

# **In search of Lost Time in children and adolescents epilepsy**

## **À la recherche du temps perdu**



**Virtually in Rome, 17-18 December 2020**

## FACULTY

<i>Eleonora Aronica</i>	The Netherlands
<i>Alexis Arzimanoglou</i>	France
<i>Stéphane Auvin</i>	France
<i>Giulia Barcia</i>	France
<i>Francesca Bisulli</i>	Italy
<i>Ingmar Blumcke</i>	Germany
<i>Geraldine Boylan</i>	Ireland
<i>Isabella Brambilla</i>	Italy
<i>Kees Braun</i>	The Netherlands
<i>Antonino Caridi</i>	Italy
<i>Helen Cross</i>	UK
<i>Paolo Curatolo</i>	Italy
<i>Thierry Darcis</i>	France
<i>Carmen Fons</i>	Spain
<i>Tiziana Granata</i>	Italy
<i>Renzo Guerrini</i>	Italy
<i>Majid Jafar</i>	United Arab Emirates
<i>Floor Jansen</i>	The Netherlands
<i>Reetta Kalviainen</i>	Finland
<i>Teia Kobulashvili</i>	Austria
<i>Lieven Lagae</i>	Belgium
<i>Frans Leijten</i>	The Netherlands
<i>Gaetan Lesca</i>	France
<i>Monica Lucente</i>	Italy
<i>Tony Marson</i>	UK
<i>Petr Marusic</i>	Czech Republic
<i>Davide Mei</i>	Italy
<i>Rima Nabbout</i>	France
<i>Emma Nott</i>	UK
<i>Finbar O'Callaghan</i>	UK
<i>Carol-Anne Partridge</i>	UK
<i>Emilio Perucca</i>	Italy
<i>Ronit Pressler</i>	UK
<i>Georgia Ramantani</i>	Switzerland
<i>Torie Robinson</i>	UK
<i>Paolo Rossi</i>	Italy
<i>Philippe Ryvlin</i>	France
<i>Nicola Specchio</i>	Italy

<i>Eugen Trink</i>	Austria
<i>Maurizio Tagliatela</i>	Italy
<i>Laura Tassi</i>	Italy
<i>Enrique Terol</i>	Belgium
<i>Paolo Tinuper</i>	Italy
<i>Federico Vigevano</i>	Italy
<i>Allison Watson</i>	UK
<i>Federico Zara</i>	Italy
<i>Sameer Zuberi</i>	UK

## Italian Network EpiCARE

*Tiziana Granata*  
*Renzo Guerrini*  
*Emilio Perucca*  
*Nicola Specchio*  
*Paolo Tinuper*  
*Federico Vigevano*

## Scientific Committee

*Alexis Arzimanoglou*  
*Isabella Brambilla*  
*Kees Braun*  
*Helen Cross*  
*Tiziana Granata*  
*Renzo Guerrini*  
*Lieven Lagae*  
*Gaetan Lesca*  
*Rima Nabbout*  
*Emilio Perucca*  
*Ronit Pressler*  
*Nicola Specchio*  
*Paolo Tinuper*  
*Eugen Trink*  
*Federico Vigevano*

# Timetable

		08:30	Session #5
09:00	Welcome Address	10:30	Break
09:30	Session #1	10:45	Session #6
11:00	Break	12:30	Break
11:15	Session #2	13:30	Session #7
13:15	Break	15:15	Break
14:00	Session #3	15:30	Session #8
15:30	Break	17:00	Break
15:45	Session #4	17:15	Session #9
17:45	Discussion and end of the day	19:15	Closing remarks and end of the meeting

# 17 December 2020, Thursday

09:00 – 09:30 **Welcome Address**

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## Session #1

***National networks and their role in implementing Guidelines in everyday clinical practice for the top-5 rare & complex epilepsies (including Dravet Syndrome, Lennox-Gastaut Syndrome, CLN2, Tuberous Sclerosis, Infantile Spasms)***

