



## **RECAP preterm**

Collaborative Research on Very Preterm Birth: Concepts and Methods – Working with the RECAP preterm Data Platform



### Dissemination, Translation and Sustainability


**Livia Nagy Bonnard**, Co-founder of Melletted A Helyem Egyesület

The importance of patient representatives as partners in research projects




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My name is Livia Nagy Bonnard from Hungary and I will give you some insight about the last 15 years of my life, as a mother of an extrem preterm boy, who was born on the 27<sup>th</sup> of week of my pregnancy in 2006.

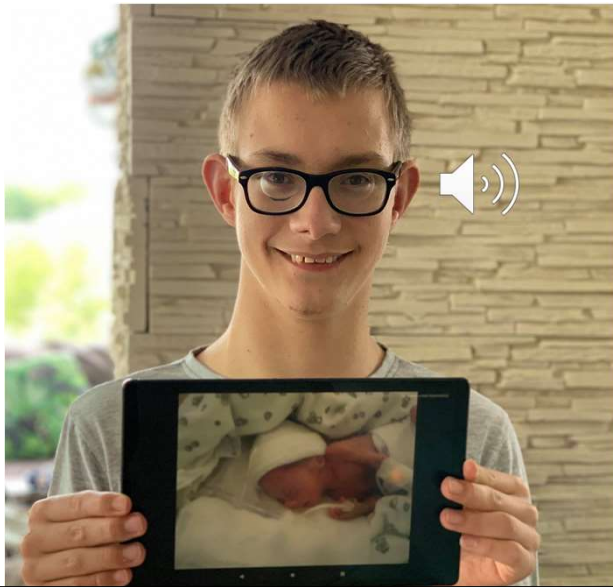


Your son was born preterm.  
Would you like to describe for us  
your personal story?



Question: Your son ws born preterm. Would you like to describe for us your personal story?

## Right(s) beside you



- BPD
- ROP
- IVH
- PVL
- CP
- multihandicap



My son was born in the 27<sup>th</sup> week of pregnancy with 890 gr. During a family vacation, in my home country. I will always remember the first time we met our son around 24 hours after his birth. I tried to prepare myself for the sight of my son, but you cannot prepare for this. Five days after his birth, the hospital released me and I had to leave my baby there. Alone. The NICU door will haunt me for the rest of my life. I was afraid of what was waiting for me behind that door. For the next 14 weeks, I stood in front of that door twice a day and pressed the bell. I was a visitor in that corridor in front of the door. Not a mother. At that time, I was confident and felt that my baby was in good hands. Never, not for one minute I questioned that my son and I did not receive the best treatment and care. Now, in hindsight, I know how dangerous this situation was. The visiting time for each child was 20 minutes, two times a day. I remember the exact day and the exact hour, when my son started to breathe without any machine. At that moment he was born a second time, but I was not there. They told me via phone. The moment when I could hold him in my arms for the first time is equally unforgettable. He was then 12 weeks old. Our son became a fantastic little boy. He is a 5-6 years old little child who lives in the body of a 15 years old boy. He walks, he is happy, he speaks 2 languages, he has his own friends.

But he cannot change his clothes, he is not able to write or read, he will never be an independent adult, he will always need someone around him for 24-7. No one knows whether my son would be healthy if he was born in France or Switzerland. But 20 minutes visiting time twice a day has definitely not helped to let him thrive. He couldn't benefit from skin-to-skin care, he wasn't breastfed. These may seem "simple things" but we know for a long time, that these are the things that contribute to making a difference. Our family has in the meanwhile accepted this destiny and we are able to cope with it - some days more, some days less. Because of these differences in care between countries, but even between single hospitals, I work voluntarily in the Hungarian parent organisation. I want to ensure that other pregnant women, other families don't have to live through the same horrific experiences we went through. NICUs in same city still have visiting time 15 years later BUT couple of kilometers from each other, in the same city, other NICU-s let parents be with their premature children 24/7. Why? How is this possible?

