

# COMMISSION ON EPIDEMIOLOGY



Dale C Hesdorffer



Ettore Beghi

## List of Members

Co-Chair	Dale C Hesdorffer (USA)
Co-Chair	Ettore Beghi (Italy)
Past Chair	Allen Hauser (USA)
Treasurer	Ley Sander (UK)
Secretary	Charles Newton (Kenya)
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Information Officer	Giancarlo Logroscino (Italy)
	Ding Ding (China)
Executive Committee Liaison	Marco Medina (Honduras)
	David Thurman (USA)

## Subcommission Members

Mortality Task Force: Giancarlo Logroscino and David Thurman (Co-Chairs), Dale Hesdorffer, Allen Hauser, Ley Sander, Charles Newton and Torbjörn Tomson

Comorbidity Task Force: Dale Hesdorffer (Chair), Ettore Beghi, Roberto Tuchman, Andres Kanner, Michael Trimble, Paola Torelli and Christoph Helmstaedter

Reliability Task Force: Ettore Beghi (Chair), Dale Hesdorffer, Donna Bergen, Allen Hauser, Peter Bergin, Jacqueline French, Marco Medina, Charles Newton, Douglas Nordli and Giuseppe Capovilla

Status Epilepticus Task Force: Shlomo Shinnar (Chair), Additional Epidemiology Commission representative to the joint Task Force: Dale Hesdorffer

## Aims

The Commission on Epidemiology's work is focused on providing standards for the conduct of epidemiological research in epilepsy and for describing the epidemiological evidence on the burden of epilepsy and potential preventive measures.

## Mission

The Commission on Epidemiology's work is focused upon the burden of epilepsy. The work that stems from this focus includes: the development of standards for the conduct of epidemiological research in epilepsy in order to best study the occurrence and burden of epilepsy; the burden of mortality in epilepsy with a specific focus upon potentially preventable causes of death; the spectrum of comorbidity in epilepsy; development of an epidemiological definition of status epilepticus; and assessment of the reliability of epilepsy classifications.

## Commission Activities

The Commission on Epidemiology outlined the task forces, their goals and their membership. Four task forces were created: (1) burden of mortality; (2) comorbidity of epilepsy; (3) reliability and applicability

of testing epilepsy classifications; and (4) definition of status epilepticus for epidemiological studies. The work of the task forces is discussed further in this report.

## Standards for the Conduct of Epidemiological Research

The Commission began its activities by embarking on a document outlining standards for epidemiologic research in epilepsy. This work led to the following manuscript which was published as an *Epilepsia* supplement:

Thurman DJ, Beghi E, Begley CE, Berg AT, Buchhalter JR, Ding D, Hesdorffer DC, Hauser WA, Kazis L, Kobau R, Kroner B, Labiner D, Liow K, Logroscino G, Medina MT, Newton CR, Parko K, Paschal A, Preux PM, Sander JW, Selassie A, Theodore W, Tomson T, Wiebe S; ILAE Commission on Epidemiology. Standards for epidemiological studies and surveillance of epilepsy. *Epilepsia* 2011;52( Suppl 7):2-26. (DOI: 10.1111/j.1528-1167.2011.03121.x)

The Commission oversaw the work in the four task forces. That work is described in the rest of this document.

## Task Force on Burden of Mortality

The objectives of the Mortality Task Force are to: 1. Work on a combined analysis of risk factors for SUDEP; 2. Identify and quantify causes of death in people with epilepsy, including underlying causes/risk factors for epilepsy, and direct consequences of epilepsy or seizures; and to identify risk factors for preventable causes of death in epilepsy; and 3. Identify potential prevention strategies to reduce the burden of mortality in epilepsy.