**Chairs:** *Nicola Specchio - Eugen Trink*

09:30 – 09:45 **Clinical Practice Guidelines – The holy grail in Evidence Based Medicine?**  
*Eugen Trink*

09:45 – 10:00 **Guidelines for Rare and Complex Epilepsies**  
*Nicola Specchio*

10:00 – 10:15 **Methodological Lecture**  
*Teia Kobulashvili*

10:15 – 10:30 **Impact of Guidelines on Prevention of Health Care Errors and improvement of Patient Safety**  
*Tony Marson*

10:30 – 11:00 **General discussion**

11:00 – 11:15 *Break*

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## Session #2

**A 3 years strategy for implementing EEG monitoring guidelines for neonates in the EU**

**Chairs:** *Carmen Fons - Ronit Pressler*

11:15 – 11:35 **What are the immediate challenges of seizures in neonatal period?**  
*Linda de Vries*

11:35 – 11:55 **When neonatal seizures are more than ‘just’ acute symptomatic? EEG as a biomarker in early onset epilepsies**  
*Ronit Pressler*

11:55 – 12:15 **Optimizing investigations for inborn errors of metabolism presenting with early onset epilepsy**  
*Carmen Fons*

12:15 – 12:35 **How can we optimize neonatal EEG monitoring across Europe? EEG guidelines and automatic seizure detection**  
*Geraldine Boylan*

12:35 – 13:15 **General discussion**

13:15 – 14:00 *Break*

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### Session #3

#### What do we learn from surgery case-reports operated on very early in the course of the epilepsy?

Chairs: *Ingmar Blumke - Tiziana Granata*

- 14:00 – 14:15 **Differences in outcome when operating on diffuse lesions: how “young” is “young”?**  
*Helen Cross*
- 14:15 – 14:30 **What can children really learn from adults (do large lobar resections in very young children compromise long-term outcome)?**  
*Georgia Ramantani*
- 14:30 – 14:45 **Is the “duration of epilepsy” criterion always pertinent?**  
*Alexis Arzimanoglou*
- 14:45 – 15:00 **Is the criterion of “drug resistance” always pertinent and for whom?**  
*Laura Tassi*
- 15:00 – 15:30 General discussion
- 15:30 - 15:45 *Break*

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### Session #4

#### Early genetic screening: when, for whom and how

Chairs: *Renzo Guerrini - Gaëtan Lesca*

- 15:45 – 15:50 **Opening presentation**  
*Renzo Guerrini*
- 15:50 – 16:05 **Genetic testing in diseases with epileptic seizures as the entry symptom epileptic:**
  - **How to proceed with genetic analysis**  
*Davide Mei*
- 16:05 – 16:20
  - **How to use genetic analysis in 2020**  
*Gaëtan Lesca*
- 16:20 – 16:35
  - **Collaborations with clinicians**  
*Renzo Guerrini*
- 16:35 – 16:50 **Experience/diagnostic algorithms of different centers**
  - *Federico Zara*
- 16:50 – 17:05
  - *Amy McTague*
- 17:05 – 17:20
  - *Giulia Barcia*
- 17:20 – 17:45 General discussion and end of the day

## 18 December 2020, Friday

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### Session #5

#### Targeted medical therapies and clinical trials: identifying the EU priorities for the next 5 years

Chairs: *Emilio Perucca - Federico Vigevano*

- 08:30 – 08:50 **From functional mechanisms to targeted treatments**  
**I. Setting priorities for monogenic epilepsies**  
*Maurizio Tagliatela*
- 08:50 – 09:10 **From functional mechanisms to targeted treatments**  
**II. Setting priorities for other rare epilepsies**  
*Eleonora Aronica*
- 09:10 – 09:30 **Challenges in designing clinical trials**  
*F. O'Callaghan*
- 09:30 – 09:50 **Challenges in developing treatments for rare epilepsies**  
*Thierry Darcis*
- 09:50 – 10:10 **EU challenges to foster development of new treatments for children**  
*Paolo Rossi*
- 10:10 – 10:30 General discussion
- 10:30 – 10:45 *Break*

