

## Epilepsy Lifestyle Registered Charity 1158587 The Nineveh Charitable Trust Grant Report October 2018

Epilepsy Lifestyle aims to improve the lives of children and adults diagnosed with epilepsy by providing funding for sleeping/monitoring equipment.

Epilepsy affects 1 in every 103 people in the UK and SUDEP (Sudden Unexpected Death in Epilepsy Patients) affects approximately 1 in 1000 epilepsy patients every year. The peace of mind that a monitor/ sleeping solution can give to a family or epilepsy patient can not be underestimated. No one should ever have to wake up to find their child or loved one has passed in the night from a seizure.

Epilepsy Lifestyle gives epilepsy patients and their families a choice of six different monitors/ sleeping solutions and we work with our beneficiaries and our suppliers to ensure the most appropriate piece of equipment is chosen specifically for their circumstances and type of epilepsy. These monitors/ solutions range in price from £50, right up to £800 and all work in very different ways. This is why we work with our beneficiaries and our suppliers to ensure the correct type of monitoring system is granted.

We were extremely fortunate to be given a grant of £1,000 from The Nineveh Charitable Trust in September 2017 to continue our work. During this financial year Epilepsy Lifestyle has funded 132 epilepsy monitors, which comprise:

30 Pulse Oximeter Packages
20 Brio Wrist Worn Epilepsy Alarms
22 Digital Video Monitors
13 Anti-suffocation Pillows
37 Emfit Tonic/Clonic Epilepsy Alarms
10 Alert-it Companion Monitors

The grant from The Nineveh Charitable Trust went a considerable way to funding these monitors and potentially saving the lives of children and adults in the UK with an epilepsy diagnosis.

## **Case Study**

Toby is four years old and has received an Alert-it Companion Monitor through the Epilepsy Lifestyle Night Time Monitoring Scheme.

The Alert-it Companion Monitor is designed to monitor Tonic Clonic seizures in a fixed location. The wired sensor is placed under a mattress and will detect sustained movements associated with seizures. Once a seizure is detected the Companion will send an alert to the pager.

Toby, who lives in Southampton with his Mum, has a diagnosis of complex epilepsy alongside developmental delay.



It really is amazing the difference such a simple piece of equipment can make to one family and, thanks to the grant from The Nineveh Charitable Trust, Epilepsy Lifestyle can work with epilepsy sufferers and their families to help keep them or their children that little bit safer at night.

Thank you from everyone at Epilepsy Lifestyle!