

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

**À la recherche du temps perdu**



**Rome, 17-19 December 2020**

Provisional Venue  
**Pontificia Università Urbaniana**

## **Italian Network EpiCARE**

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

## **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 Trinkka, Federico Vigeveno*

# TIMETABLE

	<b>17 December 2020, Thursday</b>		<b>18 December 2020, Friday</b>		<b>19 December 2020, Saturday</b>
		<b>08:30</b>	Plenary session #3	<b>08:30</b>	Plenary session #6
		<b>10:30</b>	Break	<b>10 :30</b>	Break & Poster Session
		<b>11:00</b>	Plenary session #4	<b>11 :30</b> <b>13 :00</b>	Parallel session #5
<b>11:30</b>	Welcome Lunch	<b>13:00</b>	Lunch & Poster Session	<b>11 :30</b> <b>13 :00</b>	Parallel session #6
<b>12:30</b>	Welcome Address	<b>14:30</b> <b>16:00</b>	Parallel session #3	<b>13:00</b>	Closing Remarks
		<b>14:30</b> <b>16:00</b>	Parallel session #4	<b>13:30</b>	Lunch
<b>13:00</b>	Plenary session #1	<b>16:00</b>	Break 30 min		
<b>14:30</b>	Break	<b>16:30</b> <b>18:30</b>	Plenary session #5		
<b>15:00</b> <b>17:00</b>	Parallel session #1	<b>18:30</b>	End of the day		
<b>15:00</b> <b>17:00</b>	Parallel session #2	<b>19 :00</b>	Social Event		
<b>17:00</b>	Break				
<b>17:30</b>	Plenary session #2				
<b>19:30</b>					
<b>20:00</b>	Dinner	<b>19:00</b>	Dinner		

## **Plenary Sessions**

### **Session 1**

**National networks and their role in implementing Guidelines in everyday clinical practice for the top-5 rare & complex epilepsies**

*Nicola Specchio – Eugen Trinka*

### **Session 2**

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

*Renzo Guerrini - Gaetan Lesca*

### **Session 3**

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

*Emilio Perucca - Federico Vigevano*

### **Session 4**

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

*Alexis Arzimanoglou - Helen Cross*

### **Session 5**

**Patients building bridges with the scientific world**

*Isabella Brambilla*

### **Session 6**

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

*Lieven Lagae - Paolo Tinuper*

## **Parallel Sessions**

### **Session 1**

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

*Carmen Fons - Ronit Pressler*

### **Session 2**

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

**What can be extrapolated and how to obtain answers for the remaining challenges.**

*Alexis Arzimanoglou - Helen Cross*

### **Session 3**

**Focusing Education and Training of adult and child neurologists in the EU on early diagnosis and treatment: thoughts on a strategic implementation plan for the next 5 years**

*Tiziana Granata - Paolo Tinuper*

### **Session 4**

**Epilepsy Alliance Europe and Pharma: establishing a sustainable partnership**

*Alexis Arzimanoglou - Eugen Trinka*

### **Session 5**

**Digitalized tools as future approach to improve care and management of patients with complex epilepsies.**

*Kees Braun - Philippe Ryvlin*

### **Session 6**

**Early Neurodevelopment screening and Epilepsy Care**

*Rima Nabbout*

## Plenary session 1

***National networks and their role in implementing Guidelines in everyday clinical practice for the top-5 rare & complex epilepsies***

**Chairs: Nicola Specchio - Eugen Trinkka**

- 1) **Clinical Practice Guidelines – The holy grail in Evidence Based Medicine?** *Eugen Trinkka*
- 2) **Guidelines for Rare and Complex Epilepsies** – *Nicola Specchio*
- 3) **Methodological Lecture** – *T. Kobulashvili*
- 4) **Impact of Guidelines on Prevention of Health Care Errors and improvement of Patient Safety** – *T. Marson*

## Plenary Session 2

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

**Chairs: Renzo Guerrini - Gaëtan Lesca**

- 1) **Opening presentation, transition with session 1** - *Renzo Guerrini*
- 2) **Genetic testing in epileptic disorders:**
  - **How to proceed with genetic analyses** - *Davide Mei*
  - **How to use genetic analysis in 2020** - *Gaëtan Lesca*
  - **Collaboration with clinicians** - *Renzo Guerrini*
- 3) **Experience/diagnostic algorithms of different centers**
  - *Federico Zara*
  - *Amy McTague*
  - *Giulia Barcia*
- 4) **Final Discussion**

## Plenary session 3

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

**Chairs: Emilio Perucca - Federico Vigevano**

- 1) **From functional mechanisms to targeted treatments – I. Setting priorities for monogenic epilepsies** - *Maurizio Taglialetela*
- 2) **From functional mechanisms to targeted treatments – II. Setting priorities for other rare epilepsies** – *Eleonora Aronica*
- 3) **Conducting clinical trials in rare and complex epilepsy: Finding solutions**  
*Ralph. D. Hilgers*
- 4) **Challenges in designing clinical trials in DEEs** - *F. O'Callaghan - UK*

