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## AMELIA'S STORY & SUPPORTING EPILEPSY SOCIETY'S GENOMICS RESEARCH



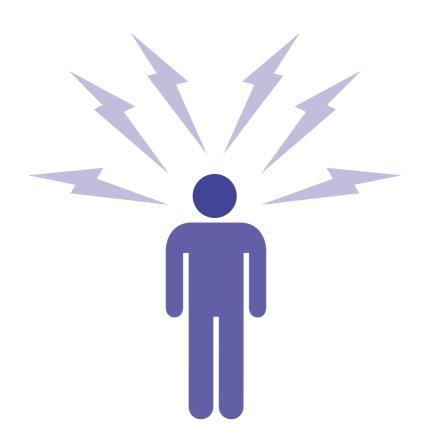


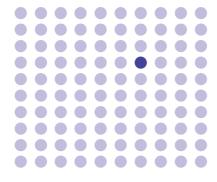
Our middle daughter Amelia died suddenly from a fatal seizure at the age of 21. She had epilepsy.

Her tragic death may have been prevented if we had been able to control her seizures.

The following story highlights the amazing work the team at Epilepsy Society are doing to achieve this.

Hamish & Debbie Roberts Spring 2019 Epilepsy is a condition caused by irregular electrical brain activity. It can change a person's life or even be fatal.





One in a hundred people have some sort of epilepsy.



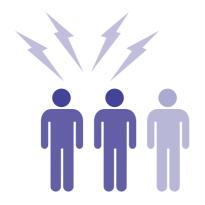
## focal aware



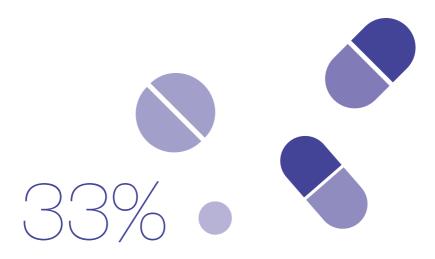
focal onset

generalised onset

There are around 40 types of epileptic seizures with varying degrees of frequency and severity complications. They can all have a huge effect on a person's ability to lead a normal life.



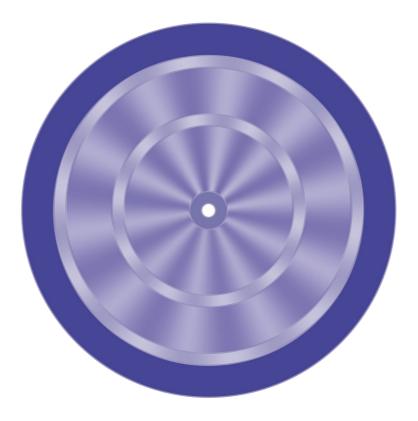
Of the 600,000 people affected by epilepsy, around a third are not receiving the right or effective treatment to control their condition.



of the 600,000 are classed as drug resistant.

There are around 25 known drugs used to try and control the condition.

Finding the right combination for the individual person is like trying to score a triple 20 on a rotating dartboard!





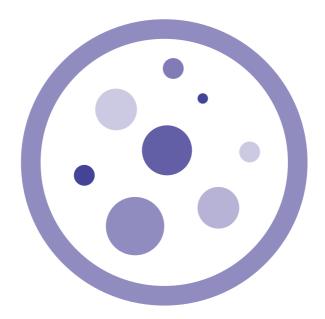
These drugs can have complex side effects and are often prescribed in conjunction with other medications. It may take months or even years to find the right combination to control the seizures.



Those who are drug resistant are more vulnerable to Sudden Unexpected Death in Epilepsy (SUDEP).

Around 600 people die each year in the UK due to SUDEP.

Epilepsy Society is providing world-leading research to better understand how to tailor the combination of drugs to enable each individual with epilepsy to have a greater chance of controlling their seizures and therefore lead a normal life.



They are carrying out detailed mapping of individuals to try to establish which drug or drugs could control their epilepsy...





...by looking at their eyes...

...the electrical activity in the brain...

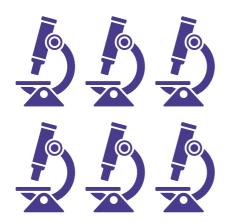




...looking at minute variations in facial structure...

...and mapping the genome sequence in each person's DNA (genetic makeup).





Epilepsy Society needs six research scientists to carry out this vital work.

The whole project will cost around £10,000,000.



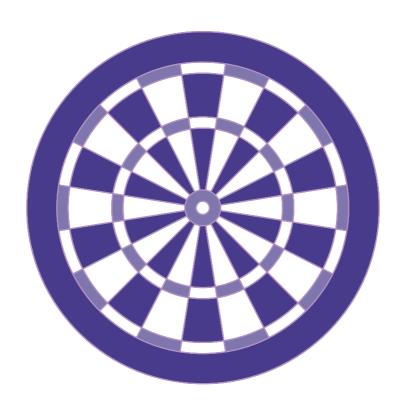


Amelia's death has led to over £240,000 in donations so far. This has helped Epilepsy Society fund the team.

Amelia had the foresight to donate her brain for epilepsy research. Anyone can do this—visit https://epilepsysociety.org.uk/donor

We would like to thank everyone for their love and support. Should you wish to support the Epilepsy Society, any donation will help continue to fund their exciting and life-changing project for the future.

Hopefully, one day they can stop the dartboard rotating enabling the experts to prescribe the effective drug combinations. Triple 20 every time!







## For more information please visit epilepsysociety.org.uk



or go to https://bit.ly/AmeliaNFRC





nfrc.co.uk