KAREN OSLAND
DEPUTY CHIEF EXECUTIVE

SUDEP Action
National Conference 2016
Welcome

STEPHEN BROWN
CHAIR

Setting the Scene
Epilepsy Foundation SUDEP Institute announces winner for second challenge: “EpSMon” mobile app – preventing epilepsy seizures

The SUDEP Institute challenged participants to come up with ideas for a method of intervention to reduce the risk of seizures, especially convulsive seizures, with the purpose of preventing SUDEP. Over 300 participants registered for the challenge, and they submitted 83 solutions from 25 countries.

Preventing epilepsy deaths – the power of communities

Jane Hanna
Chief Executive
The Epilepsy Bereaved Community

• Your struggles, your journey

• The journey of our staff and trustees

• The values that bind us

Our Values

Determination:
*The adversity our community suffers creates passion which drives our work and keeps those that have died at the heart of what we do*

Respect:
*That people should be treated how they would want to be treated or their family treated in life and after death.*

Collaboration:
*Working with individuals and partners that share our aims and our values to avoid waste and maximise effort*
The Epilepsy Deaths Register

Deaths reported to our community through the EDR

- 379 reports from UK (Over 500 international)
- Mean Age of death is 28 years
- 45 deaths reported < 18
Emerging themes before death

- Risk not communicated
- Concerns about services

**The problem:** There is no UK wide NHS Plan to reduce the epilepsy burden

- **600,000** people in UK
- **1200** deaths/year

All causes of deaths before the age of 70

- **42%** of deaths can potentially be prevented

Impact on the NHS

- **73%** of first-seizure patients are not given seizure management advice
- **63%** with no contact with health services
- **£1.5 Billion** (Yearly cost of Epilepsy)
- **60,000** additional emergency attendances
- **40,000** epilepsy-related hospital admissions

National Audit of Seizure management in Hospitals (NASH) – 2012 & 2015
• Most deaths at home
• Majority with SUDEP on death certificate
• Needs after a death as complex
• Satisfaction with SUDEP Action specialist services after a death

Impact

“The physical pain and guilt are overwhelming, and we are only just becoming able to talk about him to each other after 16 months has passed. The impact is total and devastating, and has affected both the physical and mental health of the whole family”
Hurdles?

How long does it take to change these things?

- Talking about epilepsy deaths a total taboo
- SUDEP not recognised at all
- No understanding of cause
- No understanding of risk
- Epilepsy Bereaved community did not exist
- Ways of connecting did not exist
- Nothing happening
Support for our Community

- Listening, support and generic counselling
- Supporting your journey with services and tools that you say you want:
  - Helping you with your questions
  - Information
  - Conference and Coffee Clubs
  - Communications
  - Memorial Service

The nature of our community

Our Community has borne the impact of the taboo on epilepsy mortality. Most of us were carers of people with epilepsy and continue to bear a burden from this time. Many of us continue to struggle against ignorance and lack of concern.
What empowers us

• A determined united Community
• Doctors and Nurses working alongside us
• Extensive local, national and global network
• Knowledge
• Funding
• Tools

SUDEP and Seizure Safety CheckList
For over 16s – childrens’ version coming next

SUDEP Action
Making every epilepsy death count
EpSMon developed over 5 years of work including:

**Background:**
- Extraction of risk factors from scientific evidence of over 300 peer-reviewed papers
- Tested as a SUDEP Safety Checklist in clinical and deceased populations of epilepsy patients in Cornwall
- Safety checklist applied to 350 + PWE 98% well received
- Communication of person centered recorded risk 80% + vs. 10% in 2010, 36% UK
- GP Practice finding 117 patients flagged up risks not known by GPs
- 0 SUDEP in LD service. 7 in mainstream vs. expected 25-30 for the population (Coroner & Public Health)

**UK-wide Professionals include**

- Professor Mathew Walker – Consultant Neurologist National Institute of Neurology & Neurosurgery
- Mrs. Caryn Jory – Epilepsy specialist nurse
- Dr. Tamsyn Anderson – GP - Kernow Clinical Commissioning Group Medical Director
- Dr. Elizabeth Emma Carlyon - HM Coroner for Cornwall
- Professor Henry Smithson – GP (epilepsy & medication adherence)
- Professor Leone Ridsdale – GP (epilepsy mortality and primary care)
- Dr. John Paul Leach – President International League Against Epilepsy (ILAE)
- Professor Phil Smith - President Association of British Neurologists (ABN)
- Mrs Juliet Ashton – Sapphire nurse: National Epilepsy Commissioning
- SUDEP Action

