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For the attention of the News Editor**

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Study highlights need for epilepsy mortality prevention

A study in Sweden has highlighted the need for epilepsy mortality prevention. Researchers found that people with epilepsy are 11 times more likely to die prematurely than the general population. This risk is even higher in people with other conditions such as depression.

The research, led by Oxford University's Seena Fazel, MD, Department of Psychiatry, was published in an online report in the Lancet on 22 July 2013. The 41 year old study looked at 69,995 Swedish adults with epilepsy born between 1954 and 2009 and another 660,869 within the same age group and gender from the general population. In the follow up, researchers found that 6155 (8.8%) people with epilepsy died (at a median age of 34.5 years), compared with 4892 (0.7%) people in the general population.

This is why Oxfordshire charity SUDEP Action has campaigned for prevention of epilepsy deaths for 22 years. Commenting on the significance of the study's findings, SUDEP Action Chief Executive Jane Hanna OBE added in a statement: *"We have known since the late 1990's that epilepsy carries a significant increased risk of death compared with the general public and that a focus on epilepsy mortality ought to be a priority. Research on people in the UK has also flagged up that people with epilepsy are dying prematurely and that those with depression are amongst those at high risk.*

This new research study is important because of the numbers of people in Sweden who were followed up for 41 years. It finds that 9% of people with epilepsy die young compared with 0.7 % of the general population and that preventing mortality in people with epilepsy should be a priority. It also strengthens the concern that people with epilepsy and depression should get special attention. The research found that 16% of the deaths were from accidents and suicide generally occurring in people with depression."

[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(13\)60899-5/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)60899-5/fulltext)

SUDEP Action's work has been recognised globally. The charity's Chief Executive Jane Hanna OBE was awarded a Global Impact Award on Epilepsy for her work towards epilepsy mortality prevention. The accolade which has rarely gone to non-medics was last awarded to an epilepsy specialist in the UK 30 years ago. The award, given out by the International

1/ MORE FOLLOWS

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.

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”*.

SUDEP Action also recently launched The Epilepsy Deaths Register aimed at preventing epilepsy deaths. This is the only existing register of its kind in the UK.

We would advise anyone who has concern about their epilepsy to discuss their condition and treatment with their health care team.

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 Epilepsy?** Epilepsy is a common serious neurological condition where there is a tendency to have seizures that start in the brain. There are over 500,000 people in the UK with epilepsy.
 - **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