EFCNI european foundation for the care of newborn infants

Family Involvement in Research Projects
a Parental Perspective

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Pediatrician researcher ask for parent involvement

- Clear need for more and better drug studies in children – supported by patients and families
- Examples of invaluable input of patients and families at all stages of the drug development process
  - *How to involve parents/patients in the development of relevant outcome measures?*
  - *Recruitment strategies (what information, by whom, how, timing)*
  - *Ethical issues in relation to data- and biobanking*

Challenges of parent involvement in Europe

Huge differences in:

- Preterm birth rates
- Mortality/ morbidity rates
- Care practices
- Parental involvement

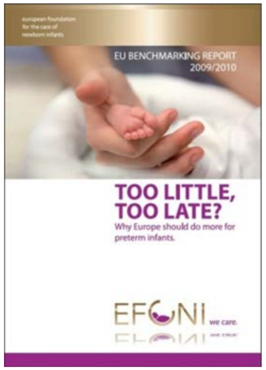
Lack of:

- National Policies/Programmes
- Standards of Care
- Standards of Research

Why we should work together?

Preterm and newborn babies are simliar all over the world.
… but the care they receive differs!

Also in Europe!



european foundation
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EU BENCHMARKING REPORT
2009/2010

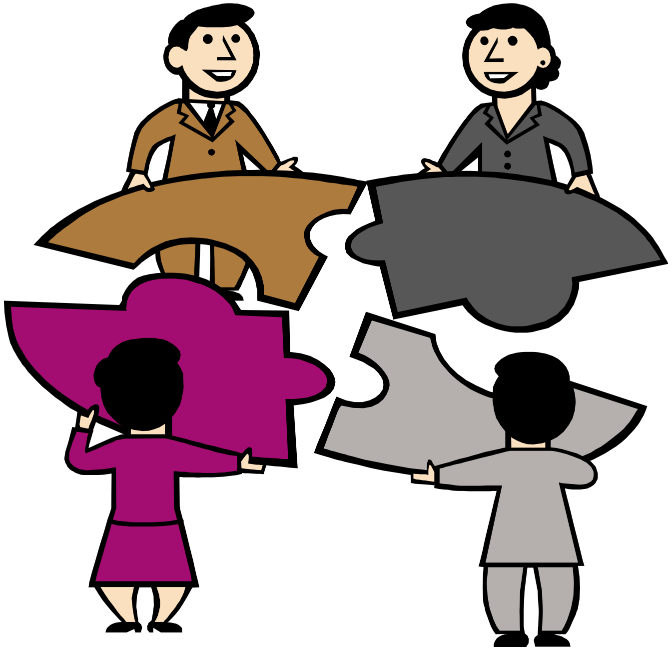
TOO LITTLE, TOO LATE?
Why Europe should do more for preterm infants.

EFCNI we care.

Different situations for parents in Europe…

Big challenge for many countries in Europe

Different understanding in „working together“



Healthcare Professionals

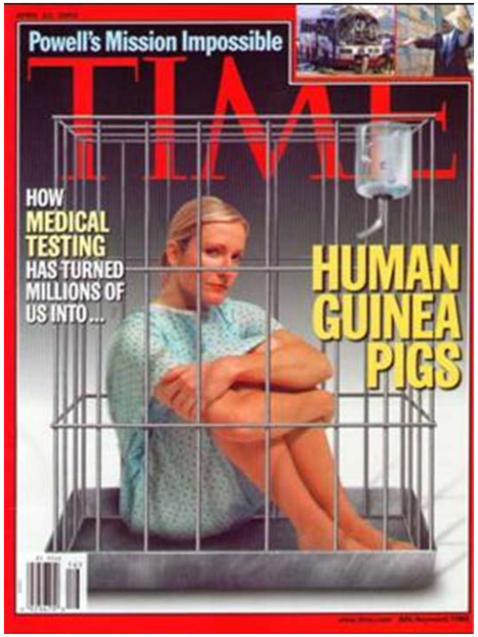
Industry

Parents

Third parties
Policy makers

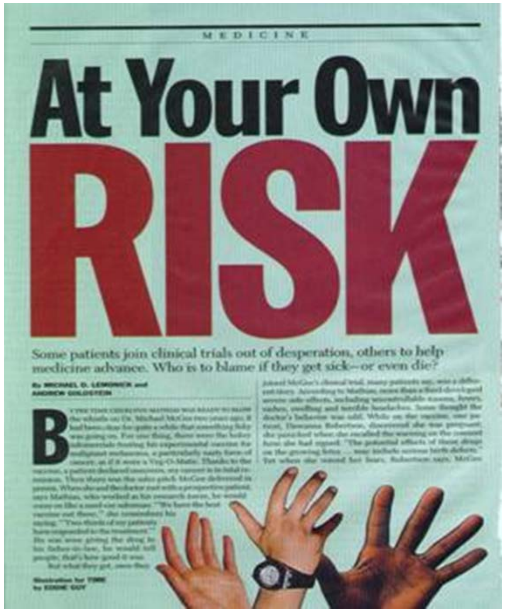
Family/children friendly research

- Reseach with children and parents needs more time and special communication training („research language“ – „how research works?“)
- Just a research object, like an animal
- Worried about risk of bad outcomes or risk on the consequences, e.g. drug studies
- Parent and parent organisations feel often not accepted and respected
- Information should be available in different languages e.g. for immigrants



Family/children friendly research

- Different social backgrounds of families – level of understanding
- Research projects are not *family/children friendly* structured:
    - Feeding difficulties
    - Extremly shy patients/location of research tests
    - Mentaly or physically disabled
    - Organising the research dates
- Missing studies for parent/patient need, like bonding, psychological support etc.



MEDICINE

At Your Own RISK

Some patients join clinical trials out of desperation, others to help medicine advance. Who is to blame if they get sick—or even die?

First step

Parent involvement is important and helpful

- Health care policy
- Grant application
- Health care quality
- Health care research
- Prevention
- Ethics
- Network and dissemination to target group

How can parents contribute?

- Our experiences, expertise and knowledge
- Our medical data
- Our ethical perspective
- Our political and social network and influence

… at national and international level

Value of parent perspective

Before the Clinical Trials

- Identify potential parent representatives, organisations or stakeholders
- Identification of indications, therapy features, patient/parent population
- Patient/Parent perspective on ethical and risk/benefit dilemmas
- Defining patient-oriented outcome measures

During

- Managing of expectations: hope or hype
- Patient/Parent inclusion and compliance
- Data and communication quality
- Patient/Parent and public confidence in clinical research

After:

- Quality of life, quality of healthcare
- Therapy compliance
- (Cost-)effectiveness
- Dissemination of results e.g. press – and media work, network to parents etc.

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We need more research in the area of maternal and newborn health

It is time to act and combine forces, now!!!