Dear reader,

in this edition of our newsletter we inform you that we launched the World Prematurity Day (WPD) poster which is available in 31 languages. We are excited that WPD is approaching fast and look forward to this important day. We also welcome a new team member, Anita Beck who joined EFCNI as Executive Secretary in September 2013. Enjoy reading!

Your EFCNI team

Free World Prematurity Day posters in 31 languages

We are delighted to inform you that this year's World Prematurity Day poster is available for free in 31 languages, this year also in Arabic, Chinese, Hebrew, Japanese or Russian amongst many other languages. We warmly invite you to use the poster and adapt it with your logo and your chosen text for your World Prematurity Day activities.

Celine Dion supports World Prematurity Day 2013

International celebrity, Celine Dion lends her voice to support World Prematurity Day around the world. She says: "It makes me sad that each year, 15 million babies are born too soon. All babies deserve time to grow and develop before they are born. It is up to all of us to make this happen."

Click the video link to view the Celine Dion public service announcement about World Prematurity Day and how you can become involved.

Photograph courtesy of Anne Geddes copyright 2013

SOCKS FOR LIFE exhibition at
EU Parliament

The SOCKS FOR LIFE exhibition will take place for a week beginning April 7, 2014 at the European Parliament. We will present the European votes for our "Call of Action" at the same time, which gives us another 5 month to gather as many votes as possible.

SOCKS FOR LIFE is rallying artists

SOCKS FOR LIFE our European art campaign for preterm babies is gaining more and more participants. So far we have gathered 18 contributions by a variety of artists. Be it painters, writers, sculptors, graphic designers or photographers. The background of the SOCKS FOR LIFE artists is also very multi-cultural, ranging from Austrian to British to German to Greek. Find out more about the artists at our blog. We are very thankful to all artists for their wonderful donations.

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EFCNI supports German initiative and petition

Every child must receive the best possible care and treatment to be healthy again as soon as possible. This should not be determined by per-case flat rates and austerity measures. ICH BIN KEINE FALLPAUSCHALE means "I am not a flat rate per case" and is an initiative to better the situation of patients at university children's hospitals in Germany. EFCNI supports the initiative and believes that each preterm and ill-born child has a right to the best possible start in life.

view more (German)
EU Parliament questions Commission
In July MEP Marc Tarabella (S&D) asked the Commission about their position on maternity and neonatal care. He also wanted to know if they were in favour of treating maternity and neonatal care, especially in cases of premature birth, as a public health priority that should be incorporated into European and national public health strategies. Answers to his question were given by Mr Borg on behalf of the Commission at the 13th of August.

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8th International Neonatal Nursing Conference Belfast 2013
Health care professionals in the disciplines of nursing, midwifery, perinatal medicine and allied health from the United Kingdom, Europe, Australasia, Canada and the Americas had the opportunity to learn new knowledge and share experiences at this year's COINN – Council of International Neonatal Nurses conference. EFCNI's conference stand was joined by Mandy Daly of Irish Premature Babies. The theme for the conference was “New Knowledge: New Care” with a focus on research and evidence for practice, and the contribution to delivery of quality care for babies and their families. Silke Mader, EFCNI's Chairwoman was honoured to speak about “the challenge to improve maternal and newborn health in Europe”.

Photograph courtesy of Martin Colton (Infant Grapevine)
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Save the Date - “Newborn Health – a Challenge for Europe”
MEP Mariya Gabriel (EPP) is organising a workshop on “Newborn Health – a challenge for Europe” in cooperation with EFCNI. The workshop will take place on Wednesday, the 13th of November 2013 at the European Parliament. It will bring together a variety of stakeholders ( European parents organisations amongst others) to share experiences and best practices on newborn infants health, in particular preterm born infants, in Europe. Further, there will be discussions about new developments in education and training in maternal and newborn health. This is an open event for everyone to freely attend but registration is required for access to the European Parliament. For more details contact us by the 28.10.2013.

Handbook for parents of preterm babies by Fundacja Wczesniak Rodzice-Rodzicom
Fundacja Wczesniak Rodzice-Rodzicom, the Polish prematurity foundation, launched the first edition of their handbook

“Niezbednika rodzica wczesniaka” which offers information to parents of preterm children. The handbook is the result of 10 years of work by the foundation and aims to prepare parents to care for their preterm baby. As for now, 2500 handbooks have been distributed to 75 facilities, hospitals and parents’ groups amongst them. The goal of the handbook is to present the most important sources of information for the parents of premature babies. The brochure has been prepared by experts whose knowledge and experience will help parents in their daily care of their preterm children.

view more (Polish)

Ilitominon's participation in congresses
Ilitominon participated in the 25th Panhellenic Conference in Ithaca (29.08. - 01.09.2013), invited by the Greek Society of Social Pediatrics and Health Promotion (E.E.K.P.P.Y.). The title of their presentation was “The role of parents’ organizations in the development of health policies for premature infants on national and European level”. They looked back on all EFCNI’s actions from its founding up to date, as well as the actions of Ilitominon. Further they pointed out the importance of collaborations for achieving their set goals.

