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For the attention of the News Editor**

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Oxfordshire Charity launches The Epilepsy Deaths Register to prevent epilepsy deaths

Oxfordshire charity, SUDEP Action launched The Epilepsy Deaths Register campaign at a Parliamentary Reception held on Tuesday 4 June 2013. The event was attended by 15 Members of Parliament (MPs) who are supporting the campaign aimed at preventing epilepsy deaths. MPs heard of the experience of SUDEP Action supporters, the Burns family, whose son Charlie aged 11 died from SUDEP following a seizure that occurred during his sleep. His family had never heard of Sudden Unexpected Death in Epilepsy (SUDEP).

Commenting on the campaign, Norman Lamb MP, Minister for Care and Support, said: *"I am hugely supportive of the important work being undertaken by SUDEP Action, and in particular their work to establish an Epilepsy Deaths Register. Their register will help to develop a clearer picture of epilepsy-related deaths nationwide, will help to improve clinicians' understanding of epilepsy, and will ultimately help to reduce sudden and unexpected deaths in epilepsy and improve patients' care."*

There are 3 epilepsy deaths every day in the UK every day often in the young puts epilepsy in the top ten of all causes of early death. Sudden Unexpected Death in Epilepsy (SUDEP) is used when someone with epilepsy dies suddenly- often after a seizure that involves loss of consciousness. SUDEP accounts for at least half of all epilepsy deaths in the UK. Whilst doctors have information to help patients avoid fatal accidents or prolonged seizures, much less is known about SUDEP. The Epilepsy Deaths Register has been launched to help with the prevention of epilepsy deaths and provide some answers to SUDEP.

1/ MORE FOLLOWS

SUDEP Action Acting CEO Karen Osland highlighted the importance of the register commenting that: “registers of epilepsy death are a vital new development in work on prevention across the world. We need everyone who knows of a death to report and we need as many supporters as possible joining our campaign to develop the register. I urge anyone with information about a death to contact the register via www.sudep.org”.

Campaigners and policy makers are working to raise awareness amongst Coroners who can play a key role in recording deaths which can help to educate the public and improve services.

Jan Burns who spoke about her son Charlie’s death from SUDEP said: *“The most significant development has been the launch of the Epilepsy Deaths Register by SUDEP Action, a place where bereaved families and friends can register an Epilepsy related death. This information will be used for medical research, in the hope that it will one day help towards finding a cure and prevent more unnecessary loss of life. This information will also highlight the number of people who are losing their lives to SUDEP.”*

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

SUDEP Action launched The Epilepsy Deaths Register, the only single point for reporting all epilepsy-related deaths in the UK. It is supported by researchers, professionals and endorsed by government. Epilepsy is among the top ten causes of premature death. To help prevent future epilepsy deaths, we need to find out what happened in as many cases as possible.

The information will help:

- Co-ordinate involvement in research.
- Improve public awareness of epilepsy-related risk and SUDEP.
- Identify and prioritise new research.
- Decide where best to put funding to improve services.
- Improve advice and treatment plans.

You can register a death no matter who you are including:

- Relative and friends (as long as you are over 18)
- Doctor, nurse, carer or social worker.
- Coroner, procurator fiscal or pathologist.

It does not matter if the same death has already been registered, as the more information the research team has on each death, the better.

Please let us know about any death reported or suspected to be:

- SUDEP (Sudden Unexpected Death in Epilepsy)
- Any sudden death in someone with evidence of a seizure that cannot be explained.
- Deaths in people with epilepsy reported as status epilepticus.
- Accidental deaths in people with epilepsy
- Deaths reported as cause unknown in people with epilepsy.

Our Epilepsy Deaths Registry team has over 50 years' combined expertise in epilepsy deaths. Research support is provided by Dr Henry Smithson and his research team at Sheffield University and by Kings Health Partners.

- To register a death fill in our online form at www.sudep.org
- Print a form from www.sudep.org and post it
- Phone our local rate number 03300881220 or

For more information visit **www.sudep.org**

SUDEP Action provide support after a death on 01235 772852.