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À la recherche du temps perdu

In search of Lost Time

Building the EpiCARE 2027 Horizon

Rome

December, 16th - 18th 2021

Istituto Patristico Augustinianum

Hybrid Event

With the unconditional support of

BIOCODEX 

Faculty

<i>Alexis Arzimanoglou</i>	France
<i>Simona Balestrini</i>	UK / Italy
<i>Carmen Barba</i>	Italy
<i>Isabella Brambilla</i>	Italy
<i>Kees Braun</i>	The Netherlands
<i>Dana Craiu</i>	Romania
<i>Helen Cross</i>	UK
<i>Valentina De Giorgis</i>	Italy
<i>Luca de Palma</i>	Italy
<i>Elena Gardella</i>	Denmark
<i>Tiziana Granata</i>	Italy
<i>Alexander Hammers</i>	UK
<i>Alina Ivaniuk</i>	Ukraine
<i>Floor Jansen</i>	The Netherlands
<i>Lara Jehi</i>	USA
<i>Reetta Kalviainen</i>	Finland
<i>Katja Kobow</i>	Germany
<i>Matthias Koepp</i>	UK
<i>Teia Kobulashvili</i>	Austria
<i>Katarzyna Kotulska</i>	Poland
<i>Lieven Lagae</i>	Belgium
<i>Monica Lucente</i>	Italy
<i>Laura Mantoan</i>	UK
<i>Petr Marusic</i>	Czech Republic
<i>Rima Nabbout</i>	France
<i>Caroline Neuray</i>	UK
<i>Eleni Panagiotakaki</i>	France
<i>Carol-Anne Partridge</i>	UK
<i>Sylvain Rheims</i>	France
<i>Rodrigo Rocamora</i>	Spain
<i>Philippe Ryvlin</i>	Switzerland
<i>Bertrand Saby</i>	Spain
<i>Francisco Sales</i>	Portugal
<i>Katia Santoro</i>	Italy
<i>Nicola Specchio</i>	Italy
<i>Rainer Surges</i>	Germany
<i>Sébile Tchaicha</i>	France
<i>Paolo Tinuper</i>	Italy
<i>Eugen Trinka</i>	Austria
<i>Federico Vigevano</i>	Italy
<i>Allison Watson</i>	UK
<i>Sameer Zuberi</i>	UK

Local Organizing Committee

Federico Vigevano
Nicola Specchio
Luca de Palma

Italian EpiCARE Centers

Azienda USL di Bologna
IRCCS Istituto delle Scienze Neurologiche,
Bologna

Azienda Ospedaliero-Universitaria A. Meyer,
UO Neurologia Pediatrica, *Firenze*

Istituto Giannina Gaslini, *Genova*

Consortium
Fondazione IRCCS Istituto Neurologico Carlo Besta
ASST Niguarda Hospital
ASST Santi Paolo e Carlo Hospital, *Milano*

Fondazione Istituto Neurologico Nazionale
Casimiro Mondino, *Pavia*

IRCCS Ospedale Pediatrico Bambino Gesù,
Roma

Ospedale Civile Maggiore di Verona Borgo Trento,
Verona



Bambino Gesù Children's Hospital will host the Workshop under the Patronage of the Italian League Against Epilepsy and ILAE Europe.

The Workshop is also supported by the European Reference Network EpiCARE.



Timetable

Thursday, December 16th

Friday, December 17th

Saturday, December 18th

			08:30 - 10:30	Plenary Session #5
		09:00 - 13:00	Plenary Session #2	The ERN EpiCARE & Pathways for epilepsy care in the EU
			Guidelines for presurgical evaluation and epilepsy surgery	
			10:30 - 11:00	Coffee break
	11:10 - 11:30	Coffee break	11:00 - 12:00	Breakdown Sessions
	11:30 - 13:00	Plenary Session #2		
				Translating brainstorming into next steps
			Guidelines for presurgical evaluation and epilepsy surgery	
			12:00 - 13:00	Debriefing and Closing Remarks
	13:00 - 14:00	Lunch		
	14:00 - 16:30	Plenary Session #3		
14:15 - 14:30	Welcome Address			
14:30 - 16:30	Plenary Session #1			
	Clinical Trials on Rare and Complex Diseases			
				Studies & Trials: Clinically meaningful variables from a patient perspective, beyond seizure frequency
16:30 - 17:00	Coffee break	16:30 - 17:00	Coffee break	
17:00 - 19:00	Plenary Session #1	17:00 - 19:00	Plenary Session #4	
	Clinical Trials on Rare and Complex Diseases		YES session on Education & Training	
19:00	End of the day	19:00	End of the day	