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Welcome: Bundesverband Bunter Kreis e.V.
We warmly welcome our new partner, the Bundesverband Bunter Kreis e.V. which incorporates around 80 aftercare facilities. These establishments are distributed all over Germany to support families with seriously and chronically ill children after their hospital stays. Affected families receive practical support via nurses specialised in follow-up care in order to support the successful reintegration of the sick child, the siblings and the whole family in everyday life.

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Welcome: The European Lung Foundation (ELF)
We warmly welcome our new partner The European Lung Foundation (ELF) which was founded by the European Respiratory Society (ERS); the world’s leading medical
organisation for respiratory experts. ELF, together with EFCNI and national parents organisations, developed Factsheets about preterm birth and the lungs which you can download in 9 languages in our position paper and faction section.

Welcome: IPOPI
The International Patient Organisation for Primary Immunodeficiencies (IPOPI), is the Association of national patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for primary immunodeficiency (PID) patients worldwide. We welcome them as new partner organisation. Their "First International Primary Immunodeficiencies Congress (IPIC) – Focus on clinical care and diagnosis" will take part from November 7-8, 2013 in Estoril (Lisbon), Portugal.

Welcome: Prof. Dominique Haumont
Dr. Dominique Haumont is Professor and Chairman of the Neonatal Unit at Saint-Pierre University Hospital in Brussels, Belgium since 1985. She has focused her efforts in the transformation of traditional neonatal units towards developmentally oriented family centered care units. Pain and stress management, protection of sleep, monitoring light and noise, careful handling and positioning, skin-to-skin, breastfeeding, and most importantly restoration of the mother-infant dyad are essential elements of neonatal care and markers of respect for the baby. She pioneered this evolution by implementing a NIDCAP training center in Brussels. We are welcoming her as the newest member to our Scientific Board.

Respiratory Syncytial Virus (RSV) - more than just a cold
RSV-season has started. Outbreaks of RSV infection tend to occur more frequently during the colder months of a year. Everyone is at risk of contracting RSV which affects almost every child and most will have been infected with the virus by the age of two. It can be very dangerous for preterm children though and have devastating outcomes. Find out more about RSV and how to lower the risk for preterm children.
News by The European Medicines Agency

The European Medicines Agency’s Pharmacovigilance Risk Assessment Committee (PRAC) has recommended suspending the marketing authorisation of the intravenous (into a vein) nutrition preparation Numeta G13%E because of a risk of hypermagnesaemia (high blood levels of magnesium).

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The European Medicines Agency has started a review of bromocriptine–containing medicines when taken by mouth for preventing or suppressing lactation (milk production) in women following childbirth.

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The European Medicines Agency has started a review of medicines called ‘short-acting beta-agonists’, to assess their safety and effectiveness when used to suppress premature labour.

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Continuing care and aftercare services still not available to all

Silke Mader, Chairwoman of EFCNI was speaking at a German conference about the long-term effects of missing family support and the lack of follow-up medical assistance after the discharge from pediatrician and neonatal units. Over 200 different healthcare professional experts discussed the need of long-term support and continuing healthcare for children of families with diabetes, cystic fibrosis, burns, heart and neurological diseases as well as preterm infants.

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Study: Mothers want to know - Preeclampsia

The majority of women prefer to know, if they have a risk of developing preeclampsia or not - even if a test is not 100% accurate. Preeclampsia is a common but severe pregnancy complication occurring in about 2 of 100 pregnant women, which threatens the health of the mother as well as of the unborn baby. The US Preeclampsia Foundation discovered these findings in a survey, asking about 1000 women- with a history of preeclampsia and without- about their opinion to better understand patient preferences around the need for screening (or prediction) tests.

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Study: Overweight women should lose weight before pregnancy

Maternal overweight and obesity is associated with an increased risk of premature death from cardiovascular events in their children. A study by Reynolds et al. published in August 2013 in the British Medical Journal included 28,540 women whose body mass index (BMI) was recorded at their first antenatal visit and their 37,709 adult children in the Aberdeen Maternity and Neonatal databank. The researchers looked at death and hospital admissions for cardiovascular events from 1950 up to 1 January 2012 in the offspring aged 34-61 years. They found an increased risk of premature death in the adult offspring of obese mothers.

Mark your calendar

Meet EFCNI at congresses and conferences in 2013
Outlook on congresses and conferences in 2013
Awareness days

Special thanks to our corporate partners for their kind support:

abbvie  Dräger  Nestlé
Start Healthy  Stay Healthy  PerkinElmer

We help to make breastfeeding easy

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