W
36W
37W
38W
39W
40W
41W
Preconceptional consultation
12W
Specialist care
12-34W
20W
37W
41W
Today
Future?


Pregnancy
Incidence of
preterm delivery
Year
Little progress
Neonatal Period
Neonatal mortality
Year
Huge progess
Due to lack of basic understanding of pregnancy and delivery
Major research effort to understand this pregnancy related issues


SUMMARY
EDUCATE THE PUBLIC, PATIENTS AND PROFESSIONALS ABOUT THE RELATION BETWEEN PREGNANCY AND ADULT HEALTH
BETTER AND HARMONIZED CROSS-COUNTRY EDUCATION AND TRAINING
MAJOR PREGNANCY RELATED RESEARCH EFFORT.

Presentation by Ms Silke Mader

EFCNI european foundation for the care of newborn infants

The voice of patients -
Impact of newborn diseases and prematurity

Silke Mader

April 24, 2013

Challenges: parents involvement in Europe

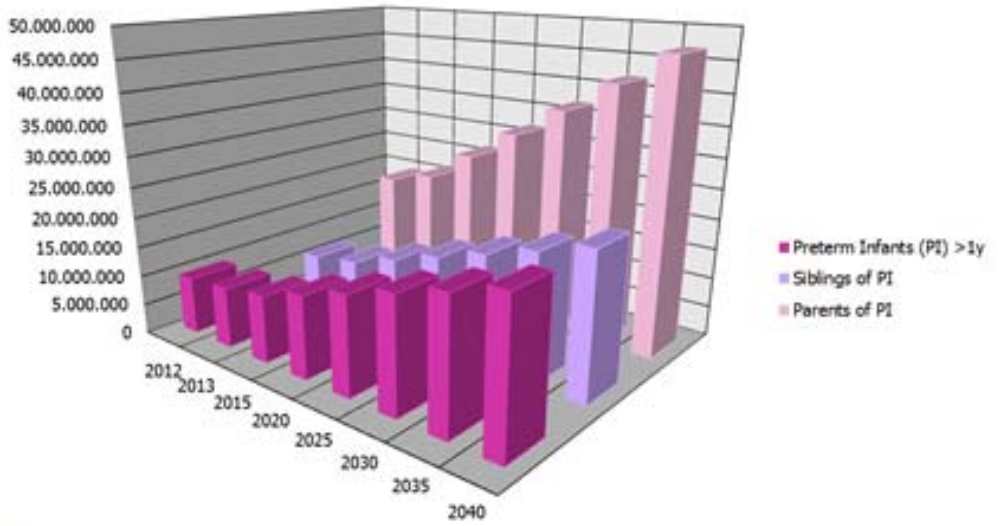
Huge differences in:

- Preterm birth rates
- Mortality/ morbidity rates
- Care practices
- **Parental involvement**

Lack of:

- **National Policies/Programmes**
- **Standards of Care**
- **Standards in Research**

Preterm birth rates are increasing



Ensuring a healthy start in life needs…

- Information, education and guidance for women of reproductive age and their partner
- Harmonised EU pregnancy booklet with checklist for all relevant information
- Early identification of women of reproductive age or pregnant women with risks for closer follow-up and screening
- Improvement of education and training of health experts
- Treatment and delivery in specialised hospitals for women at risk
- Information and follow-up for women who experienced health problems during pregnancy or delivery (e.g. preeclampsia, diabetes, depression etc.)

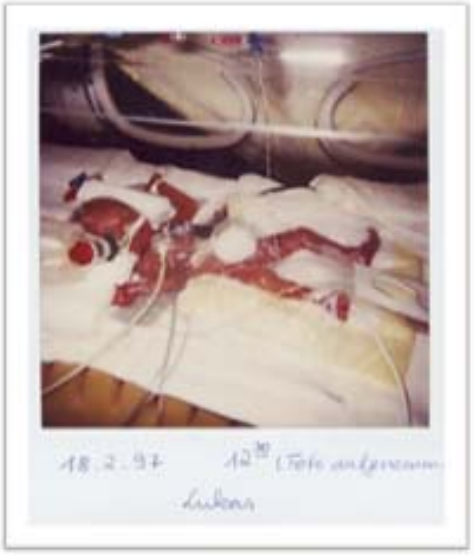
Preterm infants have preterm parents

Having a healthy baby

Preterm birth changes everything!

