

Dear friends,

We are very delighted to inform you that, at long last, we have established our new *Competence Centre for Maternal and Newborn Health*. Moving into the new facilities will not only enable us to further expand the EFCNI manpower but also finally approach another pillar of our vision for improved care: In addition to Treatment and Care in the NICU and Aftercare Services, EFCNI will now be able to focus on the essential subject of Pre-Conceptional and Maternal Care.

The next World Prematurity Day on 17 November is just around the corner and we are firmly convinced that this upcoming awareness day will be again a fascinating and outstanding event. We would like to encourage you once more to join us in this year's multitude of global, European and national activities. You will find more information on the campaign in this issue. We wish you a successful World Prematurity Day and would be glad if you share your events with us!

Enjoy reading about many more interesting topics around prematurity in this newsletter!

With best regards,



Silke Mader
Chairwoman of the Executive Board
EFCNI European Foundation for the Care of Newborn Infants

If you wish to go directly to the section you are interested in, please click below:

[World Prematurity Day 2012 · Awareness Campaigning](#) · [Our Partners in the Spotlight](#) · [About EFCNI](#) · [EFCNI on Congresses and Conferences](#) · [EU/Brussels](#) · [Developmental Care / NIDCAP](#) · [Information / Education / Training](#) · [Mark your Calendar](#) · [Awareness Days](#)

17 NOVEMBER – WORLD PREMATURETY DAY

Many parents organisations, associations, societies, professionals but also many companies and individuals around the globe join us now in celebrating November 17 as World Prematurity Day. A multitude of events and activities will be organised to draw attention to the problems and risks related to prematurity.



SOCKS LINE ACTIVITIES

In the light of last year's success of the manifold socks line activities organised throughout Europe and worldwide to celebrate World Prematurity Day, parents organisations opted to pursue the socks line idea also this year to promote the awareness day in a common campaign.

We would like to encourage you to post your individual socks line photos on the EFCNI and ene, mene, mini. facebook sites. What about also including the baby's first name, week of gestation and weight on the picture?

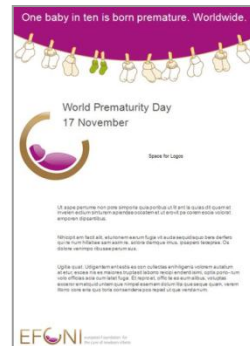
WORLD PREMATURETY DAY POSTER

Following the wish of many, EFCNI furnishes a poster with the socks line and the slogan "one baby in ten is born premature. worldwide." that has been adapted into 26 European languages.

It can be easily localized and used for various activities that will be organised to celebrate World Prematurity Day 2012 on 17 November. We warmly invite you to use the poster and to adapt it with your logo and your individual event accordingly, but please do not include any sponsoring partners or company names. You may download the poster for free in your language: [World Prematurity Day](#)

Furthermore, EFCNI will shortly provide you with a suggestion for a press release in English, hoping that the template will ease your work: you would just have to translate the suggested text into your own language and insert your individual country situation, your activity and information on your organisation.

We are very much looking forward to World Prematurity Day and many successful activities and events! We would of course be delighted if you could share your work with all of us – either by a short mail to EFCNI – or by posting it on the EFCNI / ene, mene, mini. facebook sites.



WORLD PREMATURETY DAY 2012

17 NOVEMBER – WORLD PREMATURETY DAY



CELINE DION SUPPORTS WORLD PREMATURETY DAY 2012

International superstar Celine Dion is lending her support to World Prematurity Day to help raise awareness of the 15 million babies born too soon each year around the world. Click on her photo to see her video.



WORLD PREMATURETY DAY FACEBOOK PAGE

A global social media outreach is aimed at increasing awareness of preterm birth, evoking compassion for preterm babies and a desire to address the problem. To reach people around the globe and create a surge of awareness, we need the support and engagement of all partners.

Actions we will ask people to take include “liking” our shared WPD Facebook page, posting their stories to a global map and commenting on posts in the timeline and adding their own. These interactions with the page, as well as the number of tweets around the issue, are a way we can measure our success.



