



World Preeclampsia Day

A patients view



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

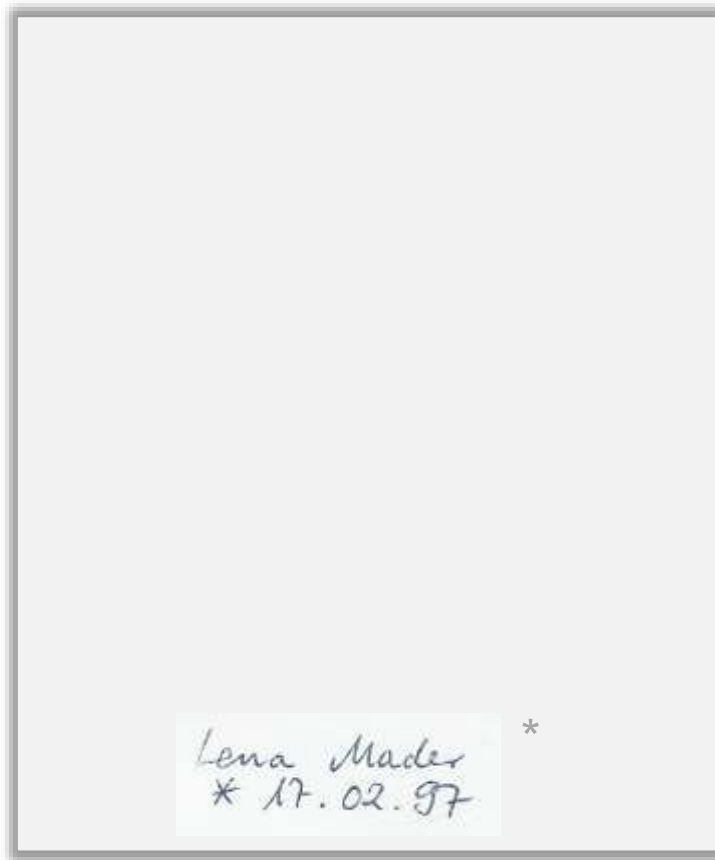


Twin pregnancy and HELLP Syndrom

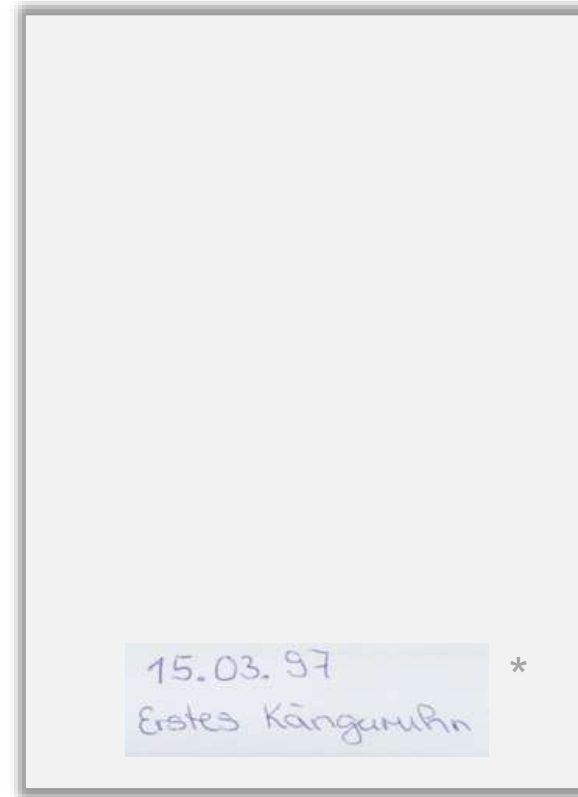
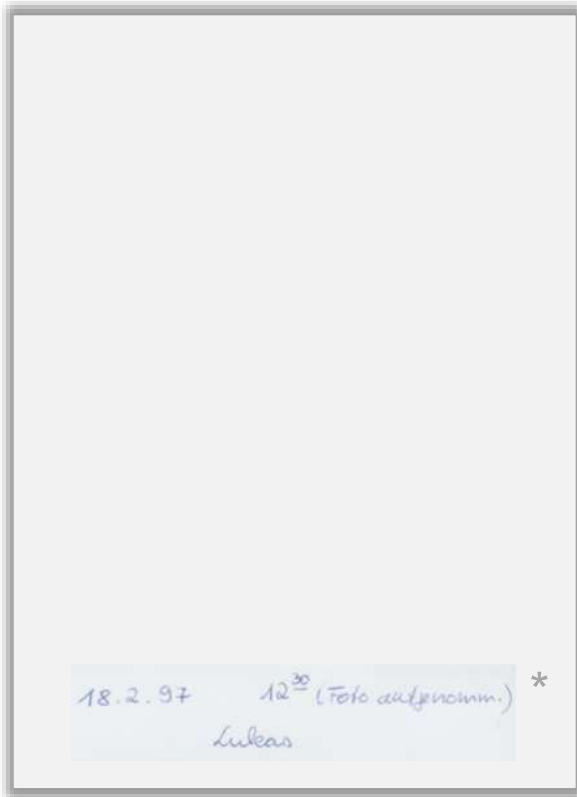
- Never even heard about a condition called pre-eclampsia
- Several pre-eclampsia risk factors, like first pregnancy, having protein in the urine and carrying twins
- 24 week: high blood pressure and feeling serious ill - pre-eclampsia was diagnosed, but far too late!!!