- Mixed feelings
- Fear and concern on the baby/ mother
- Too many things left to do
- Unknown future with all possible consequences
- Financial problems

This was not what we expected!!!



Situation in Germany and Sweden

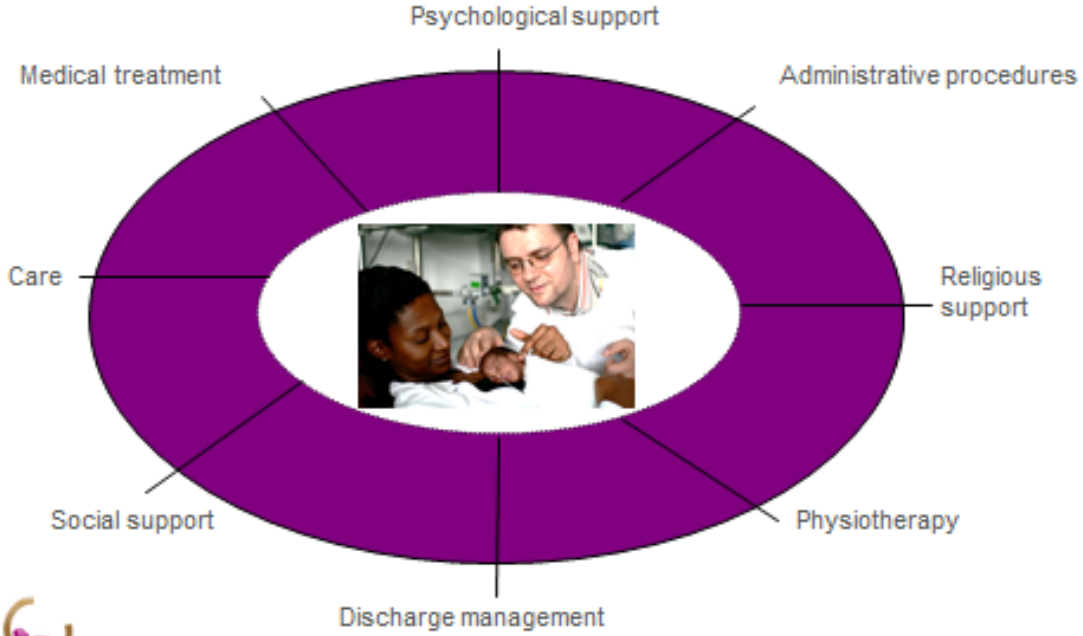
Big challenge for many countries in Europe (Belgrade 2011)

- No space for parents
- No or few visiting rights
- No family centred care system
- No support – No policy rights

How can we help parents in this situation?

- Information, education and guidance for parents
- Integrative family centred care / couplet care in hospitals
  - ➢ Stress reduction for parents and child (NICU environment)
  - ➢ Family support programmes
  - ➢ Psychosocial support
  - ➢ Visiting 24 hours / 7 days a week
- Best newborn nutrition (breastfeeding, but also safe and proved alternatives)
- Longer maternity and parental leave for parents of preterm infants and sick newborns

Family centred care integrates the whole family!



S. K. 2006 DKHD

Discharge management with a preterm or sick infant

Long-term challenges for the children and parents

- Discharge management
- Family support programmes safe expenses and ensure better outcome
- Day-care, pre-school and school systems need integration and inclusion programmes
- Long-term follow-up for newborns and families at risk
- Information, education and training for adult health experts, preparing them for the coming new patient group

Can we really accomplish all these needs in Europe?

