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For the attention of the News Editor**

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Oxfordshire Charity Chief Receives Global Impact Award on Epilepsy



Jane Hanna CEO of Wantage based charity SUDEP Action was awarded the Social Accomplishment Award in Epilepsy. The award, given out by the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE) is one of the highest honours from medical and patient organisations working in the epilepsy field. It was presented by Solomon Moshe, President of the ILAE and Mike Glynn, President of the IBE in Montreal.

Thousands of epilepsy specialists and epilepsy activists heard from Samuel Wiebe, the Director of the 30th International Epilepsy Congress how Jane's work over 22 years had made a difference in transforming research and policy and services in epilepsy.

Professor Shorvon, Chair of the ILAE (British branch) representing UK doctors and nurses who nominated Jane Hanna OBE for the award said: "She had the vision and commitment to use her experience to throw light on the largely unrecognised issue of epilepsy mortality...22 years of conviction, enthusiasm and refusal to be deflected have resulted in a seismic shift in thinking and practice on SUDEP and epilepsy mortality not only in the UK, but internationally. She has led the field successfully desensitizing SUDEP and epilepsy mortality and bringing it to the fore as a driver for improvements in care for people with epilepsy and their families".

1/ MORE FOLLOWS



Today epilepsy is recognized in the top ten of all causes of early death, yet 22 years ago a myth persisted in the medical community that people could not die from epilepsy. Jane was one of 5 women who began a campaign on Sudden Unexpected Death in Epilepsy (SUDEP) in the 1990's. Jane commented: "This award for work on SUDEP and epilepsy mortality is the best marker yet of how much progress has been made since the dark days when SUDEP was too sensitive to be talked about.

It reflects the passion and commitment of all the advocates of the SUDEP cause and the researchers and scientists who have travelled the same road with us over so many years. The award gives us all great impetus for our future programme of action to prevent deaths".

Jane dedicated the award to all those who played a part in the work of SUDEP Action from the founding of the charity as Epilepsy Bereaved in 1995 to the organisation it is today.

For more information on the award visit: <http://www.ibe-epilepsy.org/montreal-awards-2013/>.

Ends

Please contact Juliet Tumeo on 01235 772850 and at juliet.tumeo@sudep.org.uk for interviews and further information.

Please provide the following website link and contact number as there may be families affected who need to contact us or people living with epilepsy who want information and support www.sudep.org Bereavement Support 01235 772 852

2/BACKGROUND FACTS FOLLOW

Background notes

- Epilepsy Bereaved now **SUDEP Action** was founded in 1995 to get recognition of SUDEP and other epilepsy-related deaths and to work towards prevention strategies. Epilepsy is one of the top-ten causes of early death. Sudden Unexpected Death in Epilepsy or SUDEP can often be traumatic for families and distressing for professionals, all of whom have questions. At SUDEP Action, we focus our efforts on the priorities that bereaved families tell us are important:
 - To prevent deaths
 - To be supported
 - To be involved

We have won national and international honours for our achievements to date, but we recognise there is much more work to do. There are five key strands to our work:

- Providing information on SUDEP and risk in epilepsy
 - Offering support when someone has died
 - Involving people to help effect change
 - Sponsoring research and education to prevent future deaths
 - Capturing data across the UK through the Epilepsy Deaths Register
- **What is SUDEP?** – About 500 of 1150 seizure-related deaths each year in the UK are SUDEP deaths which are sudden and unexpected. They differ in cause from seizure-related accidents such as drowning or status when a person has prolonged seizures. They have been compared with cot deaths because they usually happen out of the blue; at night during sleep; and the cause is not fully understood. In many deaths, the person is young and healthy and their family, friends and community as well as the doctors are left traumatised by the shock.
 - **What does the research evidence show about who is at risk?** There is strong scientific evidence now that SUDEP deaths are seizure-related. Seizures which involve a total loss of consciousness are most associated. Other risk factors include having nocturnal seizures.
 - **What does the research evidence show about potential for prevention?** Anti-epileptic medication will fully control seizures in 70% of people and surgery can help around 3% of those whose seizures are drug resistant.
 - **What are the barriers to bringing the death rate down?** Research has identified that clinicians are often reluctant to discuss risks of SUDEP with people with epilepsy and their families and unlike Cot Death, the public remains largely unaware of SUDEP. Epilepsy remains underrepresented in terms of research funding and vital work is needed in this area.
 - **What is epilepsy?** There are over 40 different types of epilepsy, but grouped together the epilepsies are the most common serious neurological condition, affecting around half a million people in the UK alone.
 - **What should someone do if someone is having a seizure?** After the seizure, lay the person on their side in the recovery position. Stay until they have recovered. Once their breathing and colour is normal it is good to let them sleep until fully recovered. Only call an ambulance if one of the following circumstances applies:
 - The person is injured.
 - The seizure does not stop after a few minutes.
 - A seizure follows closely after another.
 - The person has trouble breathing.

For more information visit www.sudep.org