

Paris, June 14th, 2025



Letter for the EU-ILAE chapters presidents and members

Dear Colleagues, Dear Friends,

I am honoured to run for the election of the ILAE-EU members committee for the 2025-2029 term, as candidate for the French chapter of ILAE.

I am Professor of Paediatric Neurology at Université de Paris cité, Director of the epilepsy program at Necker Enfants Malades, APHP, Paris, France and leading the genetic epilepsies translational research program at institut Imagine, INSERM U1163.

My clinical activity encompasses diagnosis and care for new onset as well as complex and rare epilepsies with the development of a comprehensive epilepsy program at our institution with advanced expertise in genetics, neuroradiology, epilepsy surgery, electrophysiology, neuropsychology, intensive care, clinical investigation for CTs and rehabilitation. This holistic care path allows us to found the French national centre for rare epilepsies and to follow cohorts of patients that drive our research and our collaborations.

My research is mainly clinical with an expertise in Paediatric epilepsy syndromes delineation, outcomes beyond seizures in DEEs, transition to adult care and clinical trials (PI in different recent CTs) with an interest in the development of patients' centered end-points and innovative methodologies for personalized therapies (academia and industrial partners).

My involvement in basic research is focused on the development of cellular and animal models of rare DEEs at institute Imagine (3 PhDs in Neuroscience during the last 5 years) aiming to better understand underlying mechanisms and further support the innovation in care. I am coordinating a translational research program Innov4-ePiK dedicated to K-DEEs and participating to 2 large EU initiatives addressing rare epilepsies as ERDERA (European rare diseases research alliance) and Realise-D (transforming clinical trials for rare diseases).

I am actively involved in national societies management (member of the ExCom of the French chapter against epilepsy, president of the French pediatric Neurology society), European societies (EPNS, eanCampus faculty member with active participation in the meetings and teaching courses), European networks (member of the ExCom of EPICARE and ECET) and ILAE (coordinator of the TF on transition and member of the TF on nosology of the ILAE).

I am involved in advisory boards for pharma companies and government agencies as well as in EU policy on rare diseases.

I am in the advisory and scientific board of European and International advocacy groups and foundations (KCNT1 Foundation, SCN8A foundation, Dravet European federation, KCNB1 foundation, French Dravet alliance) with whom I promote collaborations and studies as well as dissemination at their general assemblies and meetings.

My educational activity encompasses national courses on epilepsy (coordinating the paediatric epilepsy national post graduate course and participating to different courses on epilepsy for neurologists, electrophysiologists, emergency and intensive care specialists), participating in the organizing committees and training of major EU courses (San Servolo paediatric epilepsy course, Tagliacozzo course, Gerona Course), many EEC and international ILAE teaching courses and to different ILAE chapters educational activities in EU, America, Africa and Asia.

I tutored and mentored over 50 medical post graduate fellows from all over Europe, with at least one fellow per year, receiving clinical and research training and actively participating to my group research and publication activity (Over 300 publications, pubmed, nabbout R).

I am proud to be the candidate of the French league chapter and I am ready to participate in this coming term of the EU-ILAE committee to participate and support of the major challenges facing our community, namely:

- Empowering young neurologists and paediatric neurologists through education and training with the construction of adapted programs to consolidate the place of EU-chapter webinars and EEC educational courses as attractive for young generations from EU and beyond.
- Supporting a young generation of scientists and clinical researchers to promote the leadership of EU-ILAE in epilepsy research through lobbying for networks' funds and EU large projects.
- Promoting the co-creation of a better care and guidelines with other scientific organisations, EPICARE, the ERN network for rare and complex epilepsies, societies and with patients and families' advocacy groups.
- Empowering patients and their care providers to better understand their diseases and to be active players in their care process and acces.
- Emphasizing the need of multidisciplinary in epilepsies and how to increase our attractivity for experts from other domainsas rehabilitation teams, psychiatrists...
- Being an actor in defining the social and economic cost of epilepsy care pathway and advanced therapies, its development and its accessibility in EU through EMA and HTA bodies interactions.
- Finally, consolidate and expand the place of EU-chapter within the international programs and reach of the ILAE and WHO emphasizing our actions in the field of rare diseases

I am dedicated and committed since almost 20 years to advocate and advance the epilepsy knowledge, to educate physicians, patients and care givers in this field, to collaborate with decision making agencies and all stakeholders involved in advancing diagnosis and care quality and access for patients and families.

I hope to support further our epilepsy community and these actions from the EU-chapter committee perspective.

I thank you in advance for your support and wish you my best regards.

Rima Nabbout, MD, PhD

A handwritten signature in black ink, appearing to read 'Rima Nabbout', with a long horizontal flourish underneath.