Combining Forces & Working together

„Battles for Babies" Campaign in Serbia

Campaign with TV channel B92

Winner of the European campaign award 2011

BITKA ZA BEBE
AKCIJA ZA DONACIJU 100 INKUBATORA

3 million Euros raised:

140 new incubators,

other equipment and training

Hospital in Belgrade 2012

Support from:

- Government
- Parents
- Experts and caregivers
- Media
- Industry

EFCNI european foundation for the care of newborn infants

Every baby has the right for a healthy start in life:

- Standards of care for maternal and newborn health and continuing care
- Maternal and newborn health on all national policy agendas and programmes
- Build-up an EU platform to ensure both targets

Presentation by Prof. Dr. Mats Blennow

Outline

- Size of the problem
- The spectrum of problems faced
- Newborn infants are not small adults
- Towards caring for a family
- Harmonizing the care for the next generation of EU-citizens

Disability adjusted life years (DALY) = Prematurity 3.1%

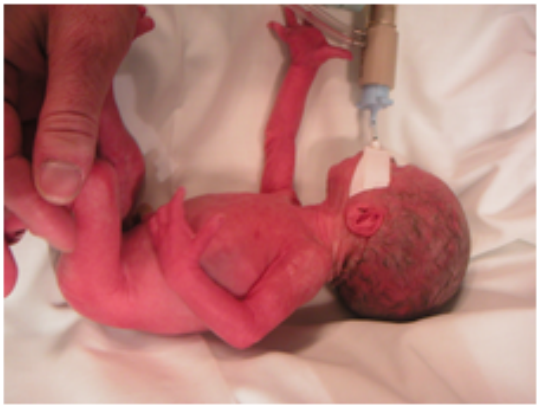
- For comparison
  - Cardiovascular disease 11.8%
  - Injuries 11.2%
  - All cancer 7.6%
  - HIV/AIDS 3.3%

DALY = Years of life lost (YLL) + Years lived with disability (YLD)

www.thelancet.com Vol 380 December 15/22/29, 2012

Most newborn infants are healthy, but..

- Prematurity
  - 500,000 infants annually born premature in Europe (7.1% of all births)



Prematurity

- Born before 37 weeks of gestation
- Extremely preterm infants born 3 months or more too early
- Hospitalized for 2-4 months
- Need respirators, intravenous nutrition, antibiotics etc,etc…, and
- Their family!

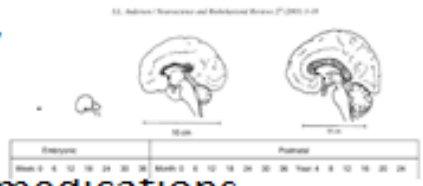

JAMA 2009, 301 (21): 2225-2233
4 out of 5 infants < 27 w
admitted to NICU
alive@1yr


Today 9 miljon European
children and teenagers
born preterm
..., 9 million families affected, 18 million European parents have experienced the worries of having a preterm baby hospitalised, caring for him/her during childhood, and noticing the shortcomings of our society in the care of our tiniest citizens

Newborns are not small adults!

Implications->

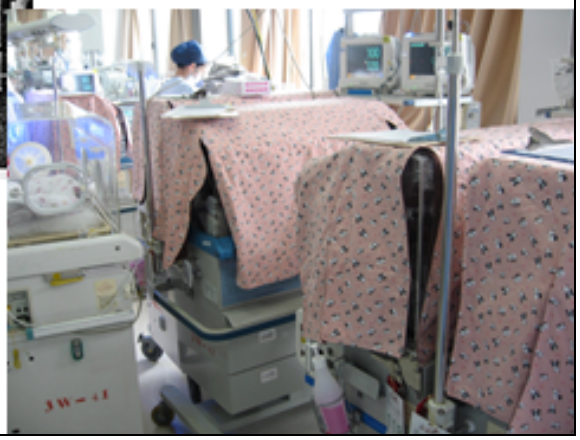
- Size
  - Specifically designed equipment necessary
  - Dosages have to be according to weight and maturity
- Maturity of organs
  - It is all there, but still "work in progress"



- Metabolism of nutrition and medications
  - Immaturity in drug metabolism in the kidneys and the liver is not fully developed
- Response to medications
  - Some medications have completely opposite effects
- All contacts are *by proxy*
  - The newborn infant lives in the context of a family that is experiencing the crisis of their lives

Caring for a family

Incubator-exhibition, early 1900[5]



