

In Search of Lost Time 7 – Scientific Program (Preliminary)

Rome, November 11th-13th 2026

Istituto Patristico Augustinianum, Rome Italy

We are delighted to welcome you to the 7th edition of *In Search of Lost Time*, a workshop designed to bring together the many disciplines involved in the care and research of complex epilepsies.

Clinicians, researchers, geneticists, surgeons, neuropsychologists, patient advocates, and industry partners will share knowledge and perspectives on the rapidly evolving field of precision medicine, epilepsy surgery, developmental outcomes, and emerging therapies.

Beyond scientific advances, this meeting aims to foster open discussion and collaboration, always keeping in focus what matters most for patients and families: improving quality of life and long-term outcomes.

We warmly welcome you to Rome and hope this workshop will be scientifically inspiring, collaborative, and enjoyable for all participants.

Scientific Organizing Committee

Chairs: Nicola Specchio, Alexis Arzimanoglou

Sandra Silva Arrieta
Stephane Auvin
Carmen Barba
Kees Braun
Andreas Brunklaus
Cinzia Correale
Helen Cross
Carmen Fons
Floor Jansen

Elena Gardella
Kasia Kotulska-Jóźwiak
Lieven Lagae
Gaetan Lesca
Rima Nabbout
Andrea Palacio
Laura Tassi
Martin Tisdall
Federico Vigevano

WEDNESDAY, NOVEMBER 11TH 2026

12H45: Welcome

Nicola Specchio, Massimiliano Raponi, Federico Vigeveno, Alexis Arzimanoglou

Session 1 – 13H00-15H00

Etiology-Specific Epilepsy Syndromes in the Era of Precision Medicine

Chairs: *Stéphane Auvin* (Paris, France) · *Elena Gardella* (Dianalund, Denmark)

- Etiology-specific spectrum of epilepsy syndromes: widening the concept of etiology specific epilepsies
Nicola Specchio (Rome, Italy)
- mTORopathies: From Genetic Landscape to Targeted Therapies
Floor Jansen (Utrecht, The Netherlands)
- Hypothalamic Hamartoma Beyond Gelastic Seizures: Expanding the Treatment Paradigm
Sophie Varadkar (London, UK)
- GLUT1 Deficiency Syndrome: Phenotypic Spectrum and Dietary Precision—How Strict Is Enough?
Valentina De Giorgis (Pavia, Italy)

15.00 – 15.30 BREAK

Session 2 – 16H00-17H30

Channelopathies I: GRIN and SYNGAP1 Disorders

Chairs: *Gaëtan Lesca* (Lyon, France) · *Ronit Pressler* (London, UK)

Glutamate Receptor Ionotropic, NMDA

- From Genotype to Phenotype: Clinical and Genetic Insights
Johannes Lemke (Leipzig, Germany)
- Functional Mechanisms and Emerging Targeted Therapies
Xavier Altafaj (Barcelona, Spain)
- Living with GRIN Disorders: The Patient Perspective
Sandra Silva Arrieta (Patient advocate) (Barcelona Spain)

Discuss with the panel of speakers

Synaptic Ras GTPase-activating protein (SYNGAP1)

- Clinical Spectrum and Natural History
Simona Balestrini (Firenze, Italy)
- Genetics and Modifier Mechanisms
Selena Aranda (Barcelona, Spain)

Discuss with the panel of speakers

END OF ACCREDITED EDUCATION ACTIVITIES

THURSDAY, NOVEMBER 12TH 2026

Session 4 – 08H30-10H00

Channelopathies II: SCN and KCNT1 Disorders

Chairs: Marina Trivisano (Rome, Italy) · Masa Malenica (Zagreb, Croatia)

Sodium voltage-gated Channel (SCN)

- From Variants to Function: In Silico Prediction and Clinical Interpretation
Rikke Müller (Dianalund, Denmark)
- SCN2A and Beyond: Functional Insights and Therapeutic Opportunities
Holger Lerche (Tübingen, Germany)

Potassium Sodium-Activated Channel Subfamily T Member 1 (KCNT1)

- Integrating Clinical, Genetic, and Functional Data in KCNT1 Disorders
Rima Nabbout (Paris, France)

Discuss with the panel of speakers

10.00 – 10.30 BREAK

Session 5 – 10H30-12H00

Early Surgery in patients with non-drug-resistant epilepsy

Chairs : Luca de Palma (Rome, Italy) · Petr Marusic (Prague, Czech Republic)

