Plenary 6
Advocacy Perspectives: How Can We Speed Up Awareness and Prevention?
June 26, 2016
8:00 a.m. - 9:15 a.m.
Moderator: Jane Hanna, SUDEP Action

Panelists:
- Mark Stevenson, FACHE, CHIE, Epilepsy Foundation
- Karen Osland, SUDEP Action
- Cyndi Wright, SUDEP Institute
- Rosemary Panelli, MPH, PhD, SUDEP Action
- Samuel Wiebe, MSc, MD, FRCPC, International League Against Epilepsy

- Panel Discussion:
  - How can we scale and speed up research, prevention and awareness?
Advocacy perspectives – How can we speed up awareness and prevention?

Jane Hanna OBE
CEO SUDEP Action

Disclosure

None
Advocacy Perspectives: How Can We Speed Up Awareness and Prevention?

Mark J. Stevenson, FACHE, CHIE
Father of Tyler, SUDEP 2011

June 26, 2016

Disclosure

None

What Do You Do Next?


University of Colorado Boulder

Tyler J. Stevenson Memorial Scholarship

One $1,000 individual merit-based scholarships ($500 fall and $500 spring) awarded annually to students with epilepsy.

Selection criteria:

• Personal statement about overcoming challenges, academic, career and life goals, and financial need, if applicable
• Letter of recommendation /support
• Minimum CU-Boulder cumulative GPA of 2.2

Colorado House Bill 13-1256, which was postposed indefinitely by the House Public Health Care and Human Services Committee, would have required the state's chief medical officer to establish a Sudden Unexpected Death in Epilepsy Awareness Program (SUDEP) to educate medical examiners and coroners about SUDEP. The chief medical officer, in consultation with county medical examiners, coroners, and organizations with expertise in SUDEP, would have established a standard protocol governing investigations involving seizure disorders in order to identify related deaths. All postmortem examinations would have had to include an inquiry to determine whether the death was a direct result of a seizure or epilepsy. Finally, the medical examiner or coroner would have been required to take certain actions once it was determined that a death was related to a seizure or epilepsy.


Advocacy perspectives – How can we speed up awareness and prevention?

Karen Osland
CEO SUDEP Action

Disclosure
None

Innovators – UK families work with clinicians to turn private pain into public purpose

With support what is possible?

What support do families need after a death –
Reporting of 251 families to EDR (March 31st 2016)
Complicated grief

Total shock: I did not know that you could die from epilepsy. It was never mentioned by any doctors at any hospital or GP surgery. The first I had ever heard of SUDEP was after Russell’s death. I have just been diagnosed with Post Traumatic Stress Disorder and I do not think I will ever get over the death of my son.”

Support after a death – reporting to EDR of families (251) to March 31st 2016

Extremely to moderately satisfied
Neither satisfied nor dissatisfied
Extremely to moderately dissatisfied

<table>
<thead>
<tr>
<th>Source of Help</th>
<th>Extremely to moderately satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Extremely to moderately dissatisfied</th>
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</thead>
<tbody>
<tr>
<td>Coroner Service or Procurator Fiscal (n=127)</td>
<td>63 (50%)</td>
<td>34 (27%)</td>
<td>30 (24%)</td>
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<tr>
<td>GP or Family Doctor (n=142)</td>
<td>70 (49%)</td>
<td>34 (24%)</td>
<td>38 (27%)</td>
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<tr>
<td>Specialist Doctor (n=180)</td>
<td>25 (28%)</td>
<td>23 (26%)</td>
<td>40 (45%)</td>
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<tr>
<td>Specialist Nurse (n=61)</td>
<td>12 (20%)</td>
<td>24 (39%)</td>
<td>30 (49%)</td>
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<tr>
<td>SUDEP Action (n=154)</td>
<td>134 (87%)</td>
<td>18 (12%)</td>
<td>2 (1%)</td>
</tr>
<tr>
<td>Other epilepsy organisations (n=156)</td>
<td>31 (48%)</td>
<td>25 (25%)</td>
<td>8 (12%)</td>
</tr>
<tr>
<td>Other bereavement service (n=98)</td>
<td>46 (52%)</td>
<td>22 (22%)</td>
<td>31 (31%)</td>
</tr>
<tr>
<td>Other sources of help (n=57)</td>
<td>31 (54%)</td>
<td>19 (33%)</td>
<td>7 (12%)</td>
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Who’s helping sign-post families?