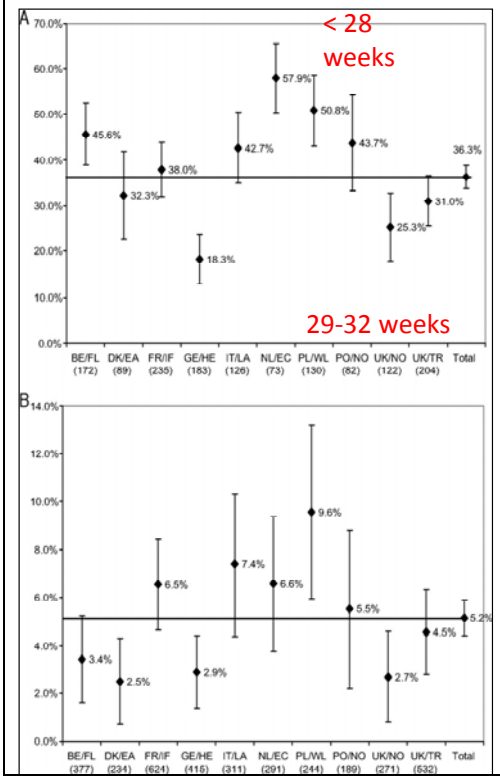
Busy and crowded NICU 2012.
Room for the family?


Family-centered couplet care facilitates optimal development
• Unlimited access for parents
• Extended parental leave
• Encourage early parental participation in the daily care
• Doctors, nurses and social support staff with dedicated education in neonatal care needed throughout Europe.
Photo: Linn Lokadotter B

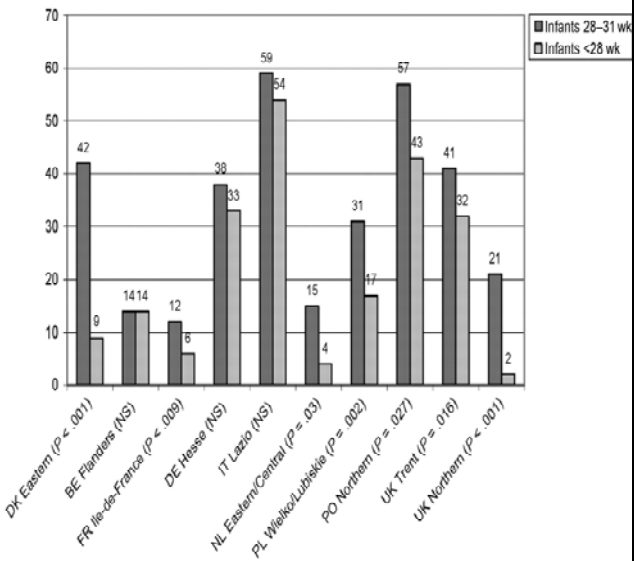

Modern NICU built for Family Centered Care. 2013.

Zeitlin J et al. Pediatrics 2008;121:e936-e944

Mortality at different gestations



Huge differences in care and results between EU countries



Van Reempts P et al. Pediatrics 2007;120:e815-e825

- Europe preterm infants urgently need
  - **Harmonizing of neonatal education**
  - **European standards for the treatment and care of the preterm infant**

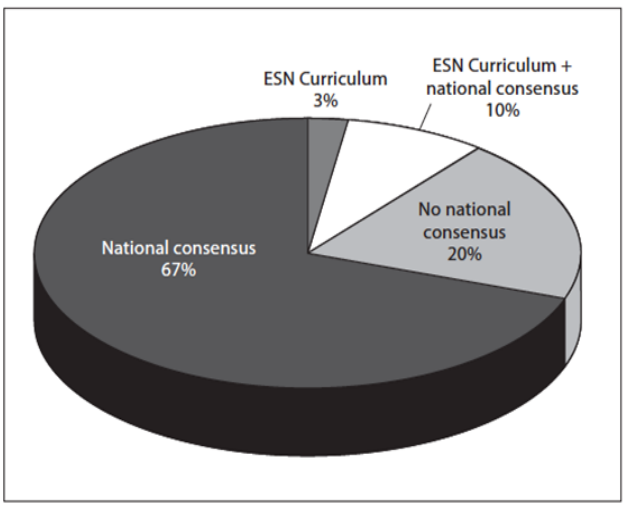
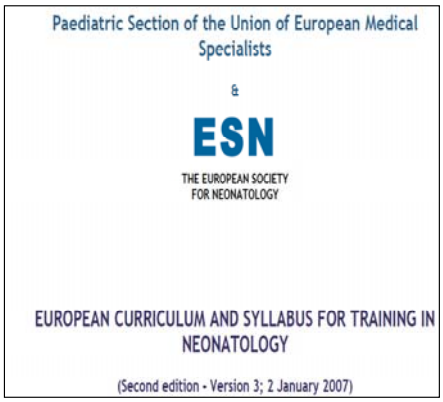