Please help promoting the World Prematurity Facebook page via your organization’s Facebook page and Twitter account beginning in the middle of October and continuing through November 17. As a rough guideline, consider promoting WPD through your social networks once a week in October and twice a week in November.

Here is the link to the global World Prematurity Day Facebook page: <http://www.facebook.com/worldprematurityday>

GLOBAL ILLUMINATION INITIATIVE

We would also like to advert one more time the Global Illumination Initiative launched by the World Prematurity Network (Global Alliance) which provides an opportunity to collectively show the concern and encourage those concerned by **illuminating landmarks, buildings, monuments etc. in a purple light**. To assist you in this ambitious project, EFCNI developed a "toolkit" containing information, ideas, sample letters and a letter of support from EFCNI and the World Prematurity Network to endorse your project.

For more information on this project and the toolkit please click here: [World Prematurity Day](#)

An inspiring example for an awareness campaign: PRE-MOTHER'S DAY EVENT IN TURKEY

Mothers marched for Premies one week before Mother's Day

In Turkey 75% of infant deaths still occur due to the low rate of accurate neonatal care and the lack of information on the risks of prematurity. In order to generate public awareness about preterm births and the importance of neonatal care and the risk factors of prematurity the Turkish patient association *El Bebek Gül Bebek* organised a Pre-Mother's day event.

According to the tradition, Mother's Day related events are very well perceived and accepted both by the national media and the public. The intention of this event was to design a special day dedicated to premie mothers and name it "Pre-Mother's Day".

Supported by the municipality of Beyoglu, the patient association *El Bebek Gül Bebek* invited premie mothers, parents and families to attend the marching event on May 8, 2012 (one week earlier than Mother's Day). The participants had a short walk holding colorful sign boards and stamping baby footprint stickers on the pavements.

This very successful event was accompanied by an extensive media coverage including a press meeting, interviews on TV and in newspapers, notices on Twitter and Facebook as well as videos on TV.

[If you want to read more on the Pre-Mother's Day Event in Turkey please click here](#)



SAVE THE DATE: 9th PARENTS ORGANISATIONS MEETING

Please mark your calendar: **The next EFCNI parents organisations meeting will take place on 25-27 January 2013 in Munich.** The official invitation and detailed information will follow soon.



EFCNI warmly welcomes the Hungarian parents organisation KORE within the common network and is looking forward to a close collaboration



KORE - HUNGARY

Koraszülöttekért Közhasznú Egyesület Association KORE for Premature Babies

KORE – KORE is a civil and non-profit organization. All members are parents of preterm babies, struggling in this unpredicted situation with all kinds of difficulties. They are volunteers, trying to help other parents with preterm babies.

At the moment KORE bases their work on providing information on their website to parents in need of help and advice. The material is provided in their native language. They can also share their experiences in a form of blog. There is a dynamic online activity among members and interested readers every day.

[Please click here to learn more about KORE](#)



POLAND

Expert Panel on Compulsory Vaccinations of Premature Babies in Poland

Fundacja Wczesniak Rodzice-Rodzicom - On 3 July 2012, the Expert Panel, dedicated to implement compulsory vaccinations of preterm babies, took place on the initiative of the Premature Baby Foundation (Fundacja Wczesniak). The discussion was led by Prof. Maria Katarzyna Borszewska-Kornacka, the President of Polish Neonatal Society and Voivodship Consultant in Neonatology for Mazovian voivodship. Amongst others, the National Consultant in Pediatrics, Neonatology, President of Polish Society of Vaccinology, Voivodship Consultant in Immunology attended the Expert Panel.

Prof. Borszewska-Kornacka drew differences between the compulsory vaccination schedule in Poland and Europe, concerning especially:

- compulsory pneumococcal conjugate vaccinations for all children,
- acellular pertussis vaccinations.

In Poland, there is the National Health Programme for the years 2007-2015, in which the newborn, the prevention of prematurity as well as low birth weight are of priority. However, there is still a lack of complex solutions and effective programmes, even those supporting parents of premature babies. A part of the gap is filled by non-governmental organizations such as the Premature Baby Foundation Parents for Parents (Fundacja Wczesniak Rodzice-Rodzicom).

