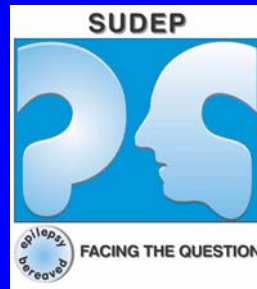


NATIONAL CLINICAL AUDIT OF EPILEPSY DEATHS

Campaign: building support and working in
partnership

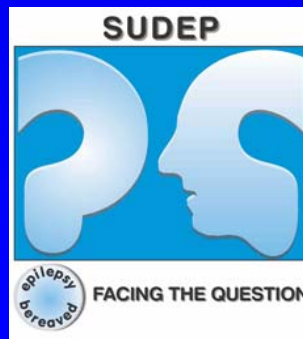
Jane Hanna
Epilepsy Bereaved



The origins of the Campaign

- William (died 1988 aged 21 years)
- Alan (died 1990 aged 27 years)
- Matthew (died 1991 aged 21 years)
- Natalie (died 1992 aged 22 years)

Five women asking why they had died ?



SUDEP

- All of families affected had experienced a child or partner dying suddenly and unexpectedly.
- All had epilepsy, but were otherwise healthy
- None of the families had been informed that seizures could be fatal
- After the death no one in their communities could answer any questions about these sudden deaths

The Aims of the Campaign

- To empower families affected by SUDEP
- To raise awareness of SUDEP
- To get SUDEP recognised and addressed by clinicians, policy makers and other key stakeholders
- To establish whether deaths were avoidable
- To promote action to prevent unnecessary deaths

The Obstacles

- Breaking the SUDEP taboo
- Motivated individuals were isolated and vulnerable
- Lack of any established SUDEP champion

Overcoming obstacles: identifying strengths

- The experience and motivation of those directly affected
- The existence of some clinical support
- Pharmaceutical organisations were interested

The Campaign Plan

- To establish a group to champion the campaign
- SUDEP Awareness Campaign
- SUDEP evidence-based consensus statement
- Lobby all UK Stakeholders
- National Lobby of UK governments

A new organisation focused on the campaign

- Epilepsy Bereaved founded as a charity in 1995
- High level of involvement by those with personal experience of SUDEP at all levels in the organisation
- Offering peer group support through to opportunities to be active

Gaining Credibility

- International SUDEP Workshop of Experts (London 1996)
 - Defining SUDEP
 - Causes of SUDEP
 - Risk Factors of SUDEP
 - Prevention

Raising Awareness

- Articles in the national media
- Getting SUDEP on the agenda at epilepsy events and conferences
- Gaining Support from Partner organisations

Partnership

- Joint Epilepsy Council for UK and Ireland
- All 23 patient epilepsy organisations
- International League against Epilepsy (UK)
- 5 Royal Medical Colleges

Political Lobby

- Petition to UK Government
- Written Questions to UK Ministers
- An Epilepsy Debate at Westminster
- Meetings with Ministers and Civil Servants in England, Scotland, Wales and Northern Ireland
- All supported by Partner organisations and individual families and health professionals

The National Audit of Epilepsy Deaths

- Epilepsy Bereaved commissioned to lead a multi-disciplinary clinical audit of epilepsy deaths
- Report findings that 40% of epilepsy-related deaths as potentially avoidable
- Commitment from Chief Medical Officers of four countries to take action to prevent unnecessary deaths

Campaign outcome: empowerment

- Families affected by SUDEP at heart of the campaign and the Audit
- Support service
- Getting Active programme to develop involvement of those directly affected

Campaign Outcome : Awareness of SUDEP

- SUDEP Awareness established amongst epilepsy professionals
- National epilepsy guidance in England and Wales includes SUDEP and lessons from the national audit (2004)
- Awareness to people with epilepsy and their families (JEC Risks Leaflet and Government sign-posting card)

Campaign Outcome: National & Local Agendas

- SUDEP and Audit as major factor in higher profile to epilepsy on national government agendas
- Evidence of increased local interest and action

Key Lessons

- Encourage full involvement of individuals personally affected by issues
- The importance of a good evidence base
- Identify all key partners and gain early support and involvement
- The importance of publicity & lobby work