## Plenary session 4

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

Chairs: Alexis Arzimanoglou - Helen Cross

- 1) **Learning from ERNs experiences: Ambitions and 2030 perspectives** - *Enrique Terrol*
- 2) **The ERN EpiCARE at the service of clinical practice in 2030** - *Reetta Kalviainen*
- 3) **The ERN EpiCARE at the service of Research in 2030** - *Kees Braun*
- 4) **Discussion**

## Plenary session 5

***Patients building bridges with the scientific world***

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

- 1) **The Role of Patients in ERNs - challenges - collaborations – achievements** - *Torie Robinson*
- 2) **From natural history to research and care** - *Isabella Brambilla* (ePAG - coordinator)
- 3) **KETONET: a patient-driven app improving medical control and patient compliance in the ketogenic diet** - *Monica Lucente* (ePAG)
- 4) **The power of a foundation of patients to advancing research** - *Antonino Caridi* (CDKL5Alliance)  
Majid Jafar (LouLou Foundation)
- 5) **Patient Advocacy bringing laser surgery to UK and Europe Challenges and Opportunities**  
*Emma Nott* (ePAG)
- 6) **Patient journeys – addressing common unmet needs** - *Allison Watson* (ePAG)
- 7) **Discussion Q&A Testimonials** Alexis Arzimanoglou - Rima Nabbout

## Plenary Session 6

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

Chairs: *Lieven Lagae* - *Paolo Tinuper*

- 1) **New perspectives in diagnosing epilepsy: how to deal with challenging semiology**  
*Floor Jansen*
- 2) **Is there a future for the concept of epileptic syndromes?** - *Sameer Zuberi*
- 3) **Managing undiagnosed epilepsies when targeted therapies are not yet available**  
*Thomas Bast*
- 4) **The lost generation: what an adult neurologist could still do?** - *Francesca Bisulli*

## Parallel session 1

### Biomarkers of neonatal seizures and early onset epilepsies

Chairs: *Carmen Fons - Ronit Pressler*

- 1) What are the immediate challenges of seizures in neonatal period? - *Linda de Vries*
- 2) When neonatal seizures are more than 'just' acute symptomatic? EEG as a biomarker in early onset epilepsies - *Ronit Pressler*
- 3) Optimizing *investigations for inborn errors of metabolism presenting with early onset epilepsy (20+5 min)* *Carmen Fons*
- 4) How can we optimize neonatal EEG monitoring across Europe? EEG guidelines and automatic seizure detection - *Geraldine Boylan*
- 5) Discussion

## Parallel session 2

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

Chairs: *Alexis Arzimanoglou - Helen Cross*

- 1) Differences in outcome when operating on diffuse lesions: how "young" is "young"?  
*Helen Cross - UK*
- 2) What can children really learn from adults (do large lobar resections in very young children compromise long-term outcome)? - *Georgia Ramantani*
- 3) Is the "duration of epilepsy" criterion always pertinent? - *Alexis Arzimanoglou*
- 4) Is the criterion of "drug resistance" always pertinent and for whom? - *Laura Tassi*

## Parallel session 3

### Focusing Education and Training in the EU on early diagnosis and treatment: thoughts on a strategic implementation plan for the next 5 years

Chairs: *Tiziana Granata - Paolo Tinuper*

- 1) How new educational and teaching programs could be used in EpiCARE setting? *Reiner Surges*
- 2) Teaching the doctors: Should the ILAE competency-based curriculum be implemented to managing rare and complex epilepsies? *Ingmar Blumcke*
- 3) Round Table: *Tiziana Granata - Petr Marusic*  
Teaching the epilepsy nurses and the social workers - *Theo Tong*  
Teaching the families and the caregivers - *Isabella Brambilla - Carol-Anne Partridge*

## Parallel Session 4

**Epilepsy Alliance Europe and Pharma: establishing a sustainable partnership**

*Chairs: Alexis Arzimanoglou - Eugen Trinkka*

- 1) Epilepsy Alliance Europe: The platform for all stakeholders to come together** - *Eugen Trinkka*
- 2) EU initiatives to foster development of new treatments for children** – *Paolo Rossi*
- 3) Challenges in developing treatments for pediatric epilepsies** - *Thierry Darcis*

## Parallel Session 5

**Digitalized tools at the service of epilepsy care**

*Chairs: Kees Braun - Philippe Ryvlin*

- 1) Do mobile apps improve self-management?** - *Stephan Auvin*
- 2) Back to the future; online prediction models** - *Kees Braun*
- 3) What about wearables?** - *Frans Leijten*
- 4) How do machines learn and what can they teach us?** - *Philippe Ryvlin*

