NEWSLETTER



Dear all,

With today's edition of our Newsletter, we hope to provide you again with many interesting news and information on ongoing projects in the field of maternal and neonatal health in Europe. Amongst others, you will find a summary of our last parents' organisations meeting, reports from the countries, main actions in and around Brussels as well as an update on our planning for the World Prematurity Day this coming November.

We hope you will enjoy reading what we have put together for you.

Wishing you all a nice summer season and relaxing holidays!

Yours sincerely,

Sille Roles

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:

<u>News from the Countries</u> . <u>EFCNI Personnel</u> . <u>Developmental Care</u> . <u>Europe</u>

World Prematurity Day 2011 . Mark your Calendar . Acknowledgement



NEWS FROM THE COUNTRIES

1st EFCNI Parents' Advisory Board Meeting held in Eching, Germany



Hans Schmidtner, Vilni Verner Holst Bloch, Petra Becker, Gert van Steenbrugge, Jacob Amholt, Nicole Thiele, Mónica Virchez, Yannic Verhaest, Lenka Novotna and Silke Mader in front of the Medela premises in Eching

Eching, March 25, 2011- This day was a special moment for EFCNI: for the first time, the Parents' Advisory Board met for discussion.

On this occasion, we would like to sincerely thank MEDELA Medizintechnik, especially Mr Hans Schmidtner, Managing Director, for kindly providing us with the meeting room facilities on their premises and the very warm welcome we received during that day.

We would like to thank all members of the Parents Advisory Board for their time, support and valuable advice! We are confident that together and with such strong support, we will achieve many things in the future.

6th European Parents' Organisations Meeting in Freising, Germany



Parents' organisations representatives in Freising

Freising, May 20 – 22, 2011 - Parents' associations from more than twenty different nations across Europe followed EFCNI's invitation to the 6th European Parents' Organisations Meeting, held on the weekend of 20-22 May 2011 near Munich, Germany.



NEWS FROM THE COUNTRIES

Czech Republic - BabyKlokánci published book in April 2011

by Ivana Antalová, BabyKloánci



The child belongs to his/her mother – healthy or ill – alive or not - the child belongs to his/ her parents

It is the first Czech publication on the early development of bonding between mother and child. The book is written in the form of an open conversation between three authors: a clinical psychologist, a mother of a preterm baby and a writer and columnist.

Click here to read more

Czech Republic - Opening of first complex aftercare centre in Prague

By Lenka Novotna, Nedoklubko os



Beginning of April, the first centre for complex aftercare for preterm infants opened its doors in Prague. It is the first centre of ist kind in the Czech Republic, gathering all specialists under one roof. Parents very much welcome the opening of this centre as it avoids travelling and stress to many families. Nedoklubko cooperates with this centre and is planning common activities in the future.

Click here to read more (in Czech)

France - First « Preemies' Parents' Feelings Awareness Day » in Paris

By Sophie Barniaud, SOS Préma



May 12, 2011 – The first "Preemies Parents' Feelings Awareness Day" (*journée de sensibilisation aux vécus des parents d'enfants prématurés*) organised by SOS Préma was a total success: 320 health professionals from all over France attended the event.



NEWS FROM THE COUNTRIES

Germany - Perinatal Center & Div. Neonatology Ludwig-Maximilian-University Munich

By PD Dr. Andreas Flemmer, University Hospital, Perinatal Center, Ludwig-Maximilian-University Munich, Grosshadern



March 16, 2011 - The all new delivery room and prenatal diagnostic clinic opened at the University Hospital, Perinatal Center, Ludwig-Maximilian-University Munich, Grosshadern, Germany.

The Perinatal Center of the Munich University is amongst the largest centers in Germany and Europe and is renown as one of the leading centers for the treatment of high risk mothers and infants born both term and preterm.

Click here to read more

Poland - Advertising campaign

Fundacja Wcześniak Rodzice-Rodzicom



The third and last part of the national-wide advertising and awareness campaign called "Preemies. A matter of great importance." to raise funds for a national preemie centre has been published.

Click on the pictures below to watch the spots:







For more information (in Polish) on the campaign and the "making off" please visit <u>http://www.wczesniak.pl/</u>

Sweden - Inauguration of Europe's most modern NICU with symposium

by Stephanie Blenckner, Föräldraföreningen för prematurfödda barn



On 12 May, the Swedish Karolinska Perinatal Medicine held a Symposium in Stockholm to celebrate the inauguration of the Karolinska University Hospital's most recent neonatal intensive care unit.