Too early, too small – but why?



That is not what we expected!



* Picture is not shown for privacy reasons

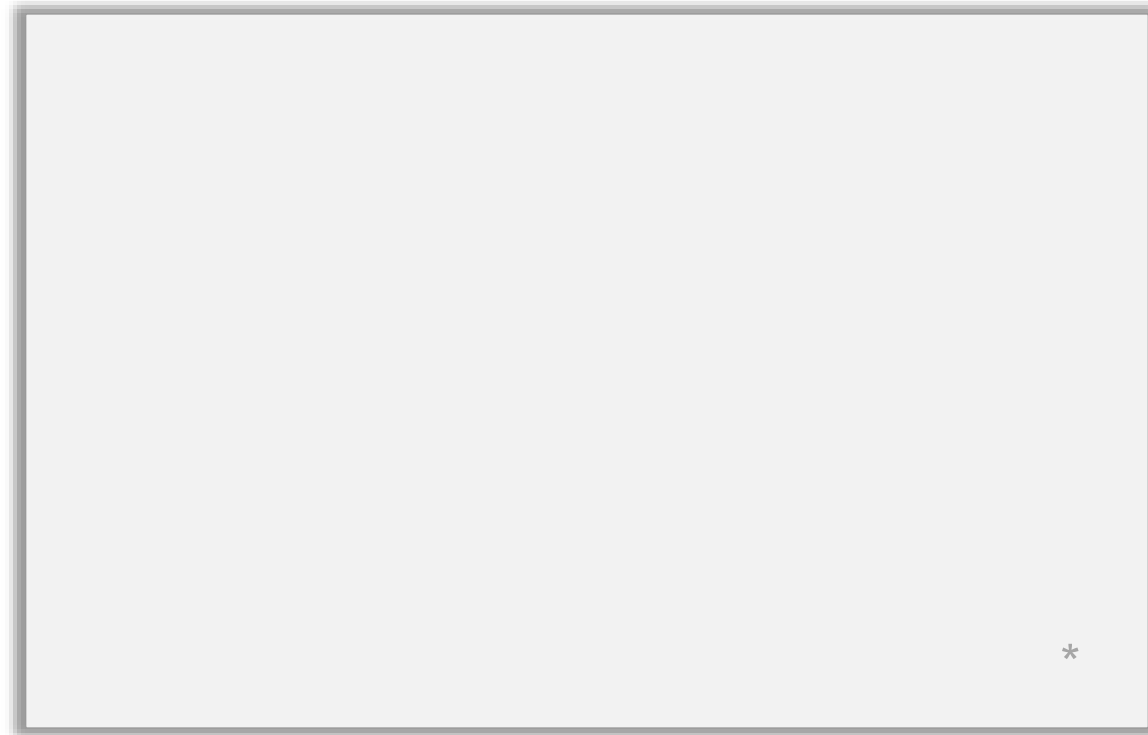
The parents' vision: Family life with a healthy baby and child



