



Future collaborations between  
healthcare, industry and patients  
for faster and better results



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Future collaborations between healthcare, industry and patients for faster and better results

- I. EFCNI works on a multi-stakeholder approach
- II. The needs and challenges
- III. Working on two different planets?
- IV. What has to be done?



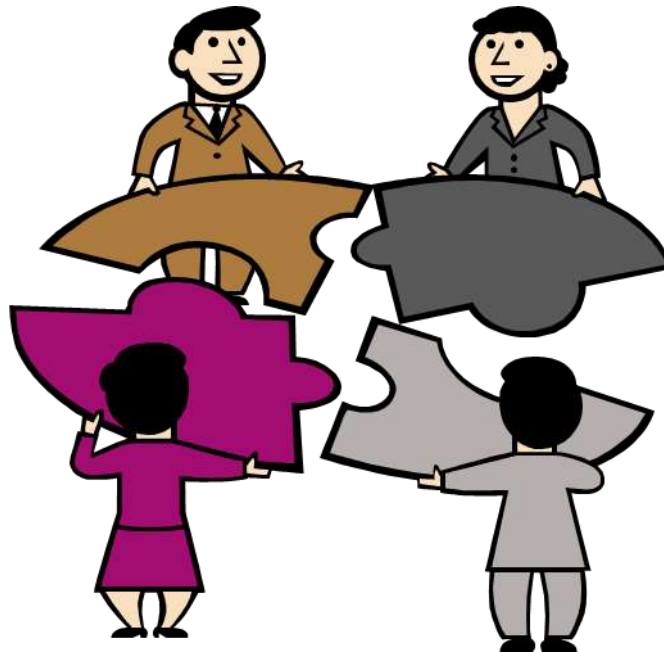
# Working together – a multi-stakeholder approach

Policy makers

Parent Organisations

Industry

Third parties



Media/Marketing

Professionals



# Parental involvement is more and more demanded

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- Clear need for more and better drug/nutrition/follow-up studies in children – supported by patients and families
- Examples show invaluable input of patients and families at ALL stages of a research project but still, a lot of questions remain:
  - *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 topics like involvement of families till data- and biobanking*



# Valuable and equal partner of research projects

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- Driving force behind clinical trials
- Co-research partner with international network to parent representatives
- Reviewer
- Advisor (“expert by experience”)
- Information provider
- Research object
- Ethical aspects
- Network to target group(s) and multipliers
- Building bridges and promotion of project
- Network helping to put research into practice



## Some critical thoughts by parents...

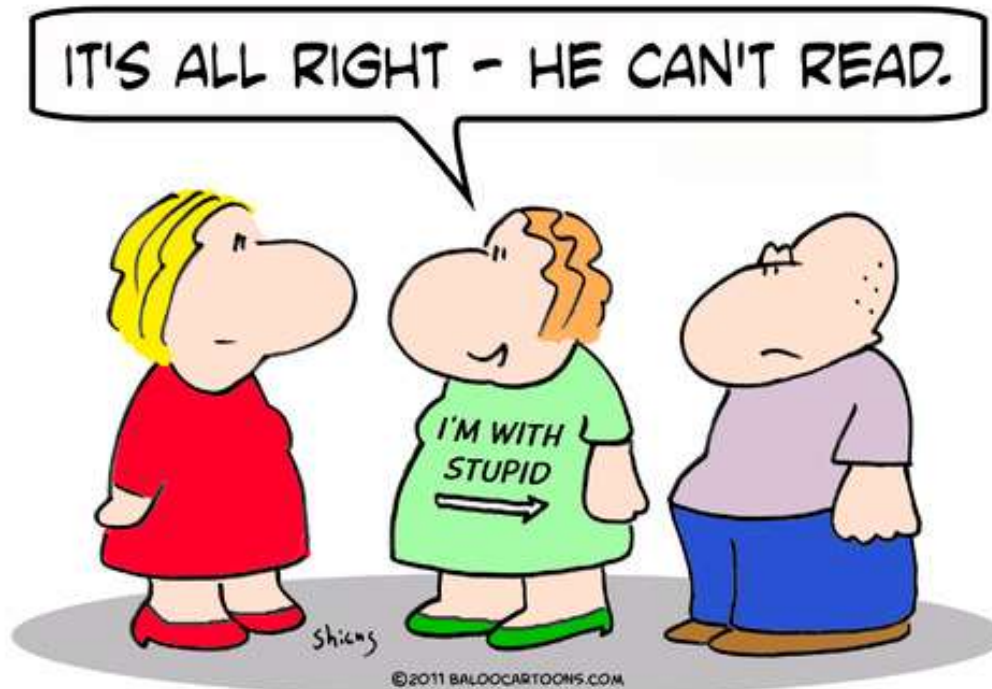
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- “In my case, I missed certain follow-up afterwards, a minimum of information in order to know if our contribution was useful, if any conclusions were obtained. Obviously, most results are to be seen at long-term, but receiving a piece of information would have made us feel recognised and valued.”
- “ We trusted them and agreed to participate - at the end, we just felt like being good for delivering data, but not being recognised as a family with our own background and needs.”
- “I have to take my child to 18 appointments per month, not including physiotherapy... 250 appointments per year. A research project adds to this – I cannot manage still another appointment and my daughter cannot afford missing again another day at school.”