[Please click here to read more](#)





BELGIUM

Putting Prematurity on the Political Agenda in Belgium

In 2010, the parents organization VVOC put prematurity on the political agenda in Belgium in order to receive full attention to the need of optimal care for preterm infants.

This journey started in early March 2010, when a Prematurity Platform set up by politicians, neonatologists and parent association VVOC organised a political roundtable to discuss issues on prematurity and the recommendations for optimal care with a short and long term perspective. The results of the EU Benchmarking Report *Too Little, Too Late? Why Europe should do more for preterm infants* published at the end of March 2010, have also been leveraged towards multiple stakeholders to underline the crucial need to take action. All these outreach activities resulted in important media visibility and a proposal of a political resolution that was published in October 2010.

In 2011, outreach activities continued mobilizing multiple stakeholders around World Prematurity Day and with the publication of *Caring for Tomorrow - EFCNI White Paper on Maternal and Newborn Health and Aftercare Services* to further built advocacy and mobilize them to stand up for a better care for premature infants. The outreach activities resulted in an increased media visibility on prematurity and its complications.

At the end of March 2012 the political resolution was voted in the Parliament with an unanimous support of all politicians who voted in support of an improved care for preterm infants.

All these activities have been valuable contributions to raise awareness of prematurity and help address the challenges that preterm infants may face throughout their lifetime.

PARENTS GROUPS WORKING IN COALITIONS – TURKEY

PremaTurk: Premature Baby Coalition has been established for premature baby health

For the past few years, there have been great improvements regarding mother and child health in Turkey. However, there is still a need for development and special efforts. Most important issues in newborn health are prematurity and its effects. Prematurity related death is still the most common type of infant death in Turkey.

Considering these facts, in order to raise awareness about preterm birth and contribute to the work that has been done in this field, *PremaTurk: Premature Baby Coalition* has been established.

[Please click here to read the complete text about *PremaTurk: Premature Baby Coalition*](#)



OUR PARTNERS IN THE SPOTLIGHT



mybabywatch

Virtual visiting system for optimizing the parent-child relationship of preterm infants



The number of preterm babies and newborn infants with illnesses in Germany and Europe is continuously rising. The intensive care of these infants limits the possibilities parents have to communicate with their babies. Medically, this leads to bonding problems, in particular between mother and child. Although not yet scientifically validated, it is assumed that this might be a reason for a baby's prolonged stay in hospital.

Although the medical staff encourages parents and family members to visit their child as often as possible in the clinic, the circumstances like long distances or working hours do not always permit to be closer to the baby.

If you want to learn how mybabywatch responds to this problem, please click here:

[mybabywatch - About mybabywatch](#)

WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

The first Spina Bifida and Hydrocephalus day will be celebrated from 23 to 25 October 2012 in the European Parliament in Strasbourg with the participation of IF members from all over the world.

Please click here to learn more on the Awareness Day: [World Spina Bifida Hydrocephalus Day, International Federation for Spina Bifida and Hydrocephalus](#)

If you want to actively join the celebration please contact your national organisations: [Members - IF Spina Bifida Hydrocephalus / Hydrocefalie](#)

EFCNI ESTABLISHES *COMPETENCE CENTRE FOR MATERNAL AND NEWBORN HEALTH*

As already announced in our last newsletter we are very happy that we finally moved into our new offices in Munich which will allow us to strengthen our manpower in order to accomplish our ambitious vision and goals!



EFCNI team (from left to right):
Nicole Thiele, Stephanie Polus, Silke Mader, Gabi Thies

Please note our new address:

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D-81379 München
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fax: +49 (0) 89 89 0 83 26-10

On this occasion we would like to sincerely thank our corporate partners for their trust and confidence in EFCNI and our work which has enabled us to establish the new *EFCNI Competence Centre*. Very special thanks go to *Dräger* for providing an exhibition incubator and *Nestlé* for the coffee machine for our new office.

WELCOME ON BOARD

Stephanie Polus - Project Manager Maternal Health

Stephanie joined EFCNI in September 2012. After her BSc in European Public Health in Maastricht, the Netherlands, she absolved her Master's degree in Public Health at Munich University. She has worked in the field of maternal and newborn health at World Health Organization in Geneva, Switzerland during her studies.





