



How do we get parents involved? A parental perspective

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- I. Some questions to the audience
- II. Patients and family members with special needs
- III. Children trials – key steps



Questions to the audience

What do you think is needed

- to speak the same “language” and to accept the parental voice as an equal and valuable partner?
- for the parent/ patient community to join the discussions and make a meaningful and valued contribution?
- to ensure that we as parent representatives can speak for the entire parent community? Which surveys must be provided first before we can become the voice of the bigger group?
- to support as a parent representative the parent community in understanding why research involvement is important for our children and the next generation of children?



Parental involvement is more and more demanded

- 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*





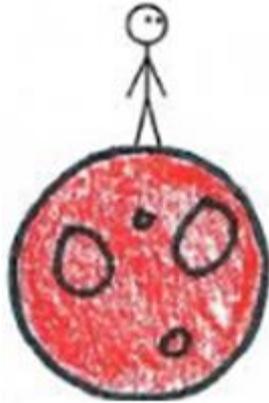
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Research and parental involvement

- Two different planets?



Researcher

Interesting questions

Good data, data analysis, evidence

Publications

Solution in the future



Parents

Emotions, trauma

Coping with daily life

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

Direct solution for child/ family



Some critical thoughts by parents...

- “This is just a way for some companies or universities to make a lot of money someday and my baby is going to be a guinea pig.”
- “I really don't know that much about studies so I would need to do a lot of additional research.”
- “If needed to help save our baby then yes but otherwise, no thanks.”
- “Fine if others want to participate but not on my baby.”



Some critical thoughts by parents...

- “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.”



Research and parental involvement – A one-way road?



Parents GIVE information, data,
their baby/child for research

What do parents RECEIVE in return?
What can help them?

Can we find ways that research is nourishing both: researcher AND families?





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First Step



Family/children friendly research

- Time for children and parents
- Special communication training
 - „Research language“ – „how research works“
 - Messages (which and how)
- Being aware of families with different social and educational backgrounds – level of understanding
- Providing understandable patient/parent information if possible in different languages, e.g. for immigrants
- Honest and complete information (also on risks) (testimonials?)
- Accepting and respecting the opinion of the child(ren) and parents



Family/children friendly research

- Involving as many parent representatives/ organisations as possible to get a bigger picture or a better feedback
- Many research projects are not *family/children friendly* structured:
 - Patients can have feeding difficulties
 - Extremely shy patients/ location of research tests
 - Mentally or physically disabled patients
- Keeping families informed about further developments and the results (and a „thank you“)
- Creating environment of trust – building valuable and equal relationship/ partnership



Working together – with parent organisation

Policy makers

Parent Organisations

Industry

Third parties



Media/Marketing

Professionals



Parent organisations meeting 2016

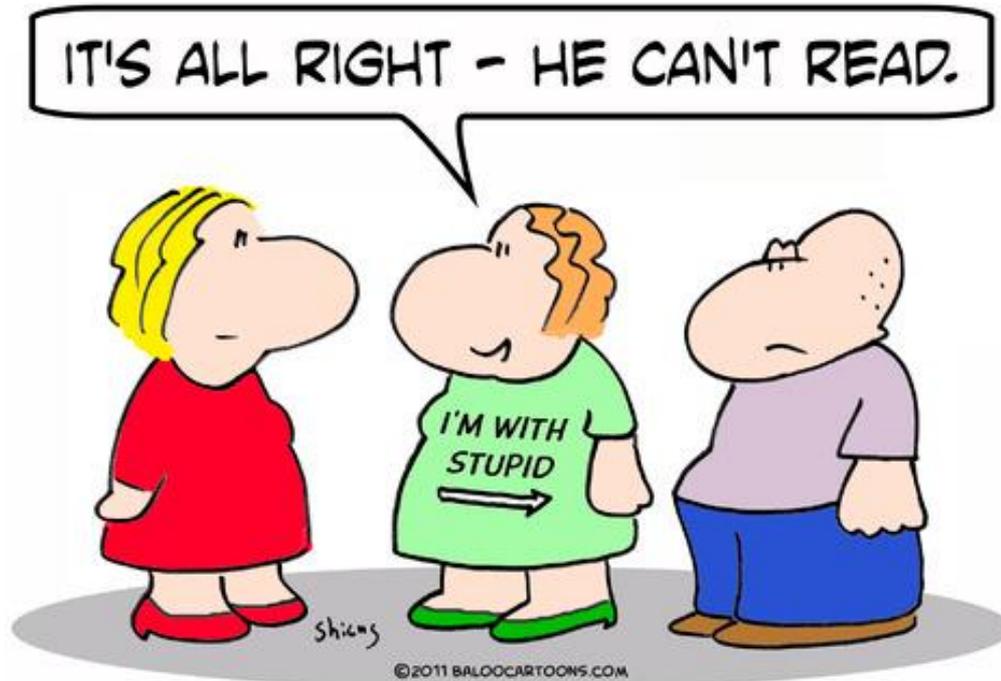


Annual meeting for:

- Training in (social) media, communication, fundraising, advocacy
- Sharing expertise and best practice examples from national parent organisations
- Developing common campaigns and projects, e.g. World Prematurity Day, European Standards of Care for Newborn Health, Socks for Life
- Presentations by stakeholders and health professionals



Being an equal partner?





Valuable and equal partner of research projects

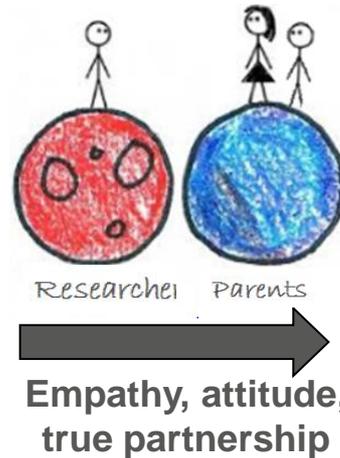
- Driving force behind clinical trials
- Co-research partner with international network to parent representatives
- Reviewer
- Advisor (“expert by experience”)
- Information provider
- Research object
- Ethical aspects
- Network to target group(s) and multipliers
- Building bridges and promotion of project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



Parental involvement

– A question of perspective?

Can we find ways that research is nourishing both: researcher AND families?



How can we get parents involved?

What do parents need to feel comfortable/ welcomed in being involved?

We have to learn more about your world

- Can you learn more about world the families are living in?

- What preoccupies them?
- What are their daily challenges?
- How can you help making involvement easier?





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

It is time to act and combine forces, now!

