

IN SEARCH OF LOST TIME - 2ND EDITION

BUILDING THE EPICARE
2027 HORIZON

16TH - 18TH DECEMBER 2021
ROME, ITALY

Event organised by the Bambino Gesù Hospital team, Rome, Italy
and supported by the ERN EpiCARE

GOAL OF THE EVENT

This event is organised as a brainstorming workshop to favour networking, debates and face-to-face discussions.

The main objective is to prepare the next steps in developing the ERN EpiCARE, the European Reference Network at the service of patients with rare and complex epilepsies.

TIMETABLE

Thursday 16th December

13:00: welcome lunch
14:15: welcome address
14:30 - 16:30: session I
16:30 : break
17:00-19:00: session I

Friday 17th December

09:00 - 11:00: Session II
11:00 : break
11:30-13:00: Session II
13:00 : lunch
14:30- 16:30: Session III
16:30: break
17:00 - 19:00: session III

Saturday 18th December

08:30 - 10:30: Session V
10:30: break
11:00-12:00: Translating brainstorming into next steps
12:00-13:00: Debriefing and closing remarks
13:00: light lunch and departures

MORE INFORMATION

Location

Istituto Patristico Augustinianum, Roma

Contact

EpiCARE: Anne Robert, anne.robert@chu-lyon.fr
PTS Roma: Maura Stella, maura.stella@ptsroma.it

Event website

<https://rareepilepsyworkshops.net>

EpiCARE website
www.epi-care.eu



FACULTY

Alexis Arzimanoglou - France
Simona Balestrini - Italy
Carmen Barba - Italy
Isabella Brambilla - Italy
Kees Braun - The Netherlands
Dana Craiu - Romania
Helen Cross - UK
Valentina De Giorgis - Italy
Luca De Palma - Italy
Elena Gardela - Denmark
Floor Jansen - The Netherlands
Reetta Kalviainen - Finland
Katja Kobow - Germany
Teia Kobulashvili - Austria
Katarzyna Kotulska -
Lieven Lagae - Belgium
Monica Lucente - Italy
Petr Marusic - Czech Republic
Rima Nabbout - France
Caroline Neuray - UK
Carol-Anne Partridge - UK
Eleni Panagiotakaki - France
Sylvain Rheims - France
Rodrigo Rocamora - Spain
Guido Rubboli - Denmark
Philippe Ryvlin - Switzerland
Nicola Specchio - Italy
Rainer Surges - Germany
Sébile Tchaicha - France
Eugen Trinko - Austria
Paolo Tinuper - Italy
Federico Vigevano - Italy
Allison Watson - UK
Sameer Zuberi - UK



THURSDAY 16th DECEMBER

SESSION I : CLINICAL TRIALS ON RARE AND COMPLEX DISEASES

Following the launching of the European Collaboration for Epilepsy Trials Group (ECET), the ERN EpiCARE, with the contribution of its Working group on Clinical Trials & Targeted therapies, is entering a new phase in its efforts to promote more focused clinical trials for antiseizure treatments, epilepsy-surgery and evaluation of outcomes. During this session several aetiologies will be individually discussed, to serve as models for future developments.

14:30 - 16:30

Chairs: Simona Balestrini (UK, Italy), Sébile Tchaicha (France)

- **The ECET initiative and the role of ERN EpiCARE HCPs**
Alexis Arzimanoglou (France)
- **Challenges in Neuronal Ceroid Lipofuscinosis clinical trials**
Nicola Specchio (Italy)
- **Challenges in Progressive Myoclonus Epilepsy type 1 clinical trials**
Reetta Kalviainen (Finland)
- **Challenges in Alternating Hemiplegia clinical trials**
Eleni Panagiotakaki (France)

16:30 : coffee break

17:00 - 19:00

Chairs: Rainer Surges (Germany), Valentina de Giorgis (Italy)

- **Not drug-resistant FCDs: is a trial necessary?**
Helen Cross (UK)
- **Challenges in Tuberous Sclerosis Complex clinical trials**
Lieven Lagae (Belgium)
- **Challenges in SCN8A-complex clinical trials**
Elena Gardela and Guido Rubboli (Denmark)
- **Challenges in ESES clinical trials**
Floor Jansen (The Netherlands)

19:00: end of day

FRIDAY 17th DECEMBER

SESSION II : GUIDELINES FOR PRESURGICAL EVALUATION AND EPILEPSY SURGERY

Challenges related to pre-surgical evaluation procedures and epilepsy surgery outcomes have been a priority even before the launching of the ERNs, through the E-epilepsy pilot network. Recently, the EpiCARE working groups on epilepsy surgery (WP 8) and guidelines (WP 13) expanded the close collaboration with the ad hoc ILAE Task Forces to also receive input from scientific societies such as the EAN and the EPNS. Currently the ERN EpiCARE is focusing on Guidelines for pre-surgical evaluation, for epilepsy surgery and for neuromodulation. This session is designed to facilitate brainstorming on all of the above.