FMF CONGRESS IN KOS, GREECE

EFCNI attended the congress organised by Fetal Medicine Foundation (FMF) end of June 2012: Each year the FMF organises a World Congress in which leading international experts and young researchers present and discuss the latest developments in fetal medicine. The World Congress is designed for those specializing in fetal medicine, for people with a more general clinical interest who want to be updated on developments in the field as well as for all those involved in the care of pregnant women and their babies.

EFCNI is very much looking forward to a closer collaboration with FMF especially in light of EFCNI's further development of competencies in maternal health and prevention.

Please click here to learn more about FMF: [Fetal Medicine](#)



ISSHP WORLD CONGRESS IN GENEVA, SWITZERLAND

In July 2012, EFCNI participated in the XVIII World Congress of the International Society for the Study of Hypertension in Pregnancy (ISSHP). ISSHP brought together top researchers and clinicians in the field of hypertension in pregnancy to share innovations and encourage collaborations in research and clinical practice. EFCNI was particularly impressed by a presentation on preeclampsia and preterm birth held by Prof. Kypros Nicolaides from the Fetal Medicine Foundation, London, who introduced the “inverted pyramid” of prenatal care. He suggests a higher concentration of visits in the beginning of pregnancy where most pregnancy complications can be predicted and thus perinatal care adapted accordingly throughout the pregnancy.

Please click here to learn more about ISSHP: [ISSHP](#)



GNPI/DGKJ CONGRESS IN HAMBURG, GERMANY

In September 2012, the congress of the GNPI (Gesellschaft für Neonatologie und Pädiatrische Intensivmedizin) was held together with the DGKJ (Deutsche Gesellschaft für Kinder- und Jugendmedizin) in Hamburg, where EFCNI participated with an own booth. In the context of a workshop on NICU design, organised by Dräger, Silke Mader presented EFCNI's future work based on *Caring for Tomorrow - the EFCNI White Paper on Maternal and Newborn Health and Aftercare Services* and emphasized the necessity of well-designed NICUs for the health of preterm babies.



An excellent example of optimal care for the preterm infant showed Dr. Erna Hattinger-Jürgenssen in the newly developed parents-baby centre in Salzburg, Austria. Family-centred care, optimal working conditions for the health workers as well as an adequate, preemie-friendly surrounding contribute to the preemie's health and development.

GNPI/DGKJ CONGRESS IN HAMBURG, GERMANY

Interview with Prof. Dieter Wolke: *“Put late preterms more into the focus of attention”*

Dieter Wolke, Professor of Developmental Psychology and Individual Differences at the Department of Psychology and Division of Mental Health & Wellbeing der University of Warwick, UK, states that also late preterm infants (birth at 34 to 36 weeks) may suffer from health problems. As the number of late preterms continually increases, it is necessary to bring this patient group more into focus.

As a member of the Editorial Board, Prof. Wolke was significantly involved in the development of the report *Caring for Tomorrow - the EFCNI White Paper on Maternal and Newborn Health and Aftercare Services*, particularly in key recommendations for aftercare services and follow-up.

Please click here to listen to the interview (in German language):
<http://www.springermedizin.de/wolke-spaete-fruehchen/3287782.html>

WORKING GROUP ON THE QUALITY OF CHILDHOOD AT THE EUROPEAN PARLIAMENT

The Alliance for Childhood invited to the 36th QoC session on 4 September 2012 in the European Parliament in Brussels. This session was hosted by MEP Peter Liese, Co-Chair of the Interest Group on Maternal and Neonatal Health, and attended by further MEPs.

The elected president of ESPR, Prof. Luc Zimmermann from Maastricht, Prof. Dominique Haumont from St. Pierre in Brussels and Silke Mader gave presentations focusing on the following topics:

- Overview of the situation in Europe regarding prematurity and its related challenges
- Special needs of preterm infants and their families
- Main components of a successful strategy to address this challenge

All sessions held by the Working Group on the Quality of Childhood at the European Parliament in 2012 will be published in a yearbook. We will keep you informed.