Fig. 1. Distribution of countries in Europe using ESN (3%), ESN + national consensus (10%), no national consensus (20%), and national consensus only (67%) for subspecialist training in neonatology.



Key-points to improve life for preterm children

- Prematurity is an endemic disease in numbers comparable to other major diseases
- Even after extreme prematurity, the children do survive and need special attention
- To improve outcome,
  - European standards for treatment and care are needed
  - The family needs attention from day 1 in the care of the newborn
  - Europe needs common training curriculi

Presentation by Prof. Dr. Neil Marlow

UCL

Post-neonatal continuing care and health needs to prevent chronic diseases later in life

Neil Marlow

Professor of Neonatal Medicine

European Society for Pediatric Research

UCL Elizabeth Garrett Anderson Institute for Women's Health

UCL

Birth and the neonatal period: an opportunity

Prevent perinatal adversity →→→ Healthy outcomes

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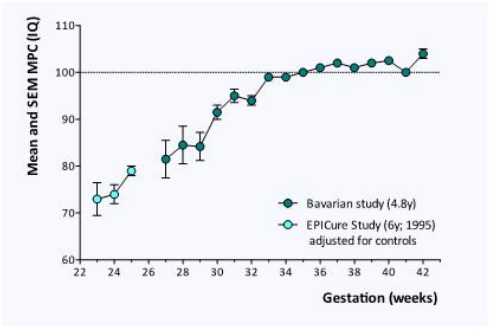
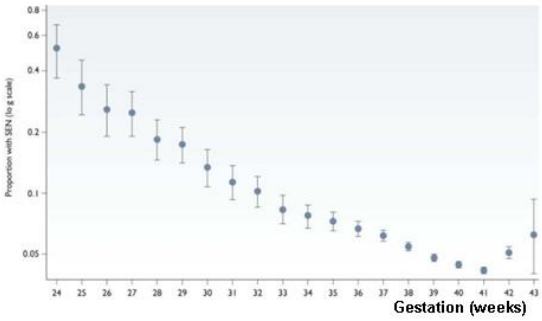
Outcomes are worse at lower gestational ages

General IQ



Marlow 2005; Wolke 2000

Log proportion with SEN



MacKay et al PLOS Medicine 2010

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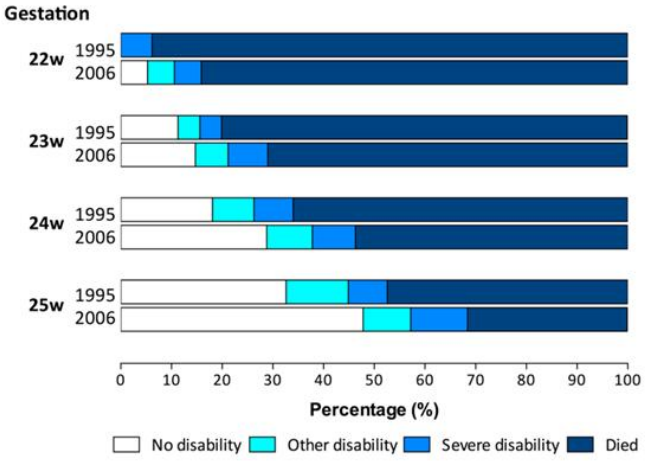
Improving perinatal outcomes