How can we let such differences happen? How can we provide the best possible care for such vulnerable little children, if there are no widely accepted regulations?

Our reality is hitting day by day. During the recent months Antoine was growing (as every teenager) extremely fast. Adolescence is so challenging to navigate and having these additional healthcare challenges make it so much more difficult. As long as he can walk and the botox is working the wheelchair is really "just" a help-out accessory. Because of his quick growing and his basic motor and orthopedic difficulties the result is scoliosis, which will need operation in a few years. He is losing his balance a lot, can not work out his "newly" long limbs so for security reasons we need to start to use the chair. As he considers himself a normal child and NOT as a HANDYCAPed child, accepting to use the wheelchair was an additional problem.

With the experiences and knowledge of the past 15 years made me a volunteer for the Hungarian and for the European patient organisation and committed myself to engage in different researches. I went back to school and became European Patient Academy Fellow Patient Expert.



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Why do you consider the inclusion  
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## Why...

- Patient relevant research
- Access to experts
- Achieve translational research
- Alignment of research agendas
- Input to lay summaries
- Meet regulatory criteria for funding, MA approval and HTA assessment
- Patient experts are multipliers of knowledge, coping strategies and empowerment.



I personally feel it is very important that research involving newborn infants becomes meaningful for the individual child and families! The importance of outcome could be different for the preterm born child or adult and to the parents, siblings-the whole family. Integrating the voice for the newborns and families is our ethical and moral right and duty. The patient representatives bring invaluable expertise and first-hand insight to the project team. For example: over the past years, I have engaged mainly as volunteer to research projects. I brought our personal experiences and perspectives as mum and as family into the project, as well as the views of the families I represent. This lived experience is something you cannot learn or study. Over the years, you gain a “phd in Lived experience”. And this is what makes the patient view so very valuable: You therefore may judge things differently: An item or topic may seem important to a researcher, but for the patient or the families, the topic is actually not so important.

Patient experts can act as peer educators for the next generation during and after the research project. Dissemination, science communication, translation of research findings for parents. Until recently, patients in newborn health have been involved in research projects to represent family=patient voice once or occasionally, maybe for certain parts of a project to get “ethical clearance” or as it was an obligation for grant application. But patient experts are important: they are multipliers of knowledge, coping strategies and empowerment.



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## Challenges as a patient representative:

- When
- Why
- Who
- What
- How



Im considering myself as a skilled and prepared representative, invested time and money to have knowledge about clinical trials or research projects.

Participating at the EUPATI project is a big commitment from day 1 till the last minute of the training. It starts with the application process and I was almost 100% sure I'm not going to be selected for the training, as the "patient" is not myself, and as I heard later the very limited number of patient representatives are applying from the maternal-newborn health field. I was so proud I'd been selected and not only a lot of commitment but you need a lot of time and a QUIET environment, which is very limited in my household. But it is rewarding and I met fantastic patient experts from all around the world and our trainers were highly prepared and committed tutors, whom we could learn a lot and count on during the whole training.

I receive proposals frequently from researchers to participate in projects, but sometimes I have to turn down these proposals as the questions above are not clear at the beginning, when they reach out for patient representatives.

First and most common challenge is TIME and TIMING. Many cases in the past few years the request from EMA or from researchers arrived in few days before meetings, grant submissions. I was glad to help those projects, but at the end, it was a huge effort to organise the life of my family to prepare for the meetings, find someone who is "replacing" me during the time of travel or even look after my children while Im preparing the grant application as patient representative.

I would very much appreciate from the research teams to provide enough time and clear informations for me to give my best knowledge to help the research project and be a valuable part of the research team, not only a tick-box. Because of the timing, to go through on project documentations, trial design makes it difficult to be prepared, but also, the common language is English, which is not my native language, I need extra time to understand every aspect of my role for the project.

Happened several times after my arrival to meetings that I had no informations about the persons are involved in the project, and in this way I felt intimated and felt reluctant to speak up as a patient among many professionals who sometimes clearly had no information about my position as a patient representative.