Thursday, December 16th

13:00 - 14:00

Welcome light lunch

14:15 - 14:30

Welcome Address

A. Arzimanoglou (France) - H. Cross (UK) - N. Specchio (Italy) - F. Vigevano (Italy)

14:30 - 16:30

Plenary Session #1 - 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

Chairs: *S. Balestrini (UK, Italy) - S. Tchaicha (France)*

14:30 - 15:00

The ECET initiative and the role of ERN EpiCARE HCPs
A. Arzimanoglou (France)

15:00 - 15:30

Challenges in Neuronal Ceroid Lipofuscinosis clinical trials
N. Specchio (Italy)

15:30 - 16:00

Challenges in Progressive Myoclonus Epilepsy type 1 clinical trials
R. Kalviainen (Finland)

16:00 - 16:30

Challenges in Alternating Hemiplegia clinical trials
E. Panagiotakaki (France)

16:30 - 17:00

Coffee Break

17:00 - 19:00

Chairs: *R. Surges (Germany) - V. De Giorgis (Italy)*

17:00 - 17:30

Not drug-resistant FCDs: is a trial necessary
H. Cross (UK)

17:30 - 18:00

Challenges in Tuberous Sclerosis Complex clinical trials
L. Lagae (Belgium)

18:00 - 18:30

Challenges in SCN8A-complex clinical trials
E. Gardella (Denmark)

18:30 - 19:00

Challenges in ESES clinical trials
F. Jansen (The Netherlands)

Friday, December 17th

09:00 - 13:00

Plenary Session #2 - 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

Chair: *Teia Kobulashvili* (Austria) - *Eugen Trink* (Austria)

09:00 - 09:40

Input from Functional Neuroimaging
P. Marusic (Czech Republic)
in collaboration with **M. Koepp** (UK) and *A. Hammers* (UK)

09:40 - 10:20

Neuromodulation
P. Ryvlin (Switzerland) - *L. Jehi* (USA)

10:20 - 11:00

Epilepsy surgery in patients with identified (or possible) gene mutations:
where do we stand
K. Braun (The Netherlands)

11:10 - 11:30

Coffee break

11:30 - 13:00

Chairs: *C. Barba* (Italy) - *S. Rheims* (France)

11:30 - 12:15

The Pre-surgical evaluation Guidelines project
T. Kobulashvili (Austria) - *E. Trink* (Austria) and the *Guidelines working group*

12:15 - 13:00

The Epilepsy Surgery Guidelines project
L. de Palma (Italy) - *P. Ryvlin* (Switzerland) and the *Guidelines working group*

13:00 - 14:00

Lunch

14:00 - 16:30

Plenary Session #3 - 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

Chair: *Monica Lucente* (Italy) - *Rima Nababout* (France)

14:00 - 14:25

COST action-Burden of disease
I. Brambilla (Italy) - *R. Nababout* (France)

14:25 - 14:45	Meaningful endpoints in GLUT-1 deficiency trials <i>V. De Giorgis (Italy) - M. Lucente (Italy)</i>
14:45 - 15:05	Meaningful endpoints in Ring Chromosome 20 trials <i>A. Watson (UK) - S. Zuberi (UK)</i>
15:05 - 15:25	Meaningful endpoints in CDKL5 trials <i>C-A. Partridge (UK) and Kuopio medical team (Finland)</i>
15:25 - 15:45	Meaningful endpoints in SYNGAP 1 trials <i>B. Saby (Spain) and the Necker-Enfants Malades team (France)</i>
15:45 - 16:30	Chairs: <i>T. Granata (Italy) and ePAG LGS K. Santoro (Italy)</i> <i>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)</i>
16:30 - 17:00	Coffee break
17:00 - 19:00	Plenary Session #4 - 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: <i>H. Cross (UK) - F. Jansen (The Netherlands)</i>
17:00 - 17:30	Educating our peers - neurologists and epileptologists <i>L. Mantoan (UK)</i>
17:30 - 18:00	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: <i>M. Malenica (Croatia) - C. Neuray (UK)</i> Where are all the young people? "Career" obstacles
18:00 - 18:30	<ul style="list-style-type: none"> ▶ Early career - <i>A. Ivaniuk (Ukraine)</i> ▶ Mid-career - <i>K. Kobow (Germany)</i> ▶ Established career - <i>H. Cross (UK)</i>
18:30 - 18:45	YES – young epilepsy section in the ILAE and what we do for future leaders <i>L. De Palma (Italy)</i>
18:45 - 19:00	Mentoring and empowerment <i>C. Neuray (UK)</i>

Saturday, December 18th

08:30 - 10:30

Plenary Session #5 - 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?

