

Pediatrics Commission



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Chair

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Members

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Jo Wilmshurst (South Africa), Past-Chair

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The commission's work is primarily guided by the operations of four Task Forces. A description of the 2019 activities of the Pediatric Commission and all related Task Forces (TFs) is found below. In addition, the ILAE Pediatric Commission continues its involvement with the PET course dissemination (see below after the TFs reports).

The ILAE Pediatric Commission has continued its involvement in the discussion and work of the Nosology TF for the definition of the epilepsy syndromes (Elissa Yozawitz, Jo Wilmshurst, Stéphane Auvin). The interactions of the Commission with the regulatory affairs the TF initiated last year have resulted in a publication in *Epilepsia Open*. This paper is a proposal for a new design to investigate anti-seizure medications in infants (Auvin et al. [Epilepsia Open 2019; 4:537-543](#))

The report of each TF is written below, and they are followed by a report on the PET course:

Neonatal Seizure Task Forces

Neonatal Seizure Guidelines Update Task Force (Co-chairs: Ronit Pressler & Hans Hartmann)

The ILAE's Pediatric Commission set up a task force to update the guidelines on neonatal seizures, which were published jointly by the WHO and the ILAE in 2012. Seizures affect at least 2 in every 1000 neonates. They often are signs of a severe acute health problem, but also

significantly contribute to the morbidity and mortality of both term and pre-term neonates. As of today, only very few high-quality studies have addressed the optimal diagnosis and treatment of neonatal seizures.

Having finished the literature search, the task force organized a workshop at the 2018 European Epilepsy Congress, aiming to kick off a critical appraisal of the evidence. This workshop was followed by an open meeting bringing together pediatricians, epileptologists, and neonatologists. Professor Linda de Vries from Utrecht (NL) gave an overview on the management of neonatal seizures, highlighting the need for international guidelines. This was followed by Professor Jo Wilmshurst from Cape Town (SA) speaking on the principles of guideline development and specific considerations for neonatal seizures. Dr. Ronit Pressler from London (UK) and Dr. Hans Hartmann from Hannover (GER) gave an update on the current guideline development. The need for further research in the field was further highlighted by case presentations and discussions given by Professor Martha Feucht from Vienna (AUT) and Professor Stéphane Auvin from Paris (FRA).

Work on the evidence profiles currently continues and following completion of the systematic literature review, the task force aims to draft the guidelines in 2019.

Neonatal Classification Task Force (Co-chair: Ronit Pressler)

The Task Force on Neonatal Seizures has created a classification for seizures in the neonate, which is based on the 2017 ILAE Classification of Seizures and Epilepsies, but modified for seizures in the neonatal period. As part of the approval and adoption process, the League published the manuscript on the ILAE website and asked its members to review and comment on the proposed classification (<https://www.ilae.org/guidelines/definition-and-classification/neonatal-seizure-classification>). A total of 72 comments from the international community and *Epilepsia* reviewers were received and over the last year reviewed by an independent second task force. The Neonatal Classification

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Task Force met at the 2019 IEC and discussed the comments. The manuscript of the proposed classification is currently adapted in line with the suggestions from the community with the aim to finalize the proposal by March 2020.

The TF successfully submitted a seminar proposal for the ICNC in October 2020 (San Diego) where Ronit Pressler & Hans Hartmann will present findings of the Neonatal Classification Task Force and the Neonatal Seizure Guidelines Update Task Force.

Medical Therapy Task Force (Chair: Lieven Lagae)

The aim of this task force is to review the current treatment options in young children with epilepsy (<4 years old), in order to stress the need for more evidence-based data. It will also be clear that most AEDs used in that age group are prescribed off-label. We will focus on six typical scenarios and review the current literature. In addition, a worldwide survey will be done to understand common treatment strategies. The six typical scenarios are based on the following clinical situations: 1. Febrile seizures; 2. Epileptic spasms; 3. Dravet syndrome; 4. Tuberous sclerosis; 5. Acquired structural lesion in the neonatal period; 6. Presumed genetic epilepsy with focal seizures.