## Parallel Session 6

**Early Neurodevelopment screening and Epilepsy Care**

*Chair: Rima Nabbout – Paolo Curatolo*

- 1) Etiology versus seizures: neuroprotection vs neurodevelopment. Insights from preclinical and clinical studies** - *Rima Nabbout*
- 2) " Un train peut en cacher un autre": suspect, diagnose and adjust the care for ASD from childhood to adulthood** – *L. Ouss - Marco Mula*
- 3) When, how and what for? Follow the neurodevelopment train and do not fall behind** (interactive session) - *Delphine Breuillard - Francesca Ragona*



## FACULTY

<i>Aronica Eleonora</i>	The Netherlands
<i>Arzimanoglou Alexis</i>	France
<i>Auvin Stéphane</i>	France
<i>Barcia Giulia</i>	France
<i>Bast Thomas</i>	Germany
<i>Bisulli Francesca</i>	Italy
<i>Blumcke Ingmar</i>	Germany
<i>Boylan Geraldine</i>	Ireland
<i>Brambilla Isabella</i>	Italy
<i>Braun Kees</i>	The Netherlands
<i>Breillard Delphine</i>	France
<i>Caridi Antonino</i>	Italy
<i>Cross Helen</i>	UK
<i>Curatolo Paolo</i>	Italy
<i>Darcis Thierry</i>	France
<i>de Vries Linda</i>	The Netherlands
<i>Fons Carmen</i>	Spain
<i>Granata Tiziana</i>	Italy
<i>Guerrini Renzo</i>	Italy
<i>Hilgers Ralph D.</i>	Germany
<i>Jafar Majid</i>	United Arab Emirates
<i>Jansen Floor</i>	The Netherlands
<i>Kalviainen Reetta</i>	Finland
<i>Kobulashvili Teia</i>	Austria
<i>Lagae Lieven</i>	Belgium
<i>Leijten Frans</i>	The Netherlands
<i>Lesca Gaetan</i>	France
<i>Lucente Monica</i>	Italy
<i>Marson Tony</i>	UK
<i>Marusic Petr</i>	Czech Republic
<i>Mc Tague Amy</i>	UK
<i>Mei Davide</i>	Italy
<i>Mula Marco</i>	UK
<i>Nabbout Rima</i>	France
<i>Nott Emma</i>	UK
<i>O'Callaghan Finbar</i>	UK
<i>Ouss Lisa</i>	France
<i>Partridge Carol-Anne</i>	UK
<i>Perucca Emilio</i>	Italy
<i>Pressler Ronit</i>	UK
<i>Ragona Francesca</i>	Italy

<i>Ramantani Georgia</i>	Switzerland
<i>Robinson Torie</i>	UK
<i>Rossi Paolo</i>	Italy
<i>Ryvlin Philippe</i>	France
<i>Specchio Nicola</i>	Italy
<i>Surges Reiner</i>	Germany
<i>Taglialatela Maurizio</i>	Italy
<i>Tassi Laura</i>	Italy
<i>Terrol Enrique</i>	Belgium
<i>Tinuper Paolo</i>	Italy
<i>Tong Theo</i>	France
<i>Trinka Eugen</i>	Austria
<i>Vigevano Federico</i>	Italy
<i>Watson Allison</i>	UK
<i>Zara Federico</i>	Italy
<i>Zuberi Sameer</i>	UK

*(The above is the Faculty list as of July 22nd)*

## PROVISIONAL VENUE

Pontificia Università Urbaniana  
Via Urbano VIII, 16  
Roma – Vatican City

Established in 1627, Pontificia Università Urbaniana (Pontifical Urbaniana University) is a non-profit private higher education institution located in the urban setting of the large city of Roma.

State Pontificia Università Urbaniana (PUU) is a very small (enrollment range: 1,000-1,999 students) coeducational higher education institution.

Its campus is located on the Janiculum Hill of Rome, in the territory of the Vatican city.

The complex is surrounded by a large green area which ensures privacy and peace.

The ancient building's main hall accommodates 450 people and is equipped with advanced technology systems.

With a pleasant walk of about 30' you will be in the heart of historic Rome, Piazza Navona, Largo Argentina, Campo dei Fiori and the Pantheon will leave you breathless.

**REGISTRATION FEE (subject to VAT 22%)**

€ 280,00

## THE REGISTRATION FEE INCLUDES

- ❖ Scientific Sessions
- ❖ Congress kit
- ❖ Certificate of attendance
- ❖ Coffee and lunches as in the program
- ❖ Welcome dinner on December 18<sup>th</sup>
- ❖ European MCE credits

*For registration and payment please refer to [www.ptsroma.it/epiCARE2020](http://www.ptsroma.it/epiCARE2020)*

*The web-site will be available starting September 3rd*

## ORGANIZING SECRETARIAT



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