England 1995-2006



Moore et al BMJ 2012

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Going home – the risks of preterm birth

- Cerebral palsy
- Learning disability
- Behaviour problems
- Psychiatric disorders
- Respiratory disease
- Cardiovascular outcomes

- Reduced educational attainment
- Reduced earning potential
- Reduced social integration
- Poor adult health

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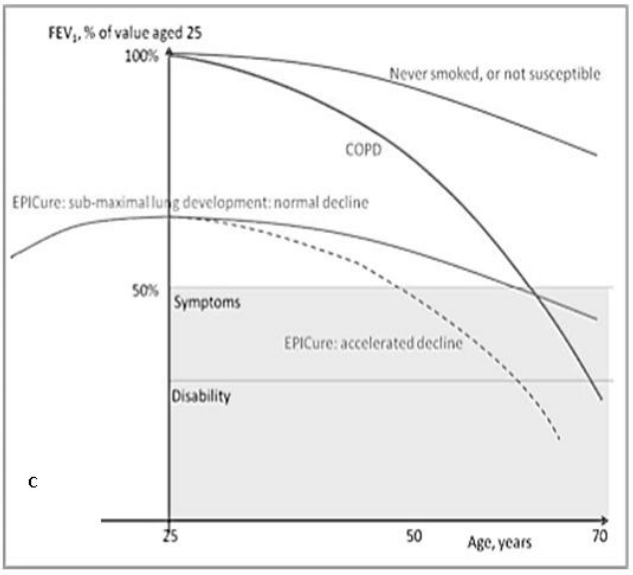
Implications for adult life



after Fletcher C, Peto R BMJ 1977

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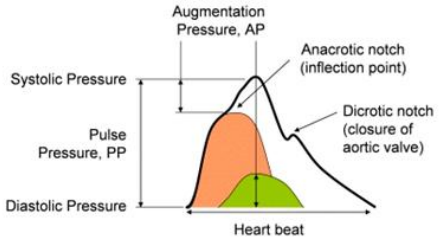
Trajectory into adulthood

- Respiratory health
  - 30% reduction in lung function after BPD
- Cardiovascular health
  - 200% increase in Aix at 11 years
- Metabolic syndrome
- Mental Health



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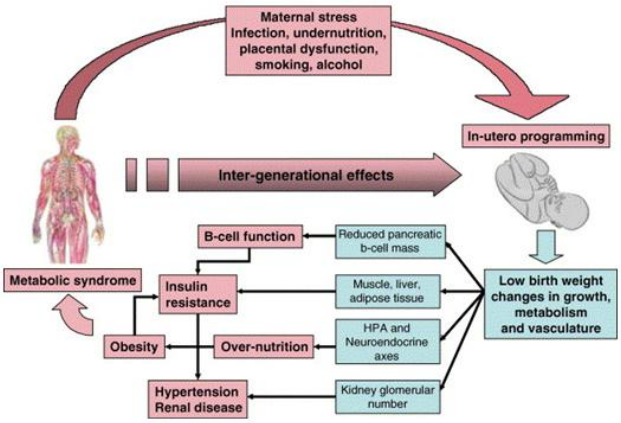
Developmental origins of adult disease



- ***Preterm birth may amplify these effects but also is more pervasive***

Good perinatal and aftercare leads to

- ***better outcomes as young adults***
- ***healthy ageing***

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Key is PREVENTION

- Optimise parent–infant interaction
- Careful ongoing assessment
- Diagnose conditions early, institute therapy

- Home support programme
- Outpatient assessment and follow up
- Develop effective interventions

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Key is PREVENTION

- Optimise parent–infant interaction
- Careful ongoing assessment
- Diagnose conditions early, institute therapy

- Home support programme
- Outpatient assessment and follow up
- Dev

77 million DALY worldwide due to prematurity (3.1% global total)

Blencowe et al 2013

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Optimal perinatal and aftercare

- Critical to preventing chronic disease
- Preventative strategies crucial
- Postnatal interventions to minimise childhood and adult disease
  - Neonatal Care
  - Follow on care
- Unique opportunity

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