

# The Pediatric Commission Report: Activities for 2014-2016

*Jo Wilmshurst, Pediatrics Commission Chair*

The child suffering with epilepsy has many unique needs. Some of these needs are linked to the cause of the epilepsy and others are tied to societal attitudes about epilepsy and to the impact that epilepsy may have on the family and the child's development. Many of these needs go unaddressed because the children often don't have a voice to call attention to these age specific and critical medical and psychosocial issues. The Commission on Pediatrics has selected three key areas specific to children with epilepsy that will be targeted during the next three years. These areas are to assure that



*Jo Wilmshurst, Chair*

children have a reliable access to medications, to develop an approach to the many comorbidities of epilepsy specific to children and to adapt seizure guidelines that are focused on neonatal and infantile seizures.

## **1. Advocacy Task Force for the rights of the child to consistent and reliable AED supply**

(Chair: Jo Wilmshurst)

The rights of the child with epilepsy are abused worldwide by the limitations on access to effective antiepileptic drugs that are often driven by pharmaceutical companies, who can withdraw or limit access to AEDs based on revenue and by the local limitations set by financial restraints. Children, especially from resource poor settings, either have no access, unreliable access, or are managed with a combination of antiepileptic drug (AED) generics of different bioavailability. Legislation exists in Europe, which states that changing a child who is stable on one brand of a drug to another is unethical. A working document will be com-

pleted based on the current practice and policies relating to access to and supply of AEDs (withdrawal of "essential" agents), and the prescribing behavior of AEDs (generic, changing over of brands), for children with epilepsy. Ideally this document will evolve into a position statement, under the auspices of the ILAE, relating to recommended good practice. Key members from the therapeutics and the Advocacy Task Forces will be invited to be part of this work.

## **2. Task Force for comorbidities in Pediatric Epilepsy**

(Chair: Stephane Auvin)

The aim for this Task Force is to develop a "user friendly text" that documents the known data (epidemiology, regional variations, etiologies), identifies what is not known, and highlights and red flags where interventions are needed for children with epilepsy. Where data are lacking, explanations for this will be sought, such as challenges from lack of resources, from the effect of stigma, and failure to disclose the presence of the disease. Known etiolo-

gies for comorbidities will be sought, differentiating them by such factors as when they are part of the “overall brain makeup” or are the result of parallel processes such as tuberous sclerosis. Other comorbidities may be the result of insults to the brain and as such are secondary or acquired, such as post meningitis. Etiologies will vary regionally, for example in resource poor countries there will be higher prevalence of acquired insults (neuroinfections, trauma, poor nutrition, lack of interventions). Knowledge of other potential influences will be investigated for example, nutritional state, social access and bonding among other influences. Clues will be used to identify when a behavioral trait is purely behavioral and when it is in fact the epilepsy. The task force will also recommend which AEDs should be avoided to minimize drug induced adverse behaviors. The evidence will be documented to support the current interventions, as well as the controversial issues such as “treating” the EEG. Red flags will be noted so as to identify patients for early intervention. A syndromic approach will also be undertaken examining comorbidities which are prevalent with specific seizure types.

### **3. Task Force for adaptation of recommendations for neonatal and infantile seizures**

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

The aim of this Task Force will be to adapt existing pediatric guidelines and recommendations into user-friendly formats for neonatal and infantile seizures and epilepsies. These templates will be further adapted to be useful at a local level (i.e. in settings with different resources). Where existing programs exist, they will be recruited to avoid duplication. Various tools will be used to translate the information in these recommendations (e.g. web, direct teaching, visiting expert programs). The regional experts will undertake pilot studies for applying these guidelines (ideally as part of established teaching programs), and will explore the best way to translate and adapt the information. Simple flow diagrams will be developed, as will leaflets, card lists and mobile “apps”. Monitoring will be incorporated to measure the success, effectiveness and usefulness of these recommendations on such things as neonatal morbidity rates on units, long term outcomes, duration of stay and improved seizure

control. There will be collaboration on this project with the Education Committee.

It is the goal and hope of the Commission on Pediatrics that these efforts will bring added attention and action to address the needs of children with epilepsy and their families. As our work progresses we will bring these issues to our colleagues for their advice on how best to improve this dire situation.

The working committee consists of Jo Wilmshurst, Chair, Patrick van Boegart, Hans Hartman, Perrine Plouin, Petia Dimova, Stephane Auvin, Amy Brooks-Kayal, Makiko Osawa, Vinayan Puthenivill, Pauline Samia, Marilisa M Guerreiro, and Helen Cross, MC Liaison. There are affiliations with key Commissions and Task Forces with complementary interests namely; epilepsy surgery (pediatric advisor - Bill Gaillard), education (Jaime Carrizosa, Lionel Carmant), neuropsychiatry (David Dunn), and neonatal classifications (Ronit Pressler, Perrine Plouin).