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For the attention of the News Editor**

## **Families, researchers, clinicians and organisations unite to promote a global conversation on sudden death in epilepsy**

A global collaboration of charities, researchers and families has created a unique online knowledge resource on sudden deaths in epilepsy. This new, web-based '**Global Conversation**' combats the myth that seizures do not kill.

Sudden Unexpected Death in Epilepsy (SUDEP) is when a person who has epilepsy dies suddenly and unexpectedly, with no other cause of death established. It accounts for the majority of deaths in people with chronic epilepsy. Deaths are also caused by accidents, status epilepticus, and suicide.

Jane Hanna, one of the editors, who has campaigned for awareness and action on epilepsy deaths since her partner died suddenly in his sleep, aged 27, in 1990 said: *"The mortality burden of SUDEP alone is high, second only to stroke amongst all neurological disorders because so many of the sudden deaths are in young people. Most people with epilepsy will live a full and normal life but we need to acknowledge the risks, especially with convulsive and night-time seizures. There are simple measures that can be taken that are known to reduce risk that people may want to know and try."*

The new 'Global Conversation' website [www.sudepglobalconversation.com](http://www.sudepglobalconversation.com) combines the latest research by international experts with the powerful accounts of bereaved families making it easily accessible to anyone in the world.

**The 'Global Conversation' will also be promoted at an exhibition at the American Epilepsy Society annual meeting in Seattle, between 6-8 December, 2014 which will be attended by about 4000 delegates.**

**ENDS**

**The press release is available for the experts and the families on this site to use.**

**If you are press, interested in helping to promote the 'Global Conversation' but are not in contact with any of the contributors or families, please contact one of the editors listed in the Intro section.**

**Please also advise us if you are using any of the family stories, so that we have an opportunity to advise the family where and when the story is likely to appear.**

## **BACKGROUND FOLLOWS/**

### **BACKGROUND FACTS**

**For FACTs on mortality, see the FACT section of the site.**

**For ‘Global Conversation’ facts, see notes below**

For over 100 years, a myth that seizures were not fatal hindered research and action to prevent epilepsy deaths worldwide. The myth was first broken in 1996, when the hard and long journeys of some tenacious families collided with those of pioneering researchers and clinicians from all over the world.

The success of the ‘Global Conversation’ is attributed to a powerful three-way collaboration between **SUDEP Action**, **Epilepsy Australia** and Canada’s **SUDEP Aware** which, together, reach out to research teams from many countries and over 60 experts from around the world, to gather and disseminate the latest information worldwide. It follows SUDEP Action’s (the working name for Epilepsy Bereaved) campaign during the 1990s, which sparked a partnership between the UK charity and Epilepsy Australia in 2005.

The new, web-based resource follows the success of two books that were produced by the partnership with more than 16,000 hard copies distributed to epilepsy communities around the world at international conferences held in Paris, Rome, Chicago, Montreal, London, Glasgow, Singapore and India, between 2005 and 2014.

The **original books online** have received more than 300,000 hits.

Sudden Unexpected Death in Epilepsy (SUDEP) is the term used when someone with epilepsy dies suddenly, often after a seizure that involves a loss of consciousness.

Dr Rosey Panelli, International Research Officer at SUDEP Action, who alongside Tamzin Jeffs, from SUDEP Aware, is promoting the resource at the Annual Conference of the American Epilepsy Society said, “By working together we can push forward the global conversation on SUDEP, which is vital to research and action on SUDEP wherever we are in the world.”

In 2013, SUDEP Action launched a Call for Openness on SUDEP, which is supported by the partnership and by the International League Against Epilepsy (ILAE); the International Bureau for Epilepsy (IBE) and 13 other epilepsy organisations around the world. Visit <https://www.sudep.org/call-openness-campaign>.

Click here to follow the **SUDEP Global Conversation on Facebook**