## Being an equal partner?

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# Research and parental/patient involvement

## - Two different planets?

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### **Researcher/Investigator/Industry**

Interesting questions

Good data, data analysis, evidence

Publications

Solution in the future



### **Patient/Parents**

Emotions, trauma

Coping with daily life

- Worries (child, family,...)
- Organisational challenges

Direct solution for child/ family



# First Step

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# How did Parent Organisations experience research involvement in the past?

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## **Limited involvement of Parent Organisations**

- Mainly - letters of support
- Rarely - participation in phone calls; reading material

## **Often overwhelming**

- Last-minute requests
- Nearly no background information or
- Mailing of extensive research documents in scientific language

## **Often feeling of „inequality“ and „exploitation“**

- Missing recognition or acknowledgement
- Barely feedback on success of application or next steps
- Barely information on project outcome
- Barely outreach to „end user“, other target groups



# Healthcare research at a turning point

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- Increased patient empowerment: Awareness of own values and capacities; better understanding of opportunities through collaboration
- Increasing awareness of importance to include “user perspective” to improve research quality
- Patient centred research carried out “with” patients rather than “to” or “for” them
- Involvement of Parent Organisations requested by grant giving bodies as of 2015



# Involving patient representatives in research

## New challenges to manage

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- Flood of research application requests
- Last minute consultation requiring rapid responses
- „Involvement“ of patient representatives not defined
- Missing clarity of new roles
- Not taking seriously this new way of collaboration
- Refusal of participation can be challenging and create pressure
- Few practical experiences to learn from



### **Change in traditional research-clinician-patient relationship:**

from advice seeker to colleague whose point of views should be considered seriously



# Working together and learn from each other

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**Learning from each  
other's worlds**





# What do patient representatives need?

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- Access to terminology
- Understanding how research works, how to read, interpret studies, how to become co-applicants for grants (targeted training!)
- Access to full information e.g. e-mail exchange or „corridor meetings“
- Access to positive facts as well as risks involved
- Access to (steering group) meetings
- Access to resources (payment and funding)
- Self-confidence to speak up in expert rounds or panels and to stakeholders



# Principles to guide meaningful collaboration (I)

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## ***Fair partnership on equal footing***

*Longterm  
collaboration  
and continued  
partnership*

*Honesty and  
transparency  
(information  
including positive  
facts and risks)*

*Independency*

*Security and clear  
expectations  
(confidential  
agreement;  
codes;  
compensation)*



## Principles to guide meaningful collaboration (II)

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### **Communication and dialogue**

*Facilitate  
communication  
(level, language)*

*Acknowledgement  
and valuing of  
contributions*



## Principles to guide meaningful collaboration (III)

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### Capacity building

#### **PATIENT**

*Research and R&D*  
*Scientific language*  
*Interaction with stakeholders*

#### **RESEARCH TEAMS**

*Understand parental concerns*  
*Understand benefits for research*  
*Interaction with patients*



# Position Paper: Giving patient representatives a voice

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## Carrying the different pieces together:

- EFCNI's own experiences of the past years
- Incoming requests for advice by Parent Organisations
- EFCNI's exchange and discussion with Parent Organisations
- Debates with EFCNI Parent Advisory Board



## Findings:

- Similar challenges, gaps and needs in different countries and settings
- Patient representatives need to speak up for themselves, to accelerate a mind change

## Position Paper:

How parents would wish to be included as representatives in research, highlighting challenges and possible solutions





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

It is time to act and combine forces, now!





# EFCNI example: drug trial / neonatal seizures (industry funded)

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- Advising on
  - Useful patient information, material, formats
  - Patient-friendliness of information material  
e.g. consent form, flyers, patient brochure,  
website content, overall „look-and-feel“
  - Patient needs and „real-life challenges“
  - Building the bridge patient/ professional
  - Communication with patients during different project phases  
e.g. recruitment; follow-up
- Identifying and establishing parental advisory board according to project focus and needs
- Coordinating parental advisory board  
(e.g. NDA, honorarium, contract, questionnaires, comment phases, feedback analysis)



# Communication plan

[illegible]

# Factsheet



Research news

## Social media

