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Charity champion who brought deaths out of the shadows to be honoured with OBE

At the start of National Epilepsy Week; 14th – 19th June, researchers, patient groups and bereaved families pay tribute to Jane Hanna, Director of Epilepsy Bereaved who has been awarded an OBE in the Queen's birthday honours list for her services to families.

Jane's partner, Alan, died suddenly and unexpectedly aged 27 in 1990. Alan had his first seizure during April that year and was referred to see a specialist in the September, but he died in his sleep following his fourth seizure in December. His death was attributed to suffocation, although there was no evidence for this. She then began the lengthy process of finding the small number of researchers who recognised Sudden Unexpected Death in Epilepsy (SUDEP). Jane founded Epilepsy Bereaved in 1995 together with Alan's mother and three other women following the sudden deaths of William aged 22; Matthew aged 21 and Natalie aged 22. William, Alan and Matthew all died in their sleep and Natalie died in the bath. Neither pathologists nor coroners nor doctors were able adequately to explain why or how these young active people had died.

Today it is recognised that three people die each day from Epilepsy in the UK and that the majority of these deaths are SUDEP¹. Experts believe that around half of these deaths are potentially avoidable². Epilepsy Bereaved are committed to helping health professionals and families understand how sudden death in epilepsy can be prevented and to get vital support for research.

Jane Hanna says, *"This award is a wonderful public recognition of the importance of the SUDEP cause. I am proud to accept it on behalf of the many people I have worked with over the years for whom the cause of awareness and prevention of SUDEP is paramount. At the core of our work are the bereaved families, many of whom are truly inspiring in their courage and support of the charity"*

Professor Phil Smith, President UK Chapter of the International League Against Epilepsy *"Jane Hanna has done so much to raise the profile of epilepsy in the UK and worldwide. I am absolutely delighted that her tremendous contribution to the welfare and safety of patients with epilepsy has been deservedly recognized"*

More follows...

¹ There were 1105 reported deaths from Epilepsy in 2008. General Register Office for Scotland 2008: Table 6.4 Deaths by sex age & cause 2008 registrations. Northern Ireland Statistics and Research Agency 2008: Table 6.4. Deaths sex age & cause 2008 registrations. Office of National Statistics 2008: Table 6.4 Deaths by age, sex & underlying cause 2008 registrations.

² Hanna et al, 2002. The National Sentinel Audit of Epilepsy Related Death. TSO London.

Professor Stephen Brown, Consultant Neuropsychiatrist and Honorary Professor of Developmental Neuropsychiatry in the Peninsula Medical School, Cornwall says

“At a time when there was a general acceptance in the medical community that seizures were benign, it took the passion and determination of the founding members of the charity to successfully break through the double taboo of epilepsy and bereavement so that work to prevent these tragic deaths could properly begin”

In 1996 the charity convened the first international workshop on SUDEP bringing dedicated researchers and bereaved families together to address key questions about SUDEP previously thought too sensitive to be raised even within the scientific community. The workshop led to increased research activity on SUDEP. Professor Tomson, Sweden whose research findings in 1998 established the strong association between SUDEP and seizures and identified key risk factors paid tribute.

“In October 1996, I took part in the international workshop on Sudden Death in Epilepsy in London. The meeting had a major impact on the direction of my research and is only one example of how Epilepsy Bereaved has provided leadership to the rest of the world on how to respond to these tragic deaths”

The workshop also produced the call for a national confidential enquiry into epilepsy deaths leading to the UK governments commissioning Epilepsy Bereaved to lead medical royal colleges in an investigation. They reported in 2002 that 400 of 1000 deaths a year might be avoided. Various national initiatives followed including national guidelines on epilepsy and on the investigation of epilepsy deaths.

