SUDEP Global Conversation raising awareness at World Congress of experts

Thousands of epilepsy specialists are attending the 31st International Epilepsy Congress (IEC) in Istanbul, which runs from 5th to 9th September, 2015.

SUDEP Global Conversation, an online resource launched in December 2014 will be promoted at IEC to raise awareness of epilepsy deaths. The SUDEP Global Conversation project, which began in 2005, aims to combat the myth that seizures do not kill and make knowledge available to tackle epilepsy deaths. It combines a collection of expert summaries with moving accounts by families bereaved from epilepsy.



Denise Chapman (left), co-editor of the SUDEP Global Conversation, is attending IEC to receive a major international award of Ambassador and is representing the SUDEP Global Conversation in Istanbul. She said:

"It is great to see that prevention of epilepsy deaths is to have a high profile at this important event in the epilepsy calendar. 'Understanding and Preventing Epilepsy Deaths' is one of the first sessions at IEC and it features speakers from around the world, all of whom are contributors to the SUDEP Global Conversation resource".

Another team of experts from the UK, Ireland and Australia, who have contributed to the SUDEP Global Conversation, are presenting a scientific poster on 'The SUDEP and Seizure Safety Check List' project and the 'EpsMon App', both new resources that are supporting professionals and people with epilepsy to engage and manage risk.

The success of the SUDEP 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, enabling effective distribution. The SUDEP Global Conversation project produced 3 books since 2005, but made the decision to go online in 2014 as scientific publications have increased massively in recent years.

Jane Hanna, SUDEP Action and co-editor of the SUDEP Global Conversation, said:

"We are able to reach audiences across the world by working closely together and having international support from the IBE. The SUDEP Global Conversation partners are also pleased to work with The Anita Kaufmann Foundation and Cassidy Megan, founder of Purple Day®, to bring greater awareness of mortality in epilepsy around the world via the distribution of bookmarks and posters directing the public to the SUDEP Global Conversation resource".

The IEC is organized by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). It is a major biennial event and is recognized as a landmark in the calendar of epilepsy specialists worldwide. In 2011, Rosey Panelli, SUDEP Action and co-editor of SUDEP Global Conversation, received the Ambassador award at the IEC. In 2013, Jane Hanna, SUDEP Action and co-editor of SUDEP Global Conversation, received the prestigious Social Accomplishment Award. The IEC gives delegates from all over the world the chance to come together and network with fellow researchers, clinicians and healthcare practitioners.

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.

Available from the IEC in Istanbul 6-8 September, 2015:

SUDEP Global Conversation bookmarks - at the IBE stand, #17; and **SUDEP Purple Day® materials** - at The Anita Kaufmann Foundation stand, #14.

For more information, visit:

SUDEP Global Conversation website http://www.sudepglobalconversation.com SUDEP Global Conversation FB page www.facebook.com/SUDEPGlobalConversation

Epilepsy Australia http://www.epilepsyaustralia.net/

SUDEP Action http://www.sudep.org/

SUDEP Aware http://www.sudepaware.org/