

EJP RD 3rd Paediatric Training Workshop

20 – 23 June 2023, Barcelona (Spain)

Hotel Front Maritim

TEDDY European Network of Excellence for Paediatric Research, in collaboration with EURORDIS and the Sant Joan de Déu Research Foundation, is organising the 3rd Paediatric Training Workshop in the framework of the European Joint Programme on Rare Diseases (EJP RD).

The EJP RD is an EU-funded project aimed at raising the level of knowledge and awareness on rare diseases (RD) research. It namely aims at

- creating expert patients by providing training materials, workshops and courses on scientific innovation and research,
- empower paediatric patients and making them ready to actively participate in scientific research by contributing with their own specific experience.

In particular, expert young people may provide a valuable contribution during the several research-related decisions processes in terms of children rights protection, children autonomy and freedom. To be active contributors, young patients need to be well trained and properly educated on the issues related to scientific and biomedical research.

Education of young people is therefore essential to enabling them to act as advisors at several steps during the drug development process. Similarly, the same capacity should be developed with regard to all the situations that are relevant for their health and wellbeing.

Tuesday 20 June

Pre-workshop On-line session - Presentation and explanation of the program, methodology and tools *Annagrazia Altavilla & Maria Cavallo (TEDDY)*

Wednesday 21 June

13.00 Welcome Ice breaking Lunch

14.00 - 15.30 SESSION Paediatric Rare Diseases challenges and Paediatric Patient engagement

INTRODUCTION - Annagrazia Altavilla & Paediatric Patient

- Living with Rare Diseases in the paediatric age, *Maria Cavaller, EURORDIS*
- The Orphan Medicinal Products development, *Kristina Larsson, Head of Orphan Office, European Medicines Agency (EMA)*
- Paediatric Orphan Medicinal products to cover paediatric needs, *Marek Migdal, Paediatric Committee (EMA), Children's Memorial Health Institute, Warsaw (Poland), European Paediatric Translational Research Infrastructure (EPTRI) (online)*
- Involvement of patients and young patients/consumers within EMA activities, *Maria Mavris, Patient Liaison, European Medicines Agency (EMA)*

15.30 - 15.45 Questions & discussion

15.45 - 16.00 Coffee Break

16.00 - 18.00 PRACTICAL ACTIVITIES

Hand-made book with slogans feedback by kids on rare disease perception, *Maria Cavallo, Eleonora Passeri (TEDDY)*

Thursday 22 June

9.30 - 13.00 - SESSION Clinical Research in Rare Diseases

9.30-10.30 Clinical Research in Rare Diseases and paediatrics peculiarities, *Joana Claverol Torres (Sant Joan de Déu Research Foundation)*

10.30 -10.45 Coffee Break

10.45- 12.15 **SESSION Play to Learn**

TEDDY serious games (*Maria Cavallo, Eleonora Passeri, TEDDY*) and FSJD serious games on clinical research (*Joana Claverol, FSJD*)

12.15-13.00 **PRACTICAL ACTIVITIES**

Kids feedback on paediatric research in RD (online form and discussion) *Maria Cavallo, Eleonora Passeri (TEDDY)*

13.00-14.00 Lunch

15.00 - 18.00 SESSION Healthcare and research for rare diseases

Learning in context - Visit of the FSJD research/healthcare institution and meeting with healthcare/patients' representatives

Friday 23 June

9.00 - 12.00 SESSION Childrens' Rights implementation in Rare Disease

9.00 - 10.15 - Children's rights in biomedical field relevant for Rare Diseases *Annagrazia Altavilla, TEDDY Network, Espace Éthique PACA-Corse (APHM/Université d'Aix-Marseille), Michela Onali, Gli Equilibristi HIBM, 2023 EURORDIS Black Pearl Awards*

- COE/TEDDY Kids video vision
- Children rights and Data Protection
- Children rights and empowerment

10.15 - 12.15 PRACTICAL ACTIVITIES

Information materials for processing and sharing data (Assent form, lay glossary) *A. Altavilla, M. Cavallo, E. Passeri (TEDDY)*