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For the attention of the News Editor**

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Researchers back SUDEP Action's call for more funding into epilepsy deaths

Researchers have joined SUDEP Action in calling for epilepsy mortality to be recognised as a top priority for UK and European research funding. Research teams from King's Health Partners; University College, London, and the Universities of Cardiff, Cork, Exeter, Glasgow and Sheffield have joined forces to back the call to plug the UK funding gap in research into prevention of deaths.

Epilepsy ranks in the top ten causes of premature deaths and is potentially avoidable. Many young and healthy people have lost their lives and in the UK more than 3 people die a day. SUDEP Action is working with research teams across the UK in a range of initiatives, but funds are urgently needed.

Research teams are working with SUDEP Action's Epilepsy Deaths Register which was established last year as a resource for research into epilepsy deaths. The register has already attracted over 310 registrations since launching less than a year ago and has won funding from Epilepsy Ireland to extend our work in Ireland. Bereaved families are helping research teams with vital information and providing their permission to be contacted to help further research.

Following a SUDEP Action research meeting in January 2014, the research teams agreed a Statement of Research Need setting out where evidence is needed to prevent deaths.

The teams recognised the importance of wider awareness that urgent funds are needed to answer all the research questions that make up the current UK research gap on prevention of epilepsy deaths.

The agreements reached will be used by SUDEP Action to urge funders to prioritise research into epilepsy deaths and as a guide to our work with research teams.

Jane Hanna OBE said:

“Through targeting epilepsy deaths SUDEP Action led the first investigation into epilepsy deaths and since then has provided funding to help identify mortality trends; risk factors; and also specific areas such as the role of medication taking and alarms. SUDEP Action has invested in The Epilepsy Deaths Register which makes research easier and cheaper for research teams by coordinating involvement in research, but to maximise these opportunities major funding is needed now”.

Professor Mark Richardson said

“SUDEP Action has worked tirelessly to fund the research gap, but external funders do not often understand the research gap or fail to prioritise it. We will use this statement of research need to gather support and to both inform and persuade funding bodies that work on prevention of deaths should be a clearly stated priority”.

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

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 the research team at Sheffield University, by Kings Health Partners; University College, London and the Universities of Exeter and Cork.

- To register a death fill in our online form at www.sudep.org
- Or call our local rate number 0330 088 1220 to report by phone or to ask for a printed form

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

SUDEP Action provide support after a death on 01235 772852.