EFCNI - Personnel

Additional expertise and support in the EFCNI Scientific Board



We feel very honoured that Prof. Dr. Bo Jacobsson joined the EFCNI Scientific Board:

Bo Jacobsson received his Medical Degree at Sahlgrenska Academy in Gothenburg, Sweden in 1991. He specialised in obstetrics and maternal/foetal medicine and got his PhD at Gothenburg University, Sweden in 2003. Subsequently 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 Director of the Perinatal Research Laboratory at Sahlgrenska University Hospital in Gothenburg where he also conducts his clinical obstetrical practice. He is also associated to Norwegian Institute of Public Health. Prof. Jacobsson's laboratory is studying basic and applied aspects of the mechanisms of preterm delivery. Another area that has attracted his interest is genetic components of the timing of delivery and also the interplay between genes and the environment. One of his main interest currently is the possibility of preventing preterm delivery through intervention with dietary products, e.g. probiotics. The main research aim is to identify and apply different strategies to prevent preterm delivery with the purpose to deliver healthy, full-term infants.

At his lab he is responsible for training researchers from different parts of Europe and Africa.

Time for goodbye



Due to private reasons, Petra Becker decided to leave EFCNI at the end of July. With her, EFCNI looses a very engaded and cordial team-member. Please join us in wishing her all the best for her future!

"Much to my regret I leave EFCNI at the end of July 2011. Private circumstances forced me to take this sad decision. I would like to take this opportunity to thank you for the professional cooperation and support during the last months. It was a pleasure for me to work with you. At this point, I would also like to thank my colleagues Silke, Nicole and Matthias for their good cooperation. We were a great team. I wish you all and EFCNI good luck and all the best for the future."- PETRA BECKER, Business Unit Manager European Patient Organisations



DEVELOPMENTAL CARE/ NIDCAP

Opening of the 6th NIDCAP Training Centre in Denmark

By Hanne Aagaard, Department of Paediatrics Aarhus Universitet



Eva Jorgensen (middle), Jonna Flojgaard Nieolsen and Rikke Schou-Hansen, certified as NIDCAP Professionals

The Neonatal Intensive Care Unit (NICU) in Aarhus University Hospital, Skejby has been generally accepted of NIDCAP Federation international (NFi) to launch the process building up and developing a NIDCAP Traning Center.

Click here to read more

Awareness spots on Developmental Care



From our last newsletter, you certainly remember the four spots produced by Prof. Dr. Dominique Haumont, CHU St-Pierre, Brussels, to create awareness for Developmental Care.

These spots now available in English, show very sensitively the preterm issue from four different perspectives– the baby, the parents, the nurse and the doctor.

We warmly thank Prof. Dr. Haumont for her engagement and for allowing us to share the spots with you.

We encourage you to take the time and watch these spots. Just click on the titles below to open the videos:

The Doctor

<u>The Baby</u>

The Parents The Nurse



EUROPE

EFCNI generates awareness for the risk of chronic respiratory diseases in preterm infants

Preterm children are particularly prone to suffer from chronic lung diseases. To generate more awareness for this important issue, EFCNI Chairwoman Silke Mader met with the European Respiratory Society (ERS) in June to discuss areas of interest and potential collaboration. ERS is a professional, medical organisation to promote and improve lung health in Europe through research, education and advocacy.

In September, EFCNI will attend the launch event for the *European Respiratory Roadmap*. The ERS Roadmap outlines health priorities in the respiratory field for the next decade, in particular, the future needs in prevention strategies, clinical care, the major research challenges, patient empowerment, and the need for excellent education and training. Also thanks to the strong commitment of Prof. Mario Rüdiger, University Hospital Dresden and Prof. Christian Poets, University Hospital Tuebingen, prematurity as risk for respiratory diseases will be included in the report.

More information will be available in our next newsletter.

CaPaNi AWARD - A status report

By Prof. Dr. Mario Rüdiger, Carl Gustav Carus University Clinic, Dreseden



Fifty per cent of extremely preterm infants suffer from chronic lung disease. This disorder, which causes chronic modifications in the lungs, is a serious problem among preterm infants which persists into adulthood.

The 2009 CaPaNi research award went to Prof. Dr. Mario Rüdiger at the Neonatology/Pediatric Intensive Medicine department at the Carl Gustav Carus University Clinic in Dresden, where Prof. Rüdiger and his team conduct research into preventive measures and treatments against this chronic disease.

