



World Preeclampsia Day A patients view

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30 March 2019





World Preeclampsia Day A patients view

- 1. A patients view on preeclampsia
- 2. Combining forces to raise awareness and improve care
- 3. World Preeclampsia Day join the campaign



- Never even heard about a condition called pre-eclampsia
- Several pre-eclampsia risk factors, like first pregnancy, having protein in the urine and carrying twins
- 24 week: high blood pressure and feeling serious ill pre-eclampsia was diagnosed, but far too late!!!





Too early, too small – but why?





\* Pictures are not shown for privacy reasons

That is not what we expected!





\* Picture is not shown for privacy reasons

### The parents' vision: Family life with a healthy baby and child









### Dreams falling apart: Unfamiliar environment, insecure future, mixed feelings





# Going home after four month in the hospital





\* Picture is not shown for privacy reasons





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Parents and healthcare professionals - two different planets?



Healthcare professionals



Parents/Patients



# EFCNI – a strong network for maternal and newborn health

- First pan-European organisation to represent the interests of preterm and ill newborn infants and their families
- Combine forces of parents, healthcare experts, scientists → reducing preterm birth rates and improving outcomes

- Fields of activities
  - Preconception and maternal care
  - Treatment and care
  - Continuing care



- >100 national parent / patient organisations worldwide
- >20 global healthcare societies
- >30 European healthcare societies
- >80 national healthcare societies

- Supranational organisations (WHO, ...)
- European institutions (EU parliament, commission, EMA,...)
- G7 preparation-meetings



global alliance for newborn care

GLANCE is the first global network to represent the interests of babies born too soon, too small or too sick and their families. Initiated and coordinated under the umbrella of EFCNI, GLANCE aims at including parents, from all parts of the world to exchange knowledge and experience. GLANCE aspires to decrease the burden of afflicted families and their preterm and sick newborns to help them thrive beyond survival.



Achieved milestones in improving maternal and newborn health – paving the way for newborn health standards



2013 +

6

- Official kick-off on the 7<sup>th</sup> of April 2014 in the EU parliament in Brussels
- Symbolic signing of the cooperation and participation in the project of politicians, presidents of various societies and parent representatives







# 220 experts from 31 countries develop 96 standards



### Development process of the standards – a five years journey



# Presentation of the standards at the EU parliament in Brussels – November 2018

 Evening event in the Bavarian representation





• Afternoon session in the European Parliament









# Why is this project so unique?

- Initiated by patient (parent) representatives for patients
- Parents are involved in every step of the development process
- About 220 experts from more than 30 countries developed the standards
- Supported by more than 150 professional healthcare societies and parent/patient organisations
- Covers the complexity of neonatal care
- Promotes the equitable and high levels of care
- Highlighted and recommended twice in The Lancet editorial as best practice example

