



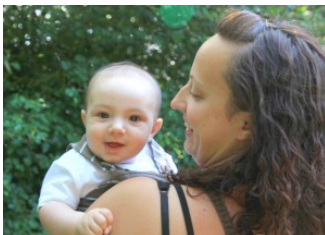
Epilepsy Bereaved Director Jane Hanna & John Inverdale

John Inverdale presents Radio 4 Appeal for Epilepsy Bereaved

Epilepsy Bereaved will feature on a BBC Radio4 Appeal on Sunday 25th July. John Inverdale from BBC Sports will be presenting the appeal on behalf of the charity.

John was motivated to help the charity in this way after hearing about a young doctor who died from Sudden Unexpected Death in Epilepsy (SUDEP) just a few months following her graduation.

The appeal will feature the story of 22 year old Rachel who died of Sudden Unexpected Death in Epilepsy, she had been found by her sister. Rachel's eight month old son was alone crying for his mum in the next room.



Rachel & Harvey

Rachel was diagnosed with Epilepsy aged 11 and she took medication to manage her seizures. She never let her Epilepsy get in the way of living her life. She was about to start training to become a primary school teacher. No one ever warned Rachel or her family that there was any risk of death from epilepsy. They had never heard of the term Sudden Unexpected Death in Epilepsy.

Rachel's mum Gill said; *"Finding Epilepsy Bereaved on the internet became a lifeline for us as a family and helped us to realise we are not alone in our loss and there is help for us through epilepsy bereaved whenever we need it"*.

In the UK, 3 people die each day from Epilepsy and the majority who die are young – between 20 and 45. Experts believe that around half of these deaths are potentially avoidable. Epilepsy Bereaved are committed to changing this – to help health professionals and families understand how Sudden Unexpected Death in Epilepsy may be prevented and to get vital support for research.

Any death is tragic for those left behind, but a sudden unexpected death like Rachel's is especially devastating & bewildering. Her family found that no one understood what they were going through until they found Epilepsy Bereaved.

The charity helps families with practical information and advice about dealing with inquests, medical information on SUDEP and other seizure related deaths along with much needed emotional support.

Broadcast details;

Sunday 25th July @ 7.55 am & 9.26 pm Thursday 29th July @ 3.27 pm

Also available on the BBC Radio Appeal website & BBC iplayer

Please 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

Tel: 01235 772852 (bereavement contact line)

BACKGROUND FACTS

- **Epilepsy Bereaved** was founded in 1995 to get recognition of SUDEP and other epilepsy-related deaths and to work towards prevention strategies. Epilepsy Bereaved raises awareness about ways of reducing the risks of sudden unexpected death from epilepsy, or SUDEP, and supports the families left behind. The charity led a partnership with medical colleges to investigate all seizure-related deaths over a 12 month period leading to a ground-breaking finding that 400 of 1000 deaths were potentially avoidable. The charity is dedicated to focusing research on prevention of future deaths. The Charity has gained international recognition for its work on SUDEP, but core to the work of the charity is providing information and support to 100 newly bereaved families and ongoing services for 1000 families.
- **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 is SUDEP?** - 500 of 1000 seizure-related deaths each year 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 if not fully understood.
- **What is known already about managing risks?** There is good evidence that deaths are seizure-related, but not all types of seizures are associated, so it is important that anyone who is not seizure-free discusses this with their doctor or nurse.
- 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.
- **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 coat.
- 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. **ENDS**

EDITORS NOTES: Contact Fiona McDonald Epilepsy Bereaved Communications Manager 01554 778450 / 07985 587554.