- Natural history of focal lesional epilepsy in children: is non-surgical “cure” an option?
Alexis Arzimanoglou (Barcelona, Spain)
- The (obvious) benefits of early surgery versus risks (if any?)
Kees Braun (Utrecht, The Netherlands)
- Can we proceed to surgery without ictal VEEG?
Laura Tassi (Milano, Italy)
- Physicians’ and parents’ attitude towards immediate surgery
Awin Chari (London, UK)

Discuss with the panel

Session 6 – 12H00-13H00

Hemispherotomy: Balancing Seizure Control and Neurodevelopmental Outcomes

Chairs: *Eugen Trinka* (Salzburg, Austria) · *Alexis Arzimanoglou* (Barcelona, Spain)

- Who and When? Indications, Pitfalls, and Surgical Risks
Martin Tisdall (London, UK)
- Seizure Outcomes Across the Lifespan: Identifying Red Flags
Georgia Ramantani (Zürich, Switzerland)
- After Surgery: Neurodevelopmental Trajectories and What Truly Matters
Andrea Palacio (Barcelona, Spain)

Discuss with the panel of speakers

13.00 – 14.15 LUNCH BREAK

Session 7 – 14H15-15H45

Non-Seizure Outcomes in drug-resistant epilepsies

Chairs: *Matthias Koepp* (London, UK) · *Isabella Brambilla* (Patient Advocate) (Verona, Italy)

- Reframing Outcomes: Insights from Basic Science Beyond Seizure Control
Gabriele Lignani (London, UK)
- The Hidden Burden: Caregiver Outcomes in Drug-Resistant Epilepsy
Colin Reilly (Gothenburg, Sweden)
- Beyond Seizures: Redefining Clinical Priorities and Real-World Decision-Making *Speaker:*
Lieven Lagae (Leuven, Belgium)

Panel Discussion on Rethinking Success: What Truly Matters Beyond Seizure Reduction?

END OF ACCREDITED EDUCATION ACTIVITIES

FRIDAY, NOVEMBER 13TH 2026

Session 9 – 08H30-12H00

The future: Giving the floor to the next generation of clinicians & researchers

Chairs: *Guido Rubboli* (Dianalund, Denmark) · *Federico Vigeveno* (Rome, Italy)

- 08:30 Epileptic encephalopathy as the presenting manifestation of propionic aciduria in infancy
Afruz Umarova (Tashkent, Uzbekistan)
- 08:40 The GABAA-Receptor Portal: An Interactive Webtool for Variant Interpretation Integrating Multimodal Data
Rebekka Dahl (Dianalund, Denmark)
- 08:50 The role of de novo variants in neurodevelopmental disorders with epilepsy
Hamidah Ghani (Dublin, Ireland)
- 09:00 Epilepsy Gene Panel Findings in Adults with MRI-Negative Drug-Resistant Focal Epilepsy
Aurelija Daskevociute (Vilnius, Lithuania)
- 09:10 Paralogues in parallel: functional and clinical convergence in GABRB1, GABRB2 and GABRB3 related neurological disorders
Sebastian Ortiz (Dianalund, Danimarca)
- 09:20 N=1-study, improved cognitive and behavioral outcomes following L-serine supplement in GRIN2A loss of function
Lisa Hauger (Oslo, Norway)
- 09:30 GRIN-associated epilepsy
Ekaterina Suvorova (Izhevsk, Russian Federation)
- 09:40 Quantifying neurodevelopmental MRI abnormalities in SCN1A
Milly Hang Chi Mak (London, United Kingdom)
- 09:50 Cognitive and adaptive outcome across the spectrum of SCN8A-related disorders
Francesca Maccarelli (Dianalund, Danimarca)
- 10:00 Diffusion MRI abnormalities localize the epileptogenic zone in children with drug-resistant epilepsy
Damjan Veljanoski (London, United Kingdom)
- 10:10 Stereoencephalography Guided Radiofrequency Thermocoagulation (SEEG RF-TC): Single Center Experience in Optimising Lesioning Parameters
Tatjana Liakina (Gothenburg, Sweden)
- 10:20 Epilepsy surgery prior to drug resistance in children with epilepsy: an European retrospective cohort study
Danique R.M. Vlaskamp (Utrecht, Netherlands)
- 10.30 – 11.00 BREAK
- 11.00 Epilepsy beyond seizures: the impact of functional neurological disorders on diagnosis, treatment and outcome in pediatric rare and complex epilepsies
Roberta Solazzi (Milan, Italy)
- 11.10 Pearls and Pitfalls of NREM-SWI in D/EE-SWAS: longitudinal electroclinical coupling from a single-centre Experience
Giulia Bellone (Dianalund, Danimarca)