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### Session #6

#### What should be the role of the ERNs in 2030: first thoughts on the evolution of EpiCARE

Chairs: *Alexis Arzimanoglou - Helen Cross*

- 10:45 – 11:05 **Learning from ERNs experiences: ambitions and 2030 perspectives**  
*Enrique Terol*
- 11:05 – 11:25 **The ERN EpiCARE at the service of clinical practice in 2030**  
*Reetta Kalviainen*
- 11:25 – 11:45 **The ERN EpiCARE at the service of Research in 2030**  
*Kees Braun*
- 11:45 – 12:05 **Platforms for all stakeholders to come together**  
*Eugen Trinkla*
- 12:05 – 12:30 General discussion
- 12:30 – 13:30 *Break*

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## Session #7

### Patients building bridges with the scientific world

Chairs: *Isabella Brambilla* (ePAG - coordinator) - *Torie Robinson* (ePAG) - *Nicola Specchio*

**The Role of Patients in ERNs - challenges - collaborations – achievements**

*Torie Robinson*

**From natural history to research and care**

*Isabella Brambilla* (ePAG - coordinator)

**KETONET: a patient-driven app improving medical control and patient compliance in the ketogenic diet**

*Monica Lucente* (ePAG)

13:30 – 14:45

**The power of a foundation of patients to advancing research**

*Antonino Caridi* (CDKL5Alliance), *Majid Jafar* (LouLou Foundation)

**Patient Advocacy bringing laser surgery to UK and Europe Challenges and Opportunities**

*Emma Nott* (ePAG)

**Patient journeys – addressing common unmet needs**

*Allison Watson* (ePAG)

14:45 – 15:15

General discussion

15:15 – 15:30

Break

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## Session #8

### Undiagnosed epilepsy patients, how to build a patient centered care pathway

Chairs: *Lieven Lagae* - *Paolo Tinuper*

15:30 – 15:50

**New perspectives in diagnosing epilepsy: how to deal with challenging semiology and the evolution of the concept of syndromes**

*Floor Jansen*

15:50 – 16:10

**Etiology versus seizures: neuroprotection vs neurodevelopment. Insights from preclinical and clinical studies**

*Rima Nabhout*

16:10 – 16:30

**The lost generation: what an adult neurologist could still do?**

*Francesca Bisulli*

16:30 – 17:00

General discussion

17:00 – 17:15

Break

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## Session #9

### Digitalized tools at the service of epilepsy care

**Chairs:** *Paolo Curatolo - Petr Marusic*

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|---------------|---|
| 17:15 – 17:35 | <b>Do mobile apps improve self-management?</b><br><i>Stéphane Auvin</i>             |
| 17:35 – 17:55 | <b>Utilizing Video to enhance management (vCreateNeuro)</b><br><i>Sameer Zuberi</i> |
| 17:55 – 18:15 | <b>Back to the future; online prediction models</b><br><i>Kees Braun</i>            |
| 18:15 – 18:35 | <b>What about wearables?</b><br><i>Frans Leijten</i>                                |
| 18:35 – 18:55 | <b>How do machines learn and what can they teach us?</b><br><i>Philippe Ryvlin</i>  |
| 18:55 – 19:15 | General discussion, closing remarks and end of the meeting                          |

### *Participation*

*Participation to the Virtual Conference is free of charge*

### *Certificate of attendance*

*The certificate of attendance will be sent to all participants*

### *Registration*

*Registration is compulsory, please refer to:  
[www.ptsroma.it/romaepicare2020](http://www.ptsroma.it/romaepicare2020)*

*For further information please refer to the:*

### *Organizing Secretariat*



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