My Epilepsy Story—Muir Maxwell Trust

Ann Maxwell, Cofounder, and Volunteer Fundraiser

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The Muir Maxwell Trust (MMT) was established by my husband and me in 2003. MMT is a Scottish registered charity based in a small town outside Edinburgh, Scotland. From there we support the United Kingdom's 120,000 children with epilepsy and also their families, including siblings, who are often struggling to cope. My husband is the Trust's Chairman, supported by 14 trustees.

I am the Trust's full-time volunteer fundraiser, supported by two full-time and one part-time employees. Although we are a small charity, we "punch way above our weight" and our reach is wide, having successfully raised over £8 million in the course of the last 10 years for our cause.

I am mother to three sons age 19, 16, and 15. Our middle son Muir is profoundly damaged by Dravet syndrome, originally diagnosed as severe myoclonic epilepsