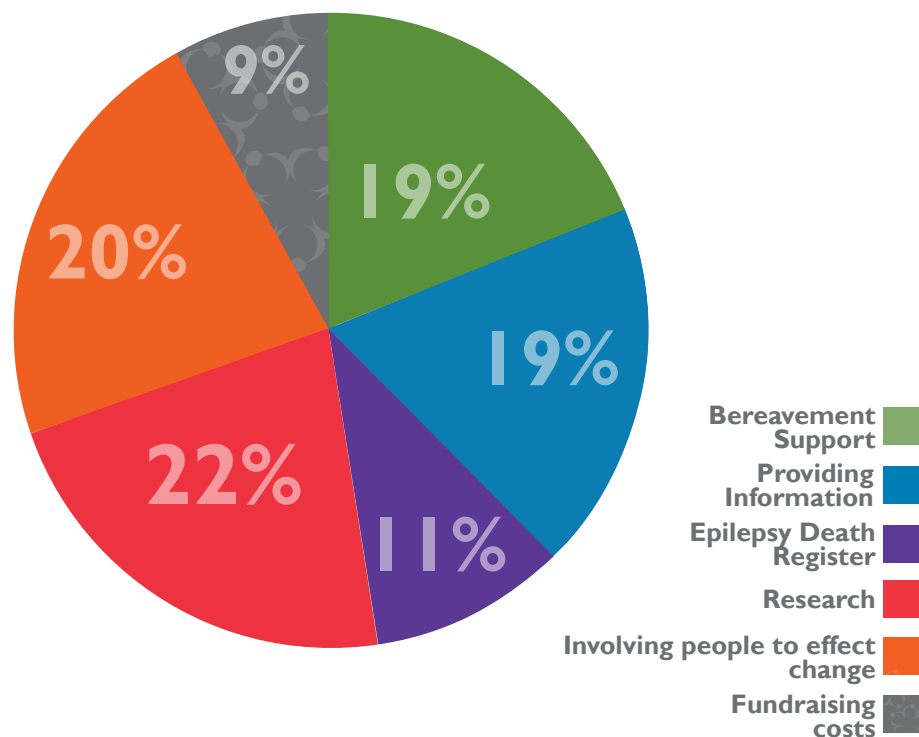


How much do we spend on all this?

In 2014, we received an income of just over £288,000.

What we spent was divided up as follows:



Please contact us for further information:

Head Office:
01235 772850
info@sudep.org

SUDEP Action Scotland
0131 516 7987
www.sudep.org

Support (direct line):
01235 772852
support@sudep.org

SUDEP.ORG

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SUDEP Action 
Making every epilepsy death count



Preventing epilepsy deaths: What we do

Our overall aim is to prevent epilepsy deaths



What do we do?

We:

- support the bereaved
- make every epilepsy death count
- produce research aimed at saving lives
- provide information
- involve everyone we can to help save lives

We support the bereaved

A sudden death is very traumatic. Our support line is staffed by qualified counsellors, who have a special interest in sudden death and understand the coroner and inquest process.

We offer:

- Email and telephone support
- Counselling
- A valuable listening space
- Help with understanding the post mortem
- Help with understanding the investigation of the death
- Help from our SUDEP and epilepsy experts
- Opportunities to meet others who have been bereaved by epilepsy

We make every epilepsy death count

We run the Epilepsy Deaths Register. This is the single point for reporting all epilepsy related deaths in the UK. It collects data on epilepsy deaths. Researchers then analyse that data to find out what is happening in as many cases as possible. This information is used to highlight recurring problems and

themes, which can be used to prevent deaths. If you know about a death in someone with epilepsy, you can help. Please fill in the form at epilepsydeathsregister.org or report a death by phone on 0330 088 1220. We also provide people with information on brain and tissue donation following a death.

We also support other countries in setting up epilepsy deaths registers. The more information held on epilepsy deaths, the sooner we will understand how best to stop these deaths.

THE
EPILEPSY DEATHS REGISTER
Making every epilepsy death count



0330 088 1220 (local call rate)
register@sudep.org

We support research aimed at saving lives

We:

- Fund research
- Collaborate with research teams and bring them around the same table
- Ensure that key messages from research which others have conducted reaches the audience it needs to reach in order to save lives

Recent projects have included:

- Funding the testing of a wearable apnoea detection device on people with epilepsy with a view to developing a sensor which can act as an early warning signal for people at risk of SUDEP
- Collaborating in the development of a smartphone app designed to allow people with epilepsy to measure their risk factor for SUDEP

- The publication and dissemination of mortality research highlighting the risk of depression and suicide amongst people with epilepsy, with a view to encouraging primary carers to look out for signs in their patients

We provide information

We:

- Produce leaflets and downloads aimed at people with epilepsy and their carers to help them learn how they can reduce their risk of dying
- Publish a layman's version of the latest epilepsy deaths research and SUDEP research on our website
- Commission articles from the world's leading SUDEP experts to create a global resource for professionals and bereaved families at www.sudepglobalconversation.com
- Provide training to carers and epilepsy staff to help them support high risk people with epilepsy and talk to them about risk and SUDEP in such a way that they feel empowered.
- Give talks to medical professionals and researchers to highlight what they can do to reduce epilepsy deaths

We involve everyone we can to help save lives

We involve the bereaved as much as possible in our work, as we know from personal experience how important it is for some people to do something in memory of the person who has died. Some people like to get involved in our campaigning work. Others throw themselves into fundraising for SUDEP Action. We receive no government funding and so we are only able to achieve our aim of ending epilepsy deaths through the efforts of people like you raising funds for us.

There are many ways in which you can support and get involved in our work:

- Write to your local MP
- Run a marathon to raise funds
- Visit your GP with copies of our leaflets
- Run coffee mornings to bring bereaved families together
- Help to raise awareness on social media
- Sell cakes at work
- Give local talks to raise awareness of the risks associated with epilepsy
- Tell people your story on SUDEP Awareness Day
- Encourage people to be open about their epilepsy