Outside of the UK international researchers and voluntary organisations have paid tribute to Epilepsy Bereaved in leading a global conversation about SUDEP. The charity has inspired and supported action on SUDEP in many countries across the world working in partnership with Epilepsy Australia (2004), SUDEP Aware in Canada (2007), the US SUDEP Task Force (2008) and working with leading international researchers. Denise Chapman, Executive Officer, Epilepsy Australia says

“SUDEP awareness in Australia owes much to the groundbreaking work of Epilepsy Bereaved. While we may be half a world apart, Epilepsy Bereaved supported us to understand the problem and the need for community awareness of SUDEP and its known risk factors and from this a working partnership developed. In 2005 Epilepsy Australia and Epilepsy Bereaved published the book SUDEP - a global conversation leading to interest and action across the world. Here in Australia, the ongoing work of Epilepsy Bereaved continues to inspire our own efforts in addressing these tragic deaths among the Australian community.”

Today Epilepsy Bereaved manages 1000 contacts each year helping families with practical information and advice about dealing with inquests, medical information on sudden unexpected death in epilepsy along with much needed emotional support.

EDITORS NOTES FOLLOW..

EDITORS NOTES: Interviews can be arranged by Epilepsy Bereaved with Jane Hanna, researchers and for access to families who have been helped by the charity. **Please contact 07985 587554.** Please do provide

our website as there may be families affected who need to contact us or people living with epilepsy who want information and support: www.sudep.org

Background notes

- **Jane's story:** Jane was a law fellow at Keble College, Oxford University when her then partner, Alan, a young barrister, died suddenly and unexpectedly aged 27. She brought a complaint following his death but the local health authority upheld the care provided because there were no recognised standards of care for people with epilepsy at that time. Choosing not to appeal, she worked with 4 other women to found Epilepsy Bereaved as a charity in 1995 and in 1997 Jane took up the role of part-time Director of the Charity. She continued to teach part-time at Oxford until 2007. Today she is Director, Epilepsy Bereaved; Vale of the White Horse District Councillor; Wantage Town Councillor and lives with her partner Andy and their young daughter Kyra and her step-son Matthew in Wantage, Oxford.
- **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 ?** The good news is that anti-epileptic medication will fully control seizures in 70% of people and surgery can help around 3% of those whose seizures are drug resistant. The National Sentinel Clinical Audit of Epilepsy-Related Deaths (2002) found there was significant potential for avoidance of premature deaths (about 40% of deaths). The Audit also found that the investigation of epilepsy-related deaths was poor, and this hampered progress in learning from the deaths. The Audit was welcomed in 2002 by all four chief medical officers in the UK as a 'landmark report', and was summarised in the Lancet as a 'wake-up call' to epilepsy management around the world.
- **What are the barriers to bringing the death rate down ?** The Chief Medical Officer stated in his annual report 2001 that epilepsy is not taken seriously compared with other chronic conditions, that this remains the case in most areas. Numerous national initiatives remain unimplemented. Today Research has also identified that clinicians are still reluctant to discuss risks of SUDEP with people with epilepsy and their families and unlike Cot Death, the public remains largely unaware of SUDEP. Finally, epilepsy remains underrepresented in terms of research funding and vital work is needed to support improved communication about managing the risks of epilepsy as well as vital development work on technology and medications that could cut the death rate dramatically.
- **What is epilepsy ?** There are over 40 different types of epilepsy, but grouped together the epilepsies are the most common serious neurological condition, affecting just under half a million people in the UK alone. There are many different types of epilepsies presenting in many different ways e.g. from a tiny flutter of the eyelids or a momentary lapse in concentration ('absences') to convulsive seizures with total loss of consciousness ('tonic-clonic'), with many different types in between. Epilepsy is normally diagnosed on the basis of two or more seizures. Seizures occur when the normal activity of the brain is interrupted. This may be as a result of an accident or injury, through scarring on the brain tissue as a result of an illness, a developmental problem, or there may be no known cause. It can develop at any age and can affect anyone.
- **What should someone do if someone is having a seizure ?** When a person has a seizure there is usually no need to call an ambulance – unless the person sustains injury or has trouble breathing, or if the seizure lasts longer than usual or if one seizure immediately follows another.
- Never try to restrain the person or stop the seizure and NEVER put anything in the mouth.
- Prevent others from crowding around; only move the person if in a dangerous place; protect the head with something soft such as a jacket or cardigan.
- When the seizure has stopped, roll the person into the recovery position, check that they are breathing normally.
- Stay with the person giving reassurance, until they have fully recovered.

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