To learn more about this meeting please click here: [Invitation to the 36th QoC session](#)



PARLIAMENTARY QUESTIONS RELATED TO PREMATURETY

In late May, Irish European Parliamentarian Liam Aylward from the liberal ALDE group submitted two Written Questions to the European Commission on the prevention of preterm births as well as on the need for premature birth aftercare.

The responses, provided by the Commissioner for Health and Consumer Policy, John Dalli, in the cause of July, point out that while the Commission does not hold any competence to adopt EU-wide measures for premature babies, it has supported several research projects on prematurity consequences on the health of the developing child. Projects have also been funded in the area of preterm birth, such as EuroNeoStat. The questions and answers can be read here: [Parliamentary Questions](#)

HEALTH FOR THE EU IN 20 SUCCESS STORIES

This report is published by the European Commission and shows a selection of successful projects funded by EU Health Programmes. Please pay special attention to the article about *EuroNeoStat II – Better care for premature babies* (page 27 in the report).

[Please click here to download the complete report](#)





Long hallways connect pods of 6 babies to private rooms that allow parents to connect with their babies as a family

CINCINNATI CHILDREN'S HOSPITAL RANKED BEST

Linda Lacina / Nidcap Trainer CCHMC - U.S. News & World Report is an American news magazine that in recent years has become particularly well known for its ranking system and annual reports on American colleges and universities, graduate schools, hospitals, businesses, and travel destinations. The latest Best Children's Hospitals rankings of U.S. News identify 80 hospitals that demonstrated expertise in children's medicine. Each year, Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio submits data to be critiqued for the national rating around clinical outcomes, the process of care, and adequacy of care-related indicators of quality such as patient volume, degree of nurse staffing, and availability of specialized programs. This year over 175 pediatric institutions submitted quality related data surveys; in addition, pediatric specialists also provided information about where they would send the sickest children in their specialty to arrive at the rankings.

[If you want to read more on the ranking of CCHM please click here](#)

PREECLAMPSIA AND HEART DISEASE



Preeclampsia is a serious problem for as many as one in twelve women during pregnancy. It generally occurs after the 20th week and is marked by a sudden increase in blood pressure and protein in the urine. Preeclampsia is a leading cause of preterm birth. It must be watched closely as it can threaten the life of both the mother and the baby. Currently, the only effective treatment is delivery, which, if too premature, may lead to serious complications for the baby.

The Preeclampsia Foundation is an empowered community of patients and experts, with a diverse array of resources and support to help you have the best possible pregnancy or to help you navigate the questions you'll have if you don't. They provide unparalleled support and advocacy for the people whose lives have been or will be affected by the condition – mothers, babies, fathers and their families.

For more information on the relation between preeclampsia and future heart disease please click here:
<http://www.preeclampsia.org/images/pdf/heartdiseasebrochure.pdf>

NEW EDITION OF THE GERMAN BROCHURE *PFLEGE & BINDUNG VON FRÜHGEBORENEN*



Following the great success of our German brochure on bonding and care of the preterm infant, *Bindung & Pflege von Frühgeborenen*, we have issued a new edition. So far, the brochure is available only in German, an English version may follow.

Please get in contact with info@efcni.org to order a print version free of charge.
[To download the brochure please click here](#)

PRENATAL SCREENING WEBCAST LECTURE

We would like to invite you to participate in an upcoming webcast lecture on *FMF Risk Algorithm* which is presented by Professor Kypros Nicolaides, Kings College Hospital London and Founder of Fetal Medicine Foundation FMF. The lecture is for health care professionals and laboratory personnel interested in today's leading edge research into improving maternal health care.

Date: 29 October 2012, 10 am (CET)

To learn more about the lecture services on pre-eclampsia-related themes and participate please click here:

<http://web8.perkinelmer.com/?elqPURLPage=7531> or www.perkinelmer.com/pre-eclampsia

NEW NICE QUALITY STANDARD FOR ANTENATAL CARE

The National Institute for Health and Clinical Excellence NICE has launched a new quality standard on the care that should be offered to women during their pregnancy. This new quality standard on antenatal care represents the first component of a suite of maternity quality standards which, along with intrapartum care and postnatal care, will form the core pathway. Other quality standards in development include hypertension in pregnancy, caesarean section and multiple pregnancy.