Chairs: *P. Tinuper* (Italy) - *F. Vigevano* (Italy)

08:30 - 09:00

The ERN EpiCARE: a learning from the past update
A. Arzimanoglou (France)

09:00 - 09:25

Epilepsy Care and National care pathways today and in 5 years

- ▶ Overview of current situations and suggested aims in Germany
R. Surges
- ▶ Overview of current situations and suggested aims in Spain
R. Rocamora
- ▶ Overview of current situations and suggested aims in Poland
K. Kotulska
- ▶ Overview of current situations and suggested aims in Romania
D. Craiu
- ▶ Overview of current situations and suggested aims in Portugal
F. Sales

09:25 - 10:30

An open Q&A discussion with all participants

10:30 - 11:00

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: *A. Arzimanoglou* (France) - *N. Specchio* (Italy)

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

Registration

Please refer to the following internet site only:

www.rareepilepsyworkshops.net

Residential: max 100 participants

Registration will be possible until December 10th.
No on-site registration will be possible due to Covid-19 restrictions.

Registration Fees

Residential fee

€ 122,00 (including VAT 22%)

Residential fee for “Member of ERN EpiCare”

For members of the Health Care Providers, Full or Affiliated members of the ERN EpiCARE and ePAG advocates a registration is necessary.

The fee for admission to scientific sessions (**residential or virtual**) is waived. For those who wish to participate on site a hospitality fee (covering coffee breaks and lunches) of € 50,00 is requested. Travel and accommodation must be handled directly and expenses are not reimbursed.

Virtual fee

€ 73,20 (including VAT 22%)

Residential fee includes:

- ▶ Admission to scientific sessions
- ▶ Coffee breaks and lunches
- ▶ Certificate of attendance (via personal user area)

CME / ECM

The Course has not CME/ECM accreditation

Certificate of attendance

The certificate of attendance will be available on your personal user area at the end of the Course

Virtual Course joining link

A couple of days before the Course participants will receive the Zoom joining link

Course venue

Istituto Patristico Augustinianum

Via Paolo VI, 25 - 00193 Roma - Italy

Ph. +39 06 06 680069 - www.patristicum.org/it

Hotel accommodation (Faculty headquarter)

Starhotel Michelangelo

Via della Stazione di San Pietro, 14 - 00165 Rome

Ph. +39 06 06 398739 - Fax +39 06 632359

www.starhotels.com/it/i-nostri-hotel/michelangelo-roma/



Suggested hotels nearby the course venue

(availability and reservations must be handled directly)

Suore Missionarie Pallottine (religious house)

<https://www.casamissionariepallottine.it/>

NG Bed & Breakfast - Roma S. Pietro

<https://www.ngbbsanpietroroma.com/gallery>

Hotel Emmaus

<https://www.emmaushotel.com/>

Gregory B&B Vatican

<http://www.gregorybb.com/>

Organizing Secretariat



Meetings & Events

Via Nizza, 45 - 00198 Roma - Italy

Ph. +39 06 85355590 - fax +39 06 85356060

E-mail: maura.stella@ptsroma.it / Web: www.ptsroma.it

What do you need to enter in Italy

According to the origin of your country please refer to the following site (Italian Ministry of Health):

<https://www.salute.gov.it/portale/nuovocoronavirus/dettaglioContenutiNuovoCoronavirus.jsp?area=nuovoCoronavirus&id=5412&lingua=english&menu=vuoto>

Tests Area

Fiumicino Airport (Arrivals at Gate nbr 3 only)

In the arrival area of Terminal 3 it is possible to obtain the rapid swab from 00:00 AM to 08:00 PM every day and the molecular swab from 00:00 AM to 05:00 PM, for all passengers arriving or departing from Fiumicino airport.

To access the service, you just need to pre-register on-line at the following link:

<https://www.adr.it/form-preaccettazione>

and go directly to the "Test Area" at the airport:

<https://www.adr.it/web/aeroporti-di-roma-en/test-areas-at-the-airport>

Prices:

Antigen test – **Euro 20,00**

Molecular test – **Euro 69,88**

Payment can be done at the airport by credit or debit cards

Ciampino Airport

Tests Area not available

Near the Course Venue

Lab Artemisia Inghirami (either antigen and molecular tests)

Piazza dei Giureconsulti, 27 - Roma

Ph. +39 06 662 0392

Working hours: 07:00 AM - 01:00 PM / 02:00 PM - 07:30 PM

For appointments send a e-mail to: inghirami@artemisialab.it

Farmacia Leone (for antigen tests only)

Via di Porta Cavalleggeri, 3 - Roma

Ph. +39 06 634356

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