Click here for a current status of the research project



EFCNI attends Annual PREBIC Workshop in Geneva

Geneva, April 27-29, 2011 - EFCNI attended this year's annual workshop of PREBIC (The International PREterm BIrth Collaborative) in Geneva.

PREBIC is an international collaborative strongly supported by WHO and international organisations such March of Dimes, USA, to support and enhance international networking among researchers in preterm birth and the establishment of multinational research projects on preterm birth to improve pregnancy and birth outcomes and optimize infant health and long-term development.

Click here to read more

EFCNI presents European challenges of preterm birth to Members of the European Parliament



Strasbourg, May 11, 2011 - The interest group on maternal and neonatal health meets in the European Parliament

The first interest group meeting on maternal and neonatal health in the European Parliament in Strasbourg on 11 May 2011 received overwhelming support. The interest group was recently founded by Dr. Angelika Niebler together with her parliamentary colleague and paediatrician, Dr. Peter Liese. Meanwhile, the group counts about 30 Members of Parliament.

Dr. Peter Liese and Dr. Angelika Niebler



EUROPE

EFCNI endorses the second report on the prevention of Neural Tube Defects



Lars Joensson, Silke Mader, Yann Le Cam, Paula Duarte Gaspar, Pierre Mertens, Denhard de Smit, Edite Estrela, Rhonda Curran

Brussels, June 29, 2011 - The second report on the prevention of Neural Tube Defects (NTDs), entitled Act against Europe's most common birth defects: one year on. Defining Neural Tube Defect prevention strategies in Europe and endorsed by EFCNI, was launched at an event which took place in Brussels under the auspices of the Hungarian EU Presidency.

Click here to read more

EFCNI liaises with active and healthy aging

"Active and healthy aging" will be the leading topic for Europe in 2012 and will remain in the focus over the next few years. According to EFCNI, healthy aging is a journey and a process that begins with a healthy pregnancy and birth.

Therefore, EFCNI responded to the consultation on the pilot European Innovation Partnership on Active and Healthy Ageing earlier this year and met with the European Commission to discuss recommendations for improvements in maternal and neonatal care.

End of June 2011, EFCNI first met with the AGE Platform in Brussels to discuss possible future fields of collaboration.

Visit the website of the Commission for more information on the Pilot Partnership and to download the report of the public consultation: <u>"Pilot European Innovation Partnership on Active and Healthy Ageing"</u>

EFCNI supports the European Charter of Health Equity

EFCNI officially signed the EPHA European Charter for Health Equity aiming at drawing public 's attention to the health inequalities that persist in European countries.

In April 2011, EPHA (European Public Health Alliance) organised its annual conference in Brussels. During the event, the European Charter for Health Equity was presented to the Health and Consumers Commissioner John Dalli.

For more information about the Charter, please refer to EPHA's website: http://www.epha.org/a/4368

To sign the Charter by registering on-line: <u>http://my.epha.org/civicrm/event/register?reset=1&id=50</u>



World Prematurity Day 2011

Continents unite to celebrate the first World Prematurity Awareness Day



For the first time ever, 17 November 2011 will be celebrated as World Prematurity Day .

To set a signal for this important day, the partner organisations from different continents -Little Big Souls (Africa), National Premmie Foundation (Australia), EFCNI (Europe) and March of Dimes (USA) - work together on global projects. A common global logo was developed and a facebook fan page called "World Prematurity Day" is being created. The page will be ready by autumn and will give many many interesting information and news.

Please join the Global Alliance in support of World Prematurity Day.

EFCNI launches pin as official European prematurity symbol



On time for the World Prematurity Day, EFCNI launches the *Care Icon* as official European symbol for

Prevention of preterm birth and birth defects

Best possible care and treatment in the NICU

·Best possible care and treatment after discharge

The pin is meant to accompany national symbols to demonstrate the united European voice in the fight for healthy birth:

Wearing the pin should demonstrate that the owner cares for neonatal and also maternal health and is part of a group in our society that cares:

"I care" = "you care"= "we care".

The pin is available in silver and gold and can be ordered as of now. Feel free to contact EFCNI (<u>info@efcni.org</u>) for more details.