In 2020, a survey with specific questions about first- and second-line treatment will be sent around and will result in a paper describing the most common practices. It is anticipated that the commonly used AEDs are prescribed without clear efficacy evidence in the younger children and that most of them are prescribed off-label. A second paper will review the existing literature on treatment in these six specific scenarios. Review strategies have been discussed in the working group and we hope to have both papers ready by the end of 2020.

Research Advocacy Task Force (Chair: Pauline Samia)

The Research Advocacy Task Force had a productive year in 2019. We planned and successfully conducted various activities, including:

Research Advocacy Workshop

Bangkok, 25th June 2019 at the 33rd International Epilepsy Congress

The Research Advocacy Workshop was held during an early morning session that was well attended and the audience included Professor Anannit Visudtibhan, President, ILAE Thailand Chapter. Jo Wilmshurst described challenges with access to care in low- and middle-income countries and outlined availability of medications, trained personnel, and other regional challenges as contributors. She indicated more research, specifically related to children with epilepsy across aetiologies, co-morbidities, management, and outcomes is needed. Pauline Samia elaborated on the challenges to research in low- and middle-income countries including lack of mentorship, and institutional and governmental facilitation. She highlighted a recent review of data on epilepsy from Kenya that re-affirmed the ongoing need for better public awareness of epilepsy as a treatable disease and for national-level action which targeted both prevention and management of epilepsy. Stéphane Auvin elaborated on strategies for developing sustainable health research capacity in low and middle-income countries, and included findings from a prospective, qualitative study which evaluated barriers and enablers to locally led clinical trials.

Research Advocacy Workshop

Entebbe, 24th August 2019 at the 4th African Epilepsy Congress

A workshop similar to the one held in Bangkok was organized during the AEC, and this one also generated considerable interest, leading to a full registration.



Additional speakers included Edward Kija, who pointed out challenges that researchers in epilepsy working in LMIC countries encounter in accessing funding, as well as the limited opportunities that currently exist for collaboration due to diverse clinical practice and regional demographics.



Joseph Raimondo's topic on basic neuroscience research in Africa, to inform the clinical management of status epilepticus, was an eye-opener to many about the possibility to conduct basic science research even in LMIC, and contribute to strategies to manage epilepsy. Markus Reuber led a session on "How to publish your research," which was well received and allowed many attendees to better understand how to identify suitable journals for their research and interact with editorial processes. Attendees expressed the need for similar workshops in the future.

Scoping Review Epilepsy: Last 30 Years in Africa

The scoping review process has so far identified over 4,000 relevant abstracts for evaluation by May of 2019, and these were to be evaluated by eight researchers. Duplicates were removed and most investigators began an evaluation of the abstracts with input onto a REDcap database by September 2019. A total of 698 records are currently archived.

Joint Task Force with the Psychiatric commission (Co-Chairs: Kette Valente and Colin Reily)

Ongoing Projects

The Task Force has two main projects conducted by the group:

1. *Project of CPG for Psychogenic Nonepileptic Seizures in Children and Adolescents: Current State and Future Directions*

After the meeting in Vienna, the task force members delineated the rationale and PICO questions for the CPG. In May 2019, the ILAE

Guideline Committee approved the CPG for Psychogenic Nonepileptic Seizures in Children and Adolescents, with suggestions regarding the PICO questions.

As suggested by the Guidelines TF, a methodologist was invited to take part in both projects. Professor Wang Pang – a psychiatrist and epidemiologist from the University of São Paulo, São Paulo, BR – accepted the invitation as part of the working group. He will provide technical support in methodology for both projects with no fees.

The TF invited experts (Drs. Sigita Plyoplis, Charlotte Rask, Isobel Heyman, and Julie Doss) in the field of Psychogenic Nonepileptic Seizures in Children as part of the working group.

During a four-hour meeting in Bangkok, the task force discussed the next steps for the CPG. Members also discussed the descriptors (MESH terms) and determined the databases for search and the completion and registration of the PROSPERO protocol.

Nathalie Jetté was contacted during the meeting and later reviewed the protocol before registration. A librarian with expertise in systematic reviews (Samantha Walsh), suggested by Dr. Nathalie Jetté, is currently assisting the task force with descriptors and duplicates, and will be part of the working group for this project. Two students, one in the UK and one in Sweden, are also helping Dr. Reilly with the search and selection process.