To read the full text and learn more on the new quality standards please click here: [New NICE quality standard for antenatal care](#)

MEET EFCNI AT CONGRESSES AND CONFERENCES IN 2012

Are you interested in exchanging views or discuss topics with EFCNI?

We would like to invite you to meet us at the following congresses and conferences:

3rd International Congress of UENPS Congress

November 14-17, 2012 – Porto, Portugal

**X. Simposio Internacional Neonatología/
VI Jornadas Enfermería Neonatal**

November 22-24, 2012 – Bilbao, Spain

FMF Course - Advances in Fetal Medicine

December 1-2, 2012 – London, UK

**Epossi: An Optimal European Chronic Care Model:
Towards Implementation and Benchmarking**

December 5, 2012 – Brussels, Belgium

2nd International Symposium on European Research in Neonatology

November 23, 2012 – Tübingen, Germany

Mark your Calendar

Eurochild Annual Conference

„Promoting the Rights of Children in Alternative Care“

October 24-26, 2012 – Sofia, Bulgaria

4th Congenital Cytomegalovirus Conference

October 29-Nov 2, 2012 – San Francisco, USA

Second Global Symposium on Health Systems Research

October 31-Nov 3, 2012 – Beijing, China

Developmental Interventions in Neonatal Care

November 7-10, 2012 – Orlando, USA

2nd International Congress on Neurology and Epidemiology (ICNE)

November 8-10, 2012 – Nice, France

3rd International Congress of UENPS Congress

November 14-17, 2012 – Porto, Portugal

Infant Development in Neonatal Intensive Care – Ireland (IDNIC-I)

November 15, 2012 – Dublin, Ireland

FMF Course - Advances in Fetal Medicine

December 1-2, 2012 – London, UK

Hot Topics in Neonatology Conference

December 3-4, 2012 – USA

Epposi: An Optimal European Chronic Care Model: Towards Implementation and Benchmarking

December 5, 2012 – Brussels, Belgium

2nd Evidence-based neonatology conference

March 13-16, 2013 - Cairo, Egypt

5th EfCCNa Congress

May 23-25, 2013 - Belgrade, Serbia

3rd Global Conference Women Deliver

May 28-30, 2013 – Kuala Lumpur, Malaysia

39th Annual Congress Gesellschaft für Neonatologie und Pädiatrische Intensivmedizin (GNPI)

June 6-8, 2013 – Freiburg, Germany

World Federation of Societies of Critical Care Medicine Congress

Aug 28-Sept 1, 2013 - Durban, South Africa

Neonatal Nursing Conference 2013

September 5-8, 2013 – Belfast, Ireland

20th Anniversary of the International Year of the Family IYF

2014

Awareness Days

- 1-7 October** **World Breastfeeding week**
Alliance for Breastfeeding Action (except for Greece and Canada)
Internet: <http://worldbreastfeedingweek.org/>
- 10 October** **International Day for Mental Health**
World Federation for Mental Health (WFMH)
Mental Health Europe,
Internet: <http://www.mhe-sme.org/>
- 11 October** **World Blindness Day**
WHO, Prevention of Blindness and Deafness
Internet: <http://www.who.int/blindness/en/>
- 25 October** **World Spina Bifida & Hydrocephalus Day**
Internet: <http://www.worldspinabifidahydrocephalusday.com/>
- 14 November** **World Diabetes Day**
International Diabetes Federation (IDF)
Internet: <http://www.worlddiabetesday.org>
- 17 November** **World Prematurity Day**
Internet: <http://www.efcni.org>
- 20 November** **World COPD Day**
Global Initiative for Chronic Obstructive Lung Disease (GOLD)
Internet: www.goldcopd.com
- 10 December** **Human Rights Day**
Internet: <http://www.un.org/en/events/humanrightsday/2011/about.shtml>

Our Thanks

We are extremely grateful to the following for their generous support of our work and the prematurity issue:



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