So far I only have positive experiences about the way of communication and could always speak honestly and been expected to listen to me and have eye-to eye conversations with my research colleagues. I always admire the people who Im working with, especially those professionals who are clearly want to make life easier for our preterm babies and their families. But I heard from other patient representatives its not always the case and had some negative experiences.

This is a job, a fantastic and meaningful job, but requires compensations, such as travel and accomodation, pay the "babysitter" who replace me and Im giving my time and my best knowledge for these projects.



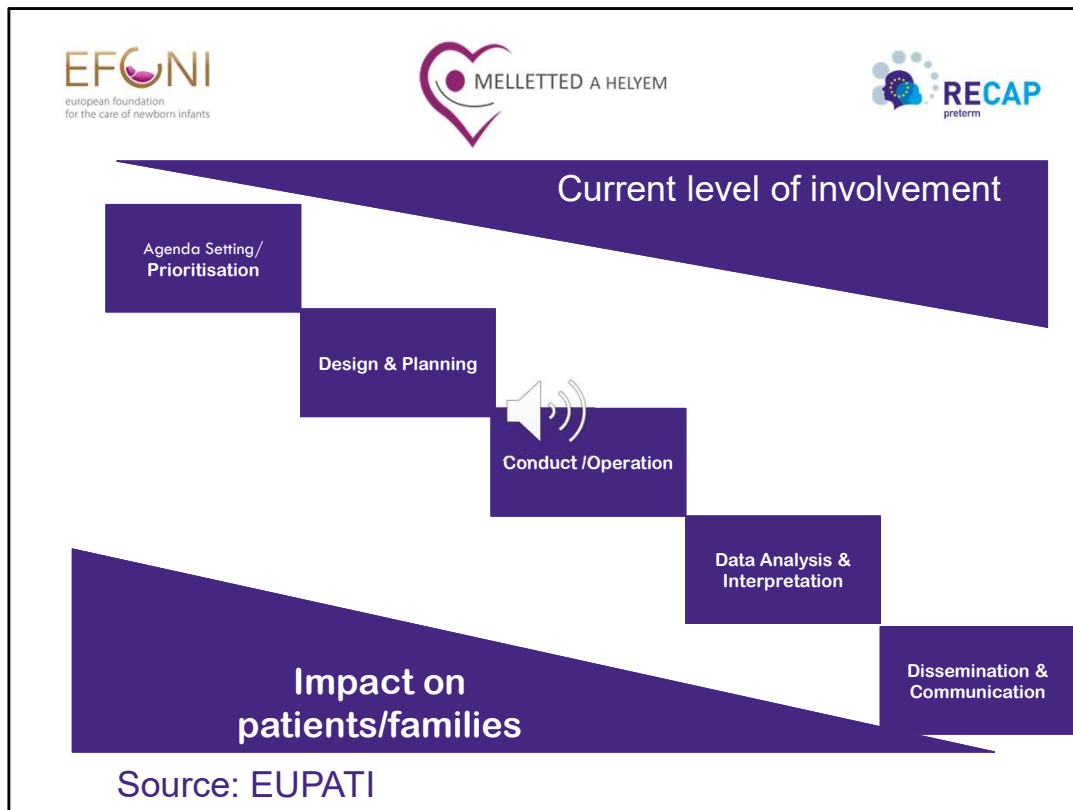
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I strongly believe that patient advocates must be included by creating true partnership and working relationship with research teams, regulatory authorities, ethic committees and industry. The patient partner or advocate, who is ideally a member of a patient organisation and has a strong network behind him or her, can become a driving force for lobbying for development and finance clinical trials. developing research protocol or even getting research team together. Also provide vaulable during study design. What are the needs of the patients, set research priorities as the outcomes being measure should be provide value for the families and for the preterm borned child/adult. Patients can lead focus groups, discussion sessions, writing or participate to write scientific articles with research results. Also review patient infos, help during recruitment, giving advice and participate in advisory groups and committees. He or she can have a role as information provider and also research participant. Historically research has been performed ON patients instead of WITH patients. And this is very true: As families, we often feel even now that our children and the families are being used as “source of data”. But please don’t forget: behind every data there is a human life. And more the research is meaningful for our babies and to us parents, the right questions been asked, the outcomes and impacts on patient and family is more it is nourishing for families and for the researchers.



