COMMISSION ON PEDIATRICS

Jo Wilmshurst

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Epilepsy Surgery Liaison
William Gaillard (USA)

MC Liaison
Helen Cross (UK)

Subcommission Members

Task Force for Adaption of the Neonatal and the Infantile Recommendations:

Chair: Hans Hartmann (Germany); Regional chairs; Pauline Samia (Africa), Vinayan Puthenivill (Asia), Marilisa Guerreiro (South America)

Task Force for comorbidities in Pediatric Epilepsy
Chair: Stephane Auvin (France)

Advocacy Task Force – the rights of the child to access consistent and reliable AEDs
Chair: Jo Wilmshurst (South Africa)

Pediatric Epilepsy Surgery Task Force
Chair: William Gaillard

Aims

The Commission on Pediatrics will aim to develop tools to enable clinicians to provide appropriate standard levels of care, and to identify the optimal levels of care, for children with epilepsy. These tools should be relevant across all settings from resource equipped to resource limited settings.
These tools should consist of

1. the accessible collation and development of relevant guidelines / recommendations,
2. the "translation" of these guidelines / recommendations to ensure they are viable and understandable in different geographical settings, ("translation" refers to more than language - to the actual integration and use of the recommendation/guideline, making sure that they are in-line with regional capacity and health-care systems)
3. facilitating chapters in lobbying for access to these resources
4. supporting education in the dispersion of these guidelines/recommendations for the management of epilepsy in children
5. identifying the "epilepsy teams" in the different regions who should be supported and targeted to promote and develop the above points. As such the definition of the "tool" extends beyond the guideline/recommendation itself and involves the role of healthcare workers (at all levels – PHC/community to tertiary), support of lobbying to government for essential aspects of the guidelines/recommendations and so on.

Commission Activities June 2013 through June 2014

The Commission has held four informal meetings 2013-2014 at major international meetings where a concentration of the commission members were present. This has allowed focused planning and discussion on the various task forces the commission is working on over the current cycle. The following outcomes have occurred.

The Task Force for Adaption of the Neonatal and the Infantile Recommendations: The adaptation of existing neonatal and infantile seizures guidelines is needed to ensure that they are viable for use at local levels. Specific teaching courses designed for this purpose have been explored, concentrating on the British Paediatric Neurology Association's (BPNA) Pediatric Epilepsy Training program (PET), which is directed to all medical professionals working at first and secondary levels of care. Options for cooperation between the BPNA and ILAE to support pediatric epilepsy training for clinicians involved in the care of children with epilepsy from the different regions are under review. This subcommission is assessing the PET1 course for its compliance with the guideline. It is proposed that a Delphi type approach involving Commission Members can be used to ensure consensus of adaptating ILAE recommendations on neonatal (published) and infantile (pending) seizure management into the PET1 format. It is envisioned that ongoing adaptation will be needed to ensure recommendations are viable at regional levels. This task force is collaborating with the Education Commission and has recruited members to join the project.

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The Task Force for Comorbidities in Pediatric Epilepsy. The aim for this task force is to develop a "user friendly text" that documents the known data, identifies what is not known and highlights red flags where interventions are needed. The task force plans to document the accepted definitions and the known epidemiology of comorbidities overall, and for pediatric epilepsy, noting where this is not known and why (lack of resources, stigma, disclosure). This will include analysis of regional variations and of differing etiologies. A co-morbidity could be regarded as part of the "overall brain make up" or parallel process e.g. tuberous sclerosis or acquired by an e.g. post meningitis. The findings are expected to vary across regions, for example in resource poor countries with prevalent acquired insults (neuroinfections, trauma, poor nutrition, lack of interventions) these will dominate the etiologies. The document will aim to address useful clues as to assessing the etiology, to identify which antiepileptic drugs (AEDs) are associated with co-morbidities and which should be avoided as a result.

Further, evidence for interventions and attempting to "normalize the EEG" will be assessed. Red flags to help identify a patient in need of early intervention will be developed. Taking the reverse view, the task force will assess the specific epilepsy syndromes in which co-morbid complications are commonly seen e.g. CSWS, LKS. Existing data will be graded using the GRADE system and recommendations must cover approaches at primary / secondary and tertiary / quaternary levels of health care.