2. *The International Consensus on Psychiatric Conditions in Pediatric Epilepsy*

After the meeting in Vienna, the rationale for the International Consensus on Psychiatric Conditions in Pediatric Epilepsy, composed of 36 pages, was written, reviewed by all members, and submitted to the Executive Committee. The

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Executive Committee approved the document and recognized its importance to the field, since there is little evidence for guidelines. As recommended, during 2019, the task force members structured the methods.

Dr. Nathalie Jetté, representing the Guidelines Committee, and Prof. Mike Kerr (Chair of the Psychiatry Commission) suggested the Delphi method and the task force described how to use a modified version of the Delphi method for this project, and resubmitted it to the ILAE Guidelines Committee for approval. In November 2019, the TF received a formal output on this project. During our four-hour meeting in Baltimore, Dr. Nathalie Jetté and the TF members reviewed the final details of this proposal. The TF delineated the topics that will be addressed in the Consensus. A group of experts in the field was determined and will be invited to work with the task force.

The task force worked both online and onsite to approve their two main projects, responding to all queries and searching for experts when requested, including a methodologist and a librarian at no cost to the ILAE.

Other Projects

In addition, during these two meetings, the TF members discussed other projects of interest. A preliminary draft of a Survey for Psychogenic Nonepileptic Seizures in Children and Adolescents, written by the Co-chairs was presented and discussed by the task force. We will submit a draft with the suggestions and comments to all members of the task force who could not join this meeting. Markus Reuber, Chair of the Psychogenic Nonepileptic Seizures Task Force, will be contacted as a collaborator and contributor for this project. The task force recognizes that there are many ongoing surveys; however, they consider this survey to be a necessary aspect of our work that is associated with the guidelines that we will implement.

In this project, a post-graduate student from the University of São Paulo with expertise in medical research will take

part and assist the task force in organizing and gathering all data. The decision was made to include a post-graduate student since the current project cannot interfere with the two main projects.

Task Force meetings and educational activities

Task Force meetings

The task force had two four-hour meetings in 2019, as will be described. These meetings were not included in the budget for the Commission of Psychiatry and Pediatrics. The continuous work of the TF members and their presence during our meetings was done with their resources.

- 33rd International Epilepsy Congress (Bangkok, June 24th, 2019) – four-hour meeting. Attendees: Profs. Choong Yi Fong, Colin Reilly, Elaine Wirrell, Kette Valente, Mike Kerr, Stephane Auvin, Symon Kairuki. Colin Reilly and Kette Valente co-chaired the meeting.
- AES annual meeting (Baltimore December 9th, 2019) – four-hour meeting. Attendees: Profs. Kette Valente, Marco Mula, MaryLou Smith, Stephane Auvin. Prof. Nathalie Jetté also attended this meeting. Stephane Auvin and Kette Valente co-chaired the meeting.

During these meetings, as described in items 1 and 2, the TF members discussed barriers and strategies to accomplish our projects.

Educational Events

The Task Force of Pediatric Psychiatric Issues participated in the Educational Symposium "Epilepsy and Psychiatry Throughout Life," held in São Paulo, Brazil, on October 25-26, 2019, by the Psychiatry Commission. The meeting, endorsed by ILAE, had 212 attendees composed of neurologists, child neurologists, psychologists, and neuropsychologists. The Task Force of Pediatric Psychiatric Issues took part, represented by Profs. Stephane Auvin, Kette Valente, Guilherme Polanczyk, and Marco Mula.

Profs. Stephane Auvin, Kette Valente, Guilherme Polanczyk, and Marco Mula participated actively in this educational activity, with lectures and case discussions. Prof. Kette Valente also helped to organize the event.

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International Conferences

The task force has discussed the relevance of our participation in meetings with forums and symposiums. In the past two years, we have submitted proposals addressing comorbidities in pediatric epilepsy.

In Bangkok (2019), members of the task force and the Psychiatry Commission proposed two sessions that were accepted - Childhood Comorbidities: From Mechanism to Management, and Key Neuropsychiatric Issues in Epilepsy, and took part in two round tables about psychiatric disorders in epilepsy.

