

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 |

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|------------------------------|---------|
| <i>Eugen Trink</i> | Austria |
| <i>Maurizio Taglialatela</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

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|-------|-------------------------------|-------|---|
| | | 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**

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*

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*

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*

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

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*

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*

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

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

Session #9

Digitalized tools at the service of epilepsy care

Chairs: *Paolo Curatolo - Petr Marusic*

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|---------------|---|
| 17:15 – 17:35 | Do mobile apps improve self-management? <i>Stéphane Auvin</i> |
| 17:35 – 17:55 | Utilizing Video to enhance management (vCreateNeuro) <i>Sameer Zuberi</i> |
| 17:55 – 18:15 | Back to the future; online prediction models <i>Kees Braun</i> |
| 18:15 – 18:35 | What about wearables? <i>Frans Leijten</i> |
| 18:35 – 18:55 | How do machines learn and what can they teach us? <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*

For further information please refer to the:

Organizing Secretariat



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