

# **PRESS RELEASE**

**Embargo: Wednesday 26<sup>th</sup> June**

**For the attention of forward planning: 26<sup>th</sup> June**

**30<sup>th</sup> International Epilepsy Congress, Montreal, Canada**

**International League Against Epilepsy**

**International Bureau for Epilepsy**

**23<sup>rd</sup> June 2013**

## **In Montreal, Call for Openness on ‘Sudden Unexpected Death in Epilepsy’ - Epilepsy Can be a Deadly Disease**

**Experts and epilepsy organisations call for openness on Sudden Unexpected Death in Epilepsy (SUDEP) as global SUDEP campaign reaches new high at the 30<sup>th</sup> International Epilepsy Congress in Montreal 23<sup>rd</sup> to 27<sup>th</sup> June.**

Epilepsy, like heart disease and stroke, ranks in the top ten causes of premature deaths and these deaths are potentially avoidable. Lack of public awareness of epilepsy mortality has meant research and treatment has lagged behind. Up to 1% of Canadians are affected by epilepsy, and this condition is more common in children. Many young and healthy people have lost their lives. Initiatives are underway in research, awareness and support for families affected, but funds are urgently needed.

Each year, about one in every thousand people with epilepsy will die suddenly with no obvious cause. This is known as Sudden Unexpected Death in Epilepsy (SUDEP) and the risk rises to 1:150 for people with seizures that are poorly controlled with medication. SUDEP, when a person with epilepsy dies suddenly and no other cause of death is found, is now recognised as a major cause of mortality associated with epilepsy and one with devastating consequences.

Jane Hanna OBE, Chief Executive of SUDEP Action who received the joint IBE and ILAE Social Accomplishment Award at the International Epilepsy Congress (IEC) this week for her work on SUDEP over

20 years and Mike Glynn, President of the International Bureau for Epilepsy (IBE), led the call for openness. Jane said:

*“Many of the deaths are in the young, putting epilepsy in some countries in the top ten of all causes of early mortality. In 1990, when my partner died out of the blue, aged 27, SUDEP was not recognised except by a handful of researchers. The world is a very different place today. Risk factors for SUDEP are being identified, and strategies to confront them are being formulated. Although research is urgently needed to advance prevention, we do now have important information for people about what they can do to reduce risk.*

There is clear evidence today that generalised-tonic seizures are the main risk factor for sudden death in people with epilepsy.

Organisations represented at the congress in Montreal who have signed up to support the call already include SUDEP Action (UK), SUDEP Aware (Canada) and the epilepsy patient organisations: Austrian Epilepsy Association; Citizens United for Research in Epilepsy (CURE, US); Epilepsy Action (UK); Epilepsy Australia; Epilepsy Foundation SUDEP Institute (US); Gambian Epilepsy Association; Epilepsy France; Epilepsy Ireland and the Swedish Epilepsy Association.

The call is for a common sense approach to alert people at risk to ways to reduce their risk of SUDEP. One way is to minimise the risk of seizures with good medical management and patient education. Disclosure can help them to understand the importance of accurately reporting their seizures, take their medication as prescribed and make lifestyle choices with seizure trigger minimisation in mind. Openness can also help reassure people who may have heard about SUDEP that in fact they have a very positive prognosis.

In Montreal the call for openness is backed by the international expert panel\* presenting a SUDEP session on Wednesday 26<sup>th</sup> June – ‘SUDEP prevention - are we there yet?’. Professor Ley Sander will present on ‘Discussing SUDEP: does disclosure reduce risk?’ outlining the reasons why early openness with patients is important. Support for early information on SUDEP for patients has grown since the first national clinical guidelines encouraging openness with patients were developed in the UK in 2004 and the UK, Australia and Canada combined forces in spreading awareness through a SUDEP Global Conversation campaign. Since then a National Institute for Neurological Disorders and Stroke (NINDS) workshop in the US, the inaugural meeting of Partners Against Mortality in Epilepsy (PAME) and a judicial enquiry in Scotland have recommended the education of all people with epilepsy about SUDEP. Current practice, however, suggests most patients are not informed about SUDEP. Later this week, Canadian epilepsy organisations will meet for the first SUDEP Professional development day.

All those backing the call for openness recognise that people with epilepsy may well respond like all other patients who receive difficult news about their condition and become temporarily anxious, but that information should only be withheld if patients are likely to suffer harm.

#### **Background:**

**\* The International Expert Panel includes Susan Axelrod (US); Professor Elizabeth Donner (Canada); and Phillippe Ryvlin (France); Professor Ley Sander (UK); Professor Elson So (US); Professor Torbjorn Tomson (Sweden).**

Epilepsy is a chronic condition characterized by recurrent seizures. Epilepsy affects 0.5%–1% of the population. Whilst deaths from accidents, status epilepticus (when a seizure is continuous and unremitting) have always been recognised as life-threatening it is only recently that the syndrome of sudden death in epilepsy has been defined and researched.

#### **Notes to Editor:**

- The 30<sup>th</sup> International Epilepsy Congress takes place in the Palais des Congrès de Montréal from the 23<sup>rd</sup> – 27<sup>th</sup> June, bringing together thousands of delegates from around the world, to discuss a range of topics which encompasses recent scientific, clinical and social advancements in the field of epilepsy.
- There are over 50 million people worldwide with epilepsy, nearly 10 million of whom live in the Americas. There are over 2.6 million people living with epilepsy in the USA and Canada alone.
- The International League Against Epilepsy (ILAE) was founded in 1909 which its membership mainly consisting of medical professionals working in the field of epilepsy worldwide.
- The International Bureau for Epilepsy (IBE) is the global body consisting of member associations who represent people with epilepsy around the world.

#### **For Further information:**

- [www.epilepsymontreal2013.org](http://www.epilepsymontreal2013.org)
- [www.sudep.org](http://www.sudep.org) (UK)
- [www.sudepaware.org](http://www.sudepaware.org) (Canada)
- [www.ilae.org](http://www.ilae.org)
- [www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)

#### **Contact:**

Alan Gallagher  
ILAE/IBE Congress Secretariat  
[alan@epilepsycongress.org](mailto:alan@epilepsycongress.org)