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



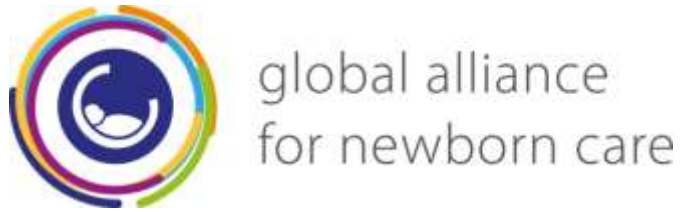
- Fields of activities
 - Preconception and maternal care
 - Treatment and care
 - Continuing care

A strong partnership with...

- | | |
|--|---|
| <ul style="list-style-type: none">• >100 national parent / patient organisations worldwide• >20 global healthcare societies• >30 European healthcare societies• >80 national healthcare societies | <ul style="list-style-type: none">• Supranational organisations (WHO, ...)• European institutions (EU parliament, commission, EMA,...)• G7 preparation-meetings |
|--|---|



Global Alliance for Newborn Care - GLANCE



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.





European Federation
of
Management
Development
Centres



Dr. M. Shafiqul Kabir, President, Bangladesh Medical Association
 (left) with Dr. Md. Shafiqul Kabir, President, Bangladesh Medical Association

Introduction

EFMD acknowledges the long-term thesis with strategies of demands: "One strategy for the patient's sake."

The 10th European Federation for the First of November 2010 (EFMD) has announced that its European Federation will be a strategic and effective for the first time - a strategic and effective for the first time.

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Catalogue of 10 demands for preterm infants

European Foundation
for the Study of
Advanced Nutrition

EU BENCHMARKING REPORT
2009/2010

**TOO LITTLE,
TOO LATE?**
Why Europe should do more for
premature infants.

EFGNI NO LIFE
WITHOUT

Key finding:
Different practices, lack
of standards

Situation in Europe

Situation in Europe

Background,
challenges,
recommendations

Need for change

Need for change

[illegible]

Standards to increase
quality of care

Establishment of
reference

Establishment of reference

Start of the project in the European Parliament

- Official kick-off on the 7th 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