World Prematurity Day 2011

European awareness campaign



The European campaign "ene, mene, mini. one baby in ten is born premature. worldwide." is taking shape. A European community website is currently developed: General information on prematurity will be given in English and German. In addition, an option for voting in favour of improving maternal and neonatal health will be available in all European languages.

Following the first World Prematurity Day, a European *Call to Action* will unite policymakers, parents and healthcare providers with the common aim to call for concrete action to be taken at national level to increase Maternal & Neonatal Health and Aftercare standards across Europe. To underline and explain the Call to Action, a *European White Paper on Raising Standards of Maternal & Neonatal Health and Aftercare* will be presented to EU politicians.

National awareness events with "ene, mene, mini" and "socks campaign"



Clothesline at Dräger booth, GNPI congress



Klára Csirková, Nedoklubko

The national parents' associations all over Europe are getting ready for a very busy autumn and have started collecting socks. Some first awareness events take already place – for example:

In Germany, the first clothesline with socks attracted attention at the Dräger booth during the German GNPI congress in Mannheim last May.

In June, the Czech organisation Nedoklubko set a Guinness world record with 181 socks and a 20 meters line. They will try to beat their own world record this coming September. Please join us in wishing them good luck! Click here to read more (in Czech)

If you are interested in joining the national events or would like to organize an event yourself, please do not hesitate to contact us at <u>info@efcni.org</u>



Mark your Calendar - 2011

8th Congress on Women's Health & Disease Second Signa Vitae® International Conference in Pediatric / Neonatal Intensive Care and Anesthesiology

Neonatal Nutrition and Gastroenterology

Neonatal Nutrition and Gastroenterology

Birth - Clinical Challenges in Labor and Delivery

Baby Friendly Neonatal Care Conference and Workshop

Pediatric Cardiology

10th World Congress International Association Maternal and Neonatal Health

PICS Europe 2011

WOFAPS Area Meeting

Neonatal Neurology

WOFAPS Area Meeting "Updates in Pediatric Surgery: Controversies and Advances"

5th International Conference on Birth Defects and Disabilities in the Developing World

9th International Scientific Meeting of the Royal College of Obstetricians and Gynaecologists September 1-3 - Island of Kos

September 2nd, 2011 Split, Croatia

September 8 - 10, 2011 - Bangalore, India

September 8 - 10, 2011 - Bangalore, India

September 9 - 11th 2011, Chicago, USA

September 14 - 16, 2011 Uppsala, Sweden

September 15 - 17, 2011 - La Spezia, Italy

September 18 - 20, 2011 - Rome, Italy

September 21 - 23, 2011 Cambridge, England

September 22 - 25, 2011, Tuzla, Bosnia-Herzegovina

September 22 - 24, 2011 - Kuala Lumpur, Malaysia

September 22 - 25 - Hotel Tuzla, Bosnia-Herzogovina

September 24 - 27, 2011 Lodz, Poland

Sept. 27 - 30 - Athens, Greece



24th ESICM LIVES Annual Congress
VI recent Advances in Neonatal Medicine
Nutrition and Gastroenterology of the Newborn
52nd Annual Meeting of the European Society for Paediatric Research
International Forum on Pediatric Pain
ERC 2011
Update on clinical management of sepsis
Advances in Fetal Imaging
22nd ESPNIC Medical & Nursing Annual Congress
Nutrition and Gastroenterology of the Newborn
7th World Congress of the World Society for Pediatric Infectious Diseases
4th Asia Pacific Congress on Controversies in Obstetrics Gynecology and Infertility (COGI)
DIVI 2011 - 11th Congress Deutsche Interdisziplinäre Vereinigung Intensivmedizin und Notfallmedizin
25. Deutsche Kongress für Perinatale Medizin

October 1-5, 2011 - Berlin, Germany

October, 2-4th, 2011 - Würzburg, Germany

October 9 - 11, 2011 - Sorrento, Italy

October 14-17, 2011 Newcastle, U.K.

October 13-16th, 2011 White Point, Canada

October 14-15, 2011 Malta, Portugal

October 28 - 30, 2011 - Cape Town, South Africa

October 28-29th, 2011 - Paris, France

November 2-5, 2011 - Hannover, Germany

November 4 - 6, 2011 - Athens, Greece

November 16-19, 2011 - Melburne, Australia

November 24-27 - Bangkog, Thailand

November 30 - December. 3rd - Leipzig, Portugal

December 1-3, 2011 Berlin, Germany



Our Thanks

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





Dräger





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