09:00 - 11:00

Chairs: Eugen Trinka and Teia Kobulashvili (Austria)

- **Input from Functional Neuroimaging**
Petr Marusic (Czech Republic) in collaboration with Matthias Koepp and Alexander Hammers (UK)
- **Neuromodulation**
Philippe Ryvlin (Switzerland) and Laura Jehdi (USA)
- **Epilepsy surgery in patients with identified (or possible) gene mutations: where do we stand**
Kees Braun (The Netherlands)

11:00 : coffee break

11:30 - 13:00

Chairs: Sylvain Rheims (France), Carmen Barba (Italy)

- **The Pre-surgical evaluation Guidelines project**
Eugen Trinka, Teia Kobulashvili (Austria) and The Guidelines working group
- **The Epilepsy Surgery Guidelines project**
Luca de Palma (Italy), Philippe Ryvlin (Switzerland) and the Guidelines working group

13:00: lunch

SESSION III : STUDIES & TRIALS: CLINICALLY MEANINGFUL VARIABLES FROM A PATIENT PERSPECTIVE, BEYOND SEIZURE FREQUENCY

For years, and even today, most clinical trials focus on control of seizures and ASMs safety issues. We are progressively entering an era of precision medicine that will hopefully take the lead. Rare and complex epilepsies certainly share common points but also have specificities. One of the missions of the EpiCARE Patient Working Group (ePAG) is to further explore the wider impact of rare and complex epilepsies from a patient and caregivers' perspective. Future clinical trial designs will have to incorporate variables important to patients and, whenever possible, translate them to endpoints. Patient advocates and clinicians will debate on meaningful variables for specific diseases, to serve as pilots for other types of rare epilepsies.

14:00 - 15:45

Chairs: Rima Nabbout (France) and Monica Lucente (Italy)

- **COST action-Burden of disease**
Rima Nabbout (France) and Isabella Brambilla (Italy)
- **Meaningful endpoints in GLUT-1 deficiency trials**
Monica Lucente and V. De Giorgis (Italy)
- **Meaningful endpoints in Ring Chromosome 20 trials**
Allison Watson and Sameer Zuberi (UK)
- **Meaningful endpoints in CDKL5 trials**
Carol-Anne Partridge (UK) and Kuopio medical team (Finland)
- **Meaningful endpoints in SYNGAP 1 trials**
Bertrand SABY (Spain) and the Necker-Enfants Malades team (France)

15:45 - 16:30

Chairs: Tiziana Granata (Italy) and ePAG LGS advocate TBC (Italy)

A round table on common meaningful variables for trials in rare and complex epilepsies (open debate involving all patients advocates and all on site participants)

16:30: coffee break

SESSION IV : YES SESSION ON EDUCATION & TRAINING

The EpiCARE Education and Training Working package developed a number of educational activities, such as webinars targeting specialists in the field of rare and complex epilepsies or e-learning modules, in collaboration with the ILAE Academy. In the coming years we are expected to also work on educational needs of non-specialists and on a comprehensive training program for the future generations of epilepsy specialists. The Young Epilepsy Section (YES) of the ILAE are certainly those that can better guide the steps to be taken.

17:00 - 18:00

Pilar 1: How and where to meet the needs of non-specialists

Chairs: Floor Jansen (The Netherlands) and Helen Cross (UK)

- **Educating our peers – neurologists and epileptologists**
- **Broadening the educational horizon – counselling and supervision in rare and complex epilepsies**

18:00 - 19:00

Pilar 2: Train the leaders – hear the young!

Chairs: Caroline Neuray (UK) and Masa Malenica (Croatia)

- **Where are all the young people? “Career” obstacles**
Early career: Alina Ivaniuk; Mid-career: Katja Kobov; Established career: Helen Cross
- **YES – young epilepsy section in the ILAE and what we do for future leaders?**
Luca De Palma (Italy)
- **Mentoring and empowerment**
Caroline Neuray (UK)

19:00: end of day

SATURDAY 18th DECEMBER

SESSION V: THE ERN EPICARE & PATHWAYS FOR EPILEPSY CARE IN THE EU

Epilepsy care is still a challenge in Europe. At a national level, how many fully equipped reference centres are needed? What should be the diagnostic and treatment facilities available on site? What should be the best practices for collaboration with smaller centres?

At an EU level what should be the role of EpiCARE as a network at the service of cross-borders clinical expertise, research networking, and knowledge generation? What should be the respective roles of national epilepsy centres of expertise and of full members of the ERN EpiCARE?

08:30 - 10:30

Chairs: Paolo Tinuper and Federico Vigevano (Italy)

- **The ERN EpiCARE: a «learning from the past» update**
Alexis Arzimanoglou (France)
- **Epilepsy Care and National care pathways today and in 5 years**
*Brief (5mn each) overview of current situations and suggested aims in **Germany** (Rainer Surges), **Spain** (Rodrigo Rocamora); **Poland** (Katarzyna Kotulsk); **Romania** (Dana Craiu); **Portugal** (Francisco Sales)*
- **An open Q&A discussion with all participants**

10:30 : coffee break

11:00 - 12:00

Breakdown sessions : Translating brainstorming into next steps

- **The Clinical Trials and Targeted Therapies WG**
- **The Epilepsy Surgery-related Guidelines WG**
- **The Education & Training WG**
- **The White Paper on “Epilepsy Care Pathways in the EU” WG**
- **The ePAG Group priorities at a European level**

12:00 - 13:00

Debriefing and Closing Remarks

Chairs: Nicola Specchio (Italy) and Alexis Arzimanoglou (France)

- **The Clinical Trials and Targeted Therapies WG**
Report: R. Surges
- **The Epilepsy Surgery-related Guidelines WG**
Report: Ph. Ryvlin
- **The Education & Training WG**
Report: M. Malenica
- **The ePAG Group priorities at a European level**
Report: I. Brambilla & Allison Watson

13:00 : light lunch and departures