Editorial Putting the family at the centre of newborn health @ The article of a resolution is a highly articipated expansion. comprehensive plan that includes fadored extraction But for furniles with preferre and if haloss, the associated I training, and employing psychosocial suggest for parents health challenges and psychological burden cast make the American of the induct's neurological status, regelies, occasion autombilions. Each year in Europe, an estimated in motor, and language development, as well as requiratory 520 000 tables-mughly 50% of all livelerthe-are form cardiometabolic; and other health concurrent should be hofuse 37 weeks of gestation. Although much progress included in continuing care. Such keep turns follow op has been made to improve survival and outcomes in the in assertial to stuble early identification of any concern past 40 years, prevealure birth remains a major cause of and capid intervention, us that these shifteen under 5 mortality and likelong murkiplities. Reportfable, continue to theire at a bool age and beyond the highly variable quality of maternal and infant care in Although these recommendations are already Europe means that yaid outcome disparition used both . Institue practice in some countries, the establishment of hotecom and within countries. a harmonized act of standards represents an important Published on Nov 28, the European Standards of Case step towards agaitable outcomes for previature and it for Newborn Health aim to define and harmonise "the -infants arous Europe. Each standard is broken down care and teatment that shall be provided by a resoratal into components. For parents and families, healthservice". Recognizing that improving resolution health is a case professionals, secondal units, hospitals, and truly collaborative effort, the project was conceptualised. Insith services-examplifying the concept that close and confinated by the parent organisation foregoan - indaheration at all levels of the builth waters is manchal. Foundation for the Care of Newborn Infants, which - Evidence-based dirical practice reach to be implemented torought together around 220 seperts across disciplines with the infant and their family in mund, suspecting that from 12 countries to work with patient representatives. Such family fundifierent mode and reasons relevidualised The resulting standards cover 11 key topics-starting from support to achieve the best outcome for their child. antenatal and periodal care, to transition to home, efficial Importantly, although some micorreventations require distinct making pulliative cars, and long-term follow-up: substantial investments, initial steps are proposed an At the heart of the standards is infant and bandy. that increadate actions can be taken. Some simple steps central developmental care. While detailed clinical include patting up a hilding screen to guaranties privacy, pullance is given on relevant more such as preventing - candidly explaining medical conditions and management bouchup-involuty deplacia and early-renet recentul plane to patents, and previding information about repair, a large proportion is denied to empowering analable professional and peer-to-peer support anvices parents in failing up their roles as primary caregover. We call on national health systems to evolve them When given individualised appart, percent participation pertainin in light of these standards, sherify priority areas in daly care procedures in the recentral informing. For Juries, and establish strategies for implementation care unit (NOI) with an rappy charges, hathing. To monitor progress and urbanic accountability, char and weighing can induce drive, minutes care-giving indicators for meeting the databash have been proposed, competency, and strengthen parent-study handling. The atthcaspic hallenger, remain in the automatic infliction of standards also advocate 24.16 access for passwite to the data-that can be compared across countries. MCD and meanmound possibility of a suggestive strengy Decades of research have refined our brandeds environment that minimum exposure to excessive light, of respectation health, and improved survival of preterm econe, and other strends) stored. Where pairold medical and if infants, it is now time to translate the ovideres proceedings are receasely, parents are encouraged to into the last goality of care for patients and they neograss that faily's decomfort signals and to provide families, so matter where they live. And it all starts with non-analysis pain wind-free anarops, by breatfinding impacting the rights and dignity of the infant and their and having skin-tz-skin contact with the infant. family, and recognizing these only weeks as a pivotal To ensure continuity of care after inspiral discharge, stage in the pathway from field. He to adulticed the standards reconversed prevaiing families with a II The Locat Child & Indefector (Instit



https://newborn-health-standards.org/



#### Make an impact – foster a change of mind, planned next steps





# World Prematurity Day: global advocacy

- EFCNI is founder of World Prematurity Day and leader of the global planning group
- About 40 members including WHO, Save the Children, UN/Every Woman Every Child, March of Dimes, UNICEF are joining forces on this day and message
- To maximise outreach and strengthen impact, the group orchestrates its activities under a common motto
- In the future, GLANCE will be the platform for global World Prematurity Day activities





# Highlights of World Prematurity Day 2018:





### World Prematurity Day 2018: Selection of events







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# Raising awareness and providing information on preeclampsia

- Factsheet on pre-eclampsia: easy-to-understand information on causes and risk factors, symptoms, HELLP syndrome, screening, prevention, diagnosis
- Translated into 9 languages
- Supported by parent organisations and KOLs





# Social media awareness campaign on preeclampsia 2018

- International social media awareness campaign • for World Preeclampsia Month – May 2018
- Several thousand reaches and impressions
- Peak on Preeclampsia Awareness Day (22 May)  ${}^{\bullet}$
- Healthcare experts and patients were involved •
- Using several languages for the campaign  ${}^{\bullet}$





"Ich war sehr froh, dass mein behandelnder Arzt dieses Screening empfohlen hat. Es verlief völlig reibungslos und fühlte sich wie eine ganz normale Untersuchung an."



### Joining forces for World Preeclampsia Day campaign 2019

- Raising awareness on preeclampsia and the need of early screening: act early! screen early!
- Videos and written statements of healthcare experts and affected mothers
- Support of key European healthcare professional societies







#### Join us in our worldwide social media campaign: act early - screen early





See you during the coffee or lunch break and make your "act earlyscreen early" campaign photo. Thanks for joining!!!















Thank you for your attention!

EFCNI European Foundation for the Care of Newborn Infants

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