**SUDEP and Seizure Safety Checklist**

**SUDEP Action**

**Making every epilepsy death count**
For people living with epilepsy:
EpSMon risk assessment app

- Accessible to anyone with a mobile phone
- Free
- Encourages engagement with health services
- Seizure & risk management advice at the finger tips of patients
- Liked by health professionals & patients

ILAE UK 2015 – 1st prize for poster presentation

Both Checklist & EpSMon part of the national Epilepsy Commissioning
Regional TV and Radio (36), Newspapers (26); Guardian and ITV news; social media campaign supported by 43 organisations

Android launch countdown 14th March

Where are we now?
Finalists for HSJ awards in 2 categories ‘Patient Safety’ & ‘Using Technology to improve outcomes’

How can you help?
408 people downloading in last 30 days!
Can you tell people about EpSMon?
Our E-learning Tool – Coming April
For all GPs who are members of the RCGP

World interest in our work

- Partners Against Mortality Epilepsy
  JUNE 23 - 26, 2016 | WASHINGTON, D.C.

- Centre for SUDEP Research (CSR). UK partner for involving bereaved families

- World Epilepsy Congress Sept 2017 – EpSMon Self-Monitor in first session on technologies to enhance safety
2016 - the Race hots up

The Future - Electronic Devices to Help Prevent Epilepsy Deaths?
What anyone can do to help

• Get the media to cover our news and learn about our Community!

• Share your story with us so we can help the world to understand our Community

• Campaign through us so our Community is heard

• Helping other initiatives to connect with us
Sharing your story

Making every epilepsy death count

Call us now on 03 772850

My Story

SUDEP Action is a national epilepsy umbrella group representing the interests of people affected by sudden unexpected death in epilepsy (SUDEP). We campaign for better understanding, prevention and support for families. Our vision is to ensure that people living with epilepsy have access to the best possible care and that every person affected by SUDEP receives the best possible support.

Latest news

SUDEP Action welcomes commitment by Sharma to international collaboration on SUDEP

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People with neurological conditions without symptoms - 25 Mar 2016

Features

Andy, Bex, Alex and Ali talk about living with SUDEP.

Our younger daughter Emily was 11 when she died and very much loved. Dad now的感受 is very sad.

SUDEP Action

Making every epilepsy death count
Our community:
sharing their stories across the world

www.sudepglobalconversation.com

SUDEP-the Global Conversation:
provides short summaries of key SUDEP research

www.sudepglobalconversation.com
SUDEP Awareness Day: 23rd October

In its third year!

www.sudepawarenessday.org

SUDEP Awareness Day – 23rd October
Over 130 Supporting organisations worldwide!

SUDEP Action
Making every epilepsy death count
Supported Involvement in the cause of the Community

- Listening to you to give us direction
- Epilepsy Deaths Register
- Helping you share your story – we know grief can be triggered at any time
- Looking out for your interests as world interest increases demands on families after a death
- Our community fundraising offers you a supportive context – we know that grief can be triggered at any time

Help us develop the way forward?

- How we spend our funds
- Understanding your struggles – Jumping the hurdles workshop
- How we strengthen our Community
- Charter of the Bereaved – who we are/what we want
- UK meeting with organisations supporting
What can you do?

- SUDEP Action receive no statutory funding
- Total funds carried forward to do our work £279,725.84
- A reserve of about 6 months from general funds
- £123,500 held for WADD - £41,000 still needed

What we want to do

Safety first: Reducing exposure to known risk

- 2016 update and promotion of Safety Tools (SUDEP & Seizure Safety Checklist & EpSMon)
- Children’s /Carer/Learning Disability
- Support other sites working with us on the Tools - UCL, Oxford, Norfolk, Johns Hopkins

Future: Research on risks and Responding to life-threatening crisis:

- Trial on WADD/ Wearables with EpSMon
How much do we spend on all this?

In 2015, we received an income of just over £377,000.

What we spent was divided up as follows:

- Bereavement: 19%
- Support: 18%
- Providing Information: 20%
- Epilepsy Death Register: 11%
- Research: 11%
- Involving people to affect change: 11%
- Fundraising costs: 0%