- 11.20 Sleep-dependent memory network dysfunction in self-limited epilepsy with centrotemporal spikes
Rouge Coralie (Brussels, Belgium)
- 11.30 Sleep instability in GLUT1 Deficiency syndrome
Carlo Alberto Quaranta (Pavia, Italy)
- 11.40 Spike-Wave Activation in Sleep (SWAS) in SHANK3-related Phelan-McDermid Syndrome (PMS): A Multicenter Case Series
Francesca Ferraro (Pavia, Italy)

Session 10 – 12H00-14H00

Non-Seizure Outcomes in Developmental and Epileptic Encephalopathies (DEEs)

Chairs: · *Reetta Kälviäinen* (Kuopio, Finland), *Mortem Lossius* (Osle, Norway)

- Charting the Course: Natural History and Developmental Trajectories in DEEs
Andreas Brunklaus (Glasgow, Scotland)
- From Floor Effects to Real Change: Measuring What Matters in Cognition and Behaviour
Cinzia Correale (Rome, Italy)
- Beyond Seizures: Behavioural, Psychiatric, and Developmental Profiles in DEEs
Kasia Kotulska-Jóźwiak (Warsaw, Poland)
- Defining What Counts: Quality of Life and Meaningful Outcomes in DEEs
Jose Aibar (Patient advocate) (Madrid, Spain)

Panel Discussion: From Trajectories to Impact: What Makes Non-Seizure Outcome Meaningful?

END OF ACCREDITED EDUCATION ACTIVITIES

14.00 – 14.45 LIGHT LUNCH

INDUSTRY SPONSORED SESSIONS

WEDNESDAY, NOVEMBER 11TH 2026

Session 3 – 17H30-18H30

The New Frontier: Navigating Emerging Therapies together with Pharma - I

Chairs: *Sébile Tchaicha* (Lyon, France) · *Nicola Specchio* (Rome, Italy)

- 17:30 Updates from the DEEp clinical development program for the treatment of seizures in developmental and epileptic encephalopathies (DEEs)
Mette Foged (Lundbeck)
- 17:50 Radiprodil, an Investigational GluN2B-Selective Negative Allosteric Modulator of NMDA Receptors: Expanded Interim Analysis of the Phase 1b Honeycomb Study in GRIN-Related Neurodevelopmental Disorder (GRIN-NDD)
TBC (Neurvati)
- 18:10 RNA therapeutics for targeted genetic upregulation in DEEs and ASCEND Phase 1/2 in *SYNGAP1*
Yuri Maricich (CAMP4 Therapeutics)

THURSDAY, NOVEMBER 12TH 2026

Session 8 - 16H00-18H40

The New Frontier: Navigating Emerging Therapies together with Pharma - II

Chairs: *Sébile Tchaicha* (Lyon, France) · *Nicola Specchio* (Rome, Italy)

- 16:00 Addressing SCN1A in Dravet Syndrome: An Update on Zorevunersen
Eva Thoma (Biogen)
- 16:20 Beyond the Pipeline: Neuraxpharm's Move into Digital Solution for Seizure Risk Prediction
Paolo Roncon (Neuraxpharm)
- 16:40 Navigating Polytherapy: Practical Guidance for Polytherapy Management in Dravet Syndrome
Constance Bellaigue de Bughas (Biocodex)
- 17:00 Measuring What Matters: Patient-Relevant outcomes of Fenfluramine
Jan-Peer Elshoff (UCB)
- 17:20 Toward a New Treatment Paradigm in DEEs: Emerging Therapies Across the Pipeline
Raquel Miralles (Praxis)
- 17:40 The KANDLE clinical trial, an antisense oligonucleotide for the treatment of KCNT1-DEE
Carlos Estévez Fraga (Servier)
- 18:00 A Phase 2, Open-Label Study of Adjunctive OV329 Safety and Pharmacokinetics in Adolescents and Children with Tuberous Sclerosis Complex- Related Epilepsy
Andrés Cruz-Herranz (OVID Therapeutics)
- 18:20 A novel GABA-A selective compound, the therapeutic potential for seizure and non-seizure endpoints in DEEs
Karin Sandager Nielsen (Saniona)