For Geneva (2020), two sessions were accepted: "What Should Child Neurologists Know When Treating Children with Comorbidities?" and "Diagnosing Neuropsychiatric Conditions in Pediatric Epilepsy."

ILAE Educational Program

The task force is committed to participating in the Educational Program by ILAE. It has been involved in new ILAE e-learning modules focusing on psycho-social issues of epilepsy.

Dissemination of the Pediatric Epilepsy Training (PET) Course

The ILAE Pediatric Commission has continued its implication for the dissemination of the PET course. Jo Wilmshurst has continued the initiation and support of the African-related courses, including serving as faculty lead for some of the South Africa courses, as well as the Namibia one, serving directly on the faculty for the Uganda course, and facilitating [through promotion and funding motivations (ICNA / ILAE)] the Angola course. She also coordinated the framework to prepare for the Zambia and Zimbabwe roll out of establishing faculties – helping recruit planned faculty and getting them through their first PET1 course in preparation (bringing them out to offer the course in Uganda, Namibia and Cape Town). Over the last part of 2019, Jo Wilmshurst supported developing the logistics for the planned French PET roll out.

2019 was a great year for expanding the PET courses at an international level. The course was translated into Portuguese and rolled out in Brazil by the local faculty earlier in the year. In September, the Brazilian faculty



Figure 1: Brazilian faculty running PET course in Luanda, Angola (Kette Valente, Magda Lahorgue Nunes, Leticia Brito Sampaio, Laura Guilhoto, Maria Luiza Manreza, Ana Carolina Coan, and Marilisa Guerreiro).

(faculty leads Marilisa M. Guerreiro and Ana Carolina Coan) travelled to Angola and, with the coordination of local

host Dr. Manuel Leite Cruzeiro, taught the course to 34 local clinicians (32 pediatricians and two neurologists), as well as to two colleagues from Mozambique. Overall, the Brazilian faculty reported that the PET course was able to fill some of the gaps regarding the knowledge of diagnosis and care of children with epileptic seizures and epilepsy. The delegates evaluated the course as good or excellent, and they agreed that it fulfilled or exceeded their expectation. The exposure of the course was viewed to be so useful, especially with the content in the home language, that the Brazilian faculty have been invited to offer the course in Mozambique in 2020. This extension of the PET course to Angola was supported by joint funding from ILAE and the International Child Neurology Association. The same collaboration is planned for the 2020 project.

In addition to support of the Brazil and Angola courses, PET courses were also undertaken across Kenya (faculty leads Pauline Samia and Sam Gwer), Ghana (faculty lead Charles Hammond), Tanzania (faculty lead Edward Kija) (Figures 3 and 4), Namibia (faculty lead Jo Wilmshurst), South Africa (faculty leads Gail Scher, Jo Wilmshurst, Elmarie van Rensburg) and Uganda (faculty leads Angelina Kakooza, Richard Idro) (Figures 5 and 6). The course in Uganda, which was organized by Martin Chebet, took place immediately prior to the African Epilepsy Congress and, as such, was an opportunity for attendees at the AEC to support the Ugandan faculty; namely Helen Cross and Jo Wilmshurst.

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It is estimated that the 2019 course reached some 300 health care practitioners across Africa. The need and demand for the course keeps growing, with plans in 2020 to establish faculties for Zambia and Zimbabwe, as well as translating the course into French to make it possible to develop faculties in the French speaking countries of Africa. Thanks are extended for the ongoing support and collaboration with BPNA, which developed this innovative course. Members of the BPNA have given their time to support the courses as well. For example, Mike Pike joined the faculty for the course in Windhoek, Namibia, and Helen Cross joined for the course in Cape Town.

Report by Stéphane Auvin, Chair, Pediatrics Commission



Figure 4: Helen Cross giving out certificates to delegates who attended the Uganda PET course in Kampala.



Figure 2: Delegates from the Angola PET course, September 2019.



Figure 5: Small group tutorial teaching for the Moshi, Tanzania PET course.



Figure 3: Robert Sebunya teaching the Uganda PET course.



Figure 6: Delegates and faculty for the Moshi, Tanzania PET course.