Recommendations must state if regarded as standard (relevant for any child in any setting i.e. safe practice) or optimal (state of the art). Members of the neuropsychiatry commission have been recruited to be part of this task force. The final text will provide an approachable, clear, simple recommendation and include tables, flow diagrams and "red flag" messages. i.e. to be of use the clinician "working at the rock face"!

Advocacy Task Force – the rights of the child to access consistent and reliable AEDs. The rights of the child are threatened worldwide by the autonomy of pharmaceutical companies to withdraw or limit access to AEDs based on revenue, as well as the budget limitations on health care at a government level. There is no legislation to require a pharmaceutical company to take into account the consequences of removing access to a product. In many settings worldwide, children either have no access, unreliable access, or are managed with a combination of AED generics of different bioavailability. Legislation exists in some European countries which states that changing a child who is stable on one AED brand to another is unethical. This task force will compile initially a documentation of common practice with regard to regional variation in AED supply, and will identify where legislation exists. Data will then be collected to establish the evidence to support the hypothesized risks to children with epilepsy, of changing prescribed agents to different brands and well as the evidence to support the safety of use of AEDs in children. It is hoped that the information will permit an evidence based working document to be completed with a position statement on the matter from the ILAE. It is planned that this task force will involve recruitment of members from the therapeutics and the advocacy commission in 2015.

Pediatric Epilepsy Surgery Task Force.
This task force meets at the European and American Epilepsy Society Meetings. This year the consensus statement generated by the task force "Diagnostic test utilization in evaluation for resective epilepsy surgery in children." was published in *Epilepsia*. A satellite meeting at Stockholm, held at Gothenberg, and supported by the task force (and the Surgical Commission) convened to review and discuss current neurosurgical techniques and practices. This conference gathered neurosurgical and neurological representatives from the leading pediatric epilepsy centers from across the globe. At this meeting Arthur Cukiert reported on the task force neurosurgical survey on pediatric neurosurgical techniques and practice (50 responses), now being prepared for publication. The pediatric neuropsychology subcommission, led by Madison M. Berl, has completed their survey of pediatric neuropsychology presurgical evaluation practice. This survey was conducted in conjunction with a subcommittee of the neuropsychology subcommission of the Commission on Diagnostics. The survey examined the use of tests employed in presurgical assessments and found comparable domains are routinely assessed across sites and that several measures are commonly used. The long-term plan is to arrive at a consensus to standardize assessments and facilitate global efforts to assess neuropychological presurgical cognitive and behavioral deficits and assess post surgical outcomes. Barriers were identified and plans are being made to overcome them. Susan Koh and Guido Rubboli are leading an effort to establish

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the range of training and experience that currently exist across the globe for pediatric epilepsy surgery programs for neurology, neurosurgery, neuropsychology psychiatry and radiology. Smaller centers in resource challenged countries have expressed the view that such data would be very helpful for petitioning for resources and training. The final draft of the survey is under review and is due to be sent out in October with the aim to review results at the American Epilepsy Society meeting. Prasanna Jayakar has completed the draft of the surgical approach survey and will be moving to a second project on cortical mapping for pediatric epilepsy surgery. William D. Gaillard is leading a subtaskforce to devise a pediatric epilepsy severity scale that can be used to assess efficacy of surgical interventions on outcomes. To understand changes in epilepsy surgery practice, patient selection, diagnostic testing, and surgical techniques that have occurred over the past ten years the task force plans a survey of sites from the 2004 and 2008 surveys (all based on surgical cases 2004) for 2014. The survey has been designed by A. Simon Harvey and will be piloted at 5 sites before implementation in January 2015. The task force is planning a larger meeting in Istanbul to report on the five active projects and to plan on a follow up pediatric epilepsy surgery meeting to be held in Prague. In all the task force is establishing the range of training and practice to help establish consensus to improve assessments, treatments, and outcomes of pediatric epilepsy surgery and to evaluate advances in practice in epilepsy surgery care and outcomes.

Accomplishments (2013-2014)

Included in the narrative above.

Recommendations for Future Work

Included in the narrative above.