### Two articles were published on a combined analysis of SUDEP risk factors

Hesdorffer DC, Tomson T, Benn EKT, Sander JW, Nilsson L, Langan Y, Walczak TS, Beghi E, Brodie MJ, Hauser WA for the ILAE Commission on Epidemiology; Subcommission on Mortality. Combined analysis of risk factors for SUDEP. *Epilepsia* 2011;52:1150-1159. | (DOI: 10.1111/j.1528-1167.2010.02952.x)

Hesdorffer DC, Tomson T, Benn EKT, Sander JW, Nilsson L, Langan Y, Walczak TS, Beghi E, Brodie MJ, Hauser WA for the ILAE Commission on Epidemiology; Subcommission on Mortality. Do antiepileptic drugs or generalized tonic-clonic seizure frequency increase SUDEP risk?: A combined analysis. *Epilepsia* 2012;53:249-252.

Parallel Session at the Montreal International Epilepsy Congress, 2013: SUDEP prevention — are we there yet? Chair: E Donner: Talks: SUDEP: Identifying those most at risk, E So; Discussion SUDEP: Does disclosure reduce the risk? L Sander; Epilepsy treatment for SUDEP prevention, T Tomson; Do devices have a role in SUDEP prevention? P Ryvlin

# COMMISSION ON EPIDEMIOLOGY *(continued)*

Evidence-based literature reviews: Two subgroups of the task force are completing systematic, evidence-based literature reviews and analyses on mortality in higher-income countries and on mortality in lower income countries.

## **Task Force on Comorbidity of Epilepsy**

Objective: This task force was convened to develop a systematic review to identify the full scope of epilepsy comorbidities (psychiatric, cognitive, neurological and other somatic). The aim of the results of the systematic review was to: increase awareness of the scope of epilepsy comorbidities through educational symposia at international epilepsy and neurology meetings as well as through dissemination of materials to health departments and health ministries; propose instruments to assess epilepsy comorbidities; and create training materials for clinicians in order to identify comorbidities and understand their impact on epilepsy prognosis and quality of life.

Accomplishments: Questions were developed about the frequency of comorbidities in epilepsy compared to the general population, whether the comorbidity was associated with an increased risk for developing epilepsy, whether epilepsy was associated with an increased risk for developing the comorbidity, whether the comorbidity occurs more in the pre-ictal and post-ictal period than in other periods, and whether the comorbidity in epilepsy is phenomenologically different from the same disorder in the general population.

A literature search has been done, reviewers have selected abstracts, pdfs have been circulated and an abstraction form created. This task force will continue into the new Commission on Epidemiology.

## **Reliability Task Force**

Purpose: To develop a database and use of the database for the assessment of reliability of established and new classifications of the epilepsies. The work was done with repeated interactions with the Commission on Classification.

Accomplishments: Members of the task force were asked to participate in a validation study of different classifications of seizures and epilepsies. The aims and structure of the study focusing on the reliability of four different classifications of the epilepsies (ICD-10, the

forthcoming ICD-11 codes, etiology and seizures) were presented. The ICD-11 classification, commissioned by the WHO, was a modified version of the new ILAE Classification proposal (Berg et al, *Epilepsia* 2010; 51: 576-85). Case reports from different sources were made available for evaluation and information presented in three steps, adding more information in order to consider the situation in low income countries as well as in high income countries. A second reliability study was done during the Latin American Epilepsy Congress in Quito, November 14-17, 2012, using only the ICD-10 and ICD-11 codes. A sample of adult and child neurologists from Latin American countries attending the meeting participated and examined 25 case reports. Manuscripts have been written.

## **Status Epilepticus Task Force**

The aim of this task force was to define status epilepticus for epidemiological studies. The Commission on Classification also developed a task force on status epilepticus. In order to avoid confusion caused by the potential for two reports from the two task forces, the Commission on Epidemiology Task Force on Status Epilepticus merged with the Commission on Classification Task Force on Status Epilepticus to create a unified clinical and epidemiological definition of SE. A manuscript has been written with the contributions of both commissions. The document will be submitted to the Executive.

## **New Commission Members (2013-2017)**

David Thurman, Chair (USA)  
Dale Hesdorffer (USA)  
Ettore Beghi (Italy)  
Arturo Carpio (Ecuador)  
Jakob Christensen (Denmark)  
Wendyl D'Souza (Australia)  
Sandra Helmers (USA)  
Jie Mu (China)  
Charles Newton (Kenya)  
Kamadore Touré (Senegal)  
Emilio Perucca, EC Liaison (Italy)