

Expression of interest to participate in the second paediatric expert patients training workshop organised in the context of



2022 **i**CAN S U M M I T

Are you an adolescent aged from 12 to 18 years old with an interest in health, biomedical research, healthcare, and children rights?

Are you a patient with a chronic rare disease willing to get the skills to shape the future of research making it more inclusive for younger people?

If yes, this paediatric expert patients training workshop is for you!

The workshop will host **15 paediatric patients** in Lyon, France, from 11th to 15th July. It is organised by the TEDDY European Network of Excellence for Paediatric Research, in collaboration with EURORDIS and the Sant Joan de Déu Research Foundation 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 empowering patients and creating expert patients by providing training materials, workshops and courses on scientific innovation and research.

This course specifically aims at making young patients like you ready to actively participate in scientific research. It will help you play an important role in improving research and healthcare services for all patients by contributing with your own specific experience.

To be an active contributor, you need to be well trained and properly educated on the main subjects related to scientific and biomedical research.

Education of young people is therefore essential to incorporate you as advisors along the drug development process and to facilitate the implementation of children rights allowing you to participate in decisions regarding your health.

A patient-centered approach can improve the capacity of collaboration with the different stakeholders who participate in the translational research process and in the development of innovative medicines.

This year, the paediatric training workshop will be held during the iCAN (International Children's Advisory Network) summit that will take place on July 12th-15th at the University of Lyon (France).

Please find here more details about the summit and the programme specifically devoted to children and rare diseases <https://www.icanresearch.org/summit> .

The training workshop will foresee case studies, practical activities & discussions in order to ease your understanding of the topics presented and to assess if the expected objectives are reached.

The workshops will be performed in English and delivered by paediatricians, investigators, psychologists, representatives of patients' associations, YPAGs facilitators, legal, ethical and regulatory experts.

Are you interested in the course and advocate for rare disease research? If yes, please fill in the registration form that you can find at this link:

<https://forms.office.com/r/XBArJduWVG>

The deadline for sending your application is July 1st.

The accommodation and travel costs will be fully covered by us.

Please be informed that your personal data will be kept strictly confidential and all information will be handled through very secure electronic systems and used only for the purpose of the meeting.

All the applications will be evaluated by a Project Committee composed of members from TEDDY European Network of Excellence for Paediatric Research, Sant Joan de Déu Research Foundation and Eurordis that are leading this initiative. Results will be communicated to you and your parents at 4 July 2022.

The participants will be selected according to the following criteria:

- Good English proficiency
- Age (between 12 and 18)
- Country (to guarantee a fair geographic representation)
- Motivation and interest in improving health research Participation in specific advisory groups or paediatric patients' organisations

A specific written parental authorization and an assent form will be required.