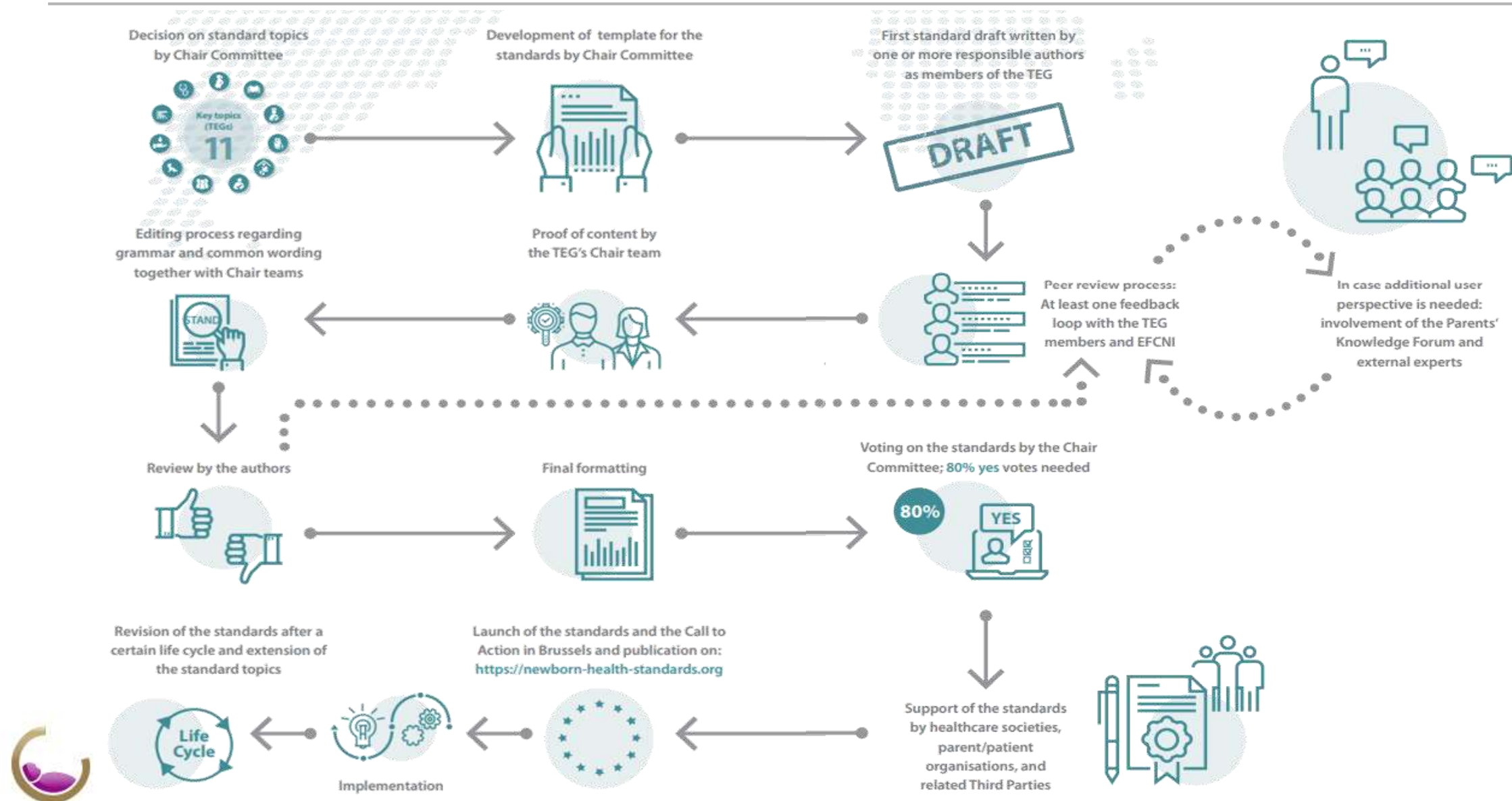
Reference standards
→ Translation for the
individual countries is
needed



Project related
communication strategy



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



<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)
- Healthcare experts and patients were involved
- Using several languages for the campaign



潘昭颀教授
香港中文大学威尔逊王浩院妇产科学系副教授

“子痫前期是一种可以导致母胎严重并发症的妊娠相关疾病。最近研究表明，高风险孕妇自孕早期开始每天服用150mg阿司匹林可以使早发性子痫前期的发病率降低80%。为了找出哪些孕妇可以从阿司匹林中获益，FMF研发了可以在11-13周常规进行的妊娠早期的综合筛查。”



Professor Kypros Herodotou Nicolaides
Professor of Fetal Medicine at Kings College and University College, London, UK; Founder and Chairman of the Fetal Medicine Foundation

“This extensive study is definitive proof that women can take simple measures in the first trimester of pregnancy to significantly reduce their chances of developing pre-term pre-eclampsia. By adding ultrasound measures and simple blood tests, we identified over 90% of cases of severe pre-eclampsia.”



Cathleen Sinnick
Prädiagnostik Screening Teilnehmende und Mutter von Martha Elisabeth geboren in der 34. SSW

„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**



Thank you for your attention!

EFCNI
European Foundation
for the Care of
Newborn Infants

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