How was the service found (n=144)

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Recognition: specialist advocacy

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SUDEP Action in UK honoured in 2010 and 2013 for services to families

- Families at heart of priority setting and planning
- Single point of contact at time of trauma
- Specialist triage service tailored to needs
- Specialist counselling
- Supported involvement in research
- Supported involvement in story sharing
- Access to peer group and experts

Empowering - sharing of experiences
Innovative Ways to Speed Up Awareness and Prevention

Cyndi Wright
Epilepsy Foundation SUDEP Institute

JUNE 2016

Disclosure

None

SUDEP Challenge Initiative Background

ARE YOU READY TO BE PART OF THE $1,000,000 SUDEP SOLUTION?

ACCEPT THE CHALLENGE
EMPOWERING PEOPLE WITH EPILEPSY

The First Challenge

The Second Challenge

ACCEPT THE CHALLENGE
Preventing Epilepsy Seizures

$30,000 REWARD
LEARN MORE »

The Current Challenge:
Predictive Biomarkers of Epilepsy Seizures
Advocacy perspectives – How can we speed up awareness and prevention?

Dr. Rosemary Panelli, MPH, PhD
University of Melbourne / SUDEP Action

JUNE 2016

Disclosure

There are no disclosures

39% of adult & 59% of child deaths potentially avoidable


Prevention of epilepsy-related death requires us to tackle known gaps in care

International Death Registers

Registers can promote tissue collection: they can also identify gaps in care

International Awareness and Action

continuing the global conversation

Part 4: Action

Help patients tell their stories: an essential step in alerting people to SUDEP

Increase awareness among patients and families

Alert national and local epilepsy organizations to SUDEP

Advocate policies to minimize SUDEP

Call for Openness – Montreal 2013

The campaign calls for a common sense approach to alert people and find ways to reduce their risk of SUDEP.

Openness can also help reassure people who may have heard about SUDEP that in fact they have a very positive prognosis
Epilepsy Foundation SUDEP Institute Announces Winner for Second Challenge:

"EpSMon" Mobile App - Preventing Epilepsy Seizures

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.

Plymouth University entered and won the prize for the partner collaboration SUDEP Action, Plymouth University, Cornwall NHS Partnership Trust and Cornwall Royal Hospital and funds will be used to bring the App to America.

The primary health sector needs to be integrated into action on epilepsy mortality.

BMJ Editorial: Avoiding premature epilepsy deaths

Avoiding premature death in epilepsy

General practice is the place to start, and much can be done.

Leone Riddatt, professor of neurology and general practice

Department of Basic and Clinical Neurosciences, Institute of Psychiatry, Psychology and Neurosciences, Academic Neurosciences Centre, London SE5 8AF.
Advocacy and Research Perspective
International League Against Epilepsy
Samuel Wiebe, MD, MSc
Executive Board, International League Against Epilepsy
University of Calgary, Canada

Learning Objectives
Following participation in this activity, learners should be able to discuss:
• Epilepsy burden of disease and mortality in global context
• Research/advocacy in non-US non-European countries
• Role of international organizations (ILAE) in research/advocacy

GLOBAL CAUSE OF DEATH 2012 – by income group

SUKER RESEARCH
Rest of the World

Disclosure
Served advisory boards:
Electrocore
Sunovion
Sponsored lecture and seminar:
UCB

Lost years due to epilepsy (death + disability) per 100,000 people

Source: global burden of disease, WHO 2012

Epilepsy
INTERNATIONAL LEAGUE AGAINST EPILEPSY
Vehicles for Advocacy – Education – Research

World View

Task Forces

Collaboration

Congresses

Wikipedia

INTERNATIONAL - REGIONAL
congresses, courses, workshops

ALL EPILEPSY MATERIAL
125 views per day

AWAWARENESS, EDUCATION
ME, NME, APN, MD, PhD

MORTALITY, EPIDEMIOLOGY,
THERAPEUTICS

Task Forces

234 COUNTRIES
on all continents

INTERNATIONAL - REGIONAL

MORTALITY, EPIDEMIOLOGY,
THERAPEUTICS

Research: Statistics, meta-analyses, definitions

3 Journals

Research, Care, Education

Collaboration: Awareness, Education

Epilepsy, Epileptic Disorders, Epilepsy Care

INTERNATIONAL – REGIONAL

Sessions, courses, workshops

Wikipedia

All Epilepsy Material

125 views per day

Collaboration: Awareness, Education

IME, NIME, APN, MD, PhD

INTERNATIONAL – REGIONAL

Sessions, courses, workshops

World View

Vehicles for Advocacy – Education – Research

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INTERNATIONAL – REGIONAL

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2015 AES Annual Meeting
www.AESnet.org