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## Experiences

- Medical conferences: jENS and annual conferences national neonatal and perinatal societies
- European Standards of Care for Newborn Health: <https://newborn-health-standards.org/>
- **PREMSTEM:** <https://www.premstem.eu/pcab/>



**I AM A TRAINED NURSE AND HAVE A 14-YEAR-OLD PREMIE SON. MY PERSONAL AND PROFESSIONAL EXPERIENCES WILL HELP ME TO GUIDE THE PREMSTEM TEAM IN THEIR COMMUNICATIONS WITH SOCIETY.**

Ms Livia Nagy  
Melletted a helyem Egyesület





PREMSTEM  
premstem.eu

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 874721

The jENS conference (joint European Neonatal Societies) is the first of its kind in the newborn health arena where a patient organisation fully integrated as equal partner and co-organiser in all respects. Patient representatives can attend all sessions which allows them to increase their competencies and skills and to network with the professional community. Also, the discussions in the congress sessions are enriched and giving the human touch of data, when the patient representatives speak up and explain their views – which sometimes can be different from those of the professional community.

European Standards of Care for Newborn Health. This is an interdisciplinary European collaboration to develop standards of care for key topics in newborn health. The project brings together around 220 healthcare professionals of different professions, parent representatives and selected industry specialists, from more than 30 countries. This project was initiated and is being led by EFCNI. It is the best example and proof of the shift of power that is currently taking place also in the area of newborn health towards shared decision making and giving the patient more power. In other health areas, it is already more common that patients and their representatives can drive and lead research project.

In the PREMSTEM study, I am part of the patient/customer advisory board and our input and recommendations help to refine and adjust the communication activities. We ensure that the voices of those born preterm and their family members and carers are heard and considered right from the start of the project.



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What would be your recommendations  
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What would be your recommendations for future research projects?

**“The only source of knowledge is experience.”  
Einstein**

- Develop a framework that actively supports the involvement of patient experts
- Provide training opportunities for patients and researchers to work on equal footing
- Engage and give proactive role to patients throughout the whole research process



Establishing a system of fair compensation, a blueprint for future projects, because it is very challenging for patient representatives to contribute voluntarily: this clearly needs a mind change

Treat parents with honesty and respect. Without prejudice and be open to help them feeling well so that they dare contributing. There are many forums such as PARADIGM and EUPATI who are engaged with training possibilities for professionals and get experience and advice from your fellow researchers who frequently working with patient representatives.

I do believe that the more informed parents are the more competent with their babies throughout the whole NICU journey. I would like to give more support to the parents to make the right choices and advocate successfully for their babies. Also to help and dialogue with clinicians to be the voice of the babies and their parents to prevent bad and outdated practices. Influence regulators to make sure they are founding and making their decisions on patient preferences and contribute in research projects to help clinicians to put the “good” questions in their hypothesis, to have the relevant and useful outcome of the research to help the patients in real-life settings.

As I mentioned before I admire and look-up for those professionals who are engaging their career to create better outcome for our children. We were not prepared to have such a trauma as preterm birth. Definitely not prepared for the over medicalised NICU and the rollercoaster we experience throughout care and fear for our babies life. Most importantly imagine like a jump from an airplane without parachute to go home from the NICU and start the life at home. We rely on your previous researches, your experiences, your data. But these information sometimes are not only unhelpful but the opposites what we experience. Please use us, experienced and trained patients who are happy to help you with our knowledge to make your research project successful. Not only for your research team or your personal beliefs but those patients who have to live their life day to day with the consequences of preterm birth.



**Thank you**



In case of questions, please feel free to contact  
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Thank you very much for your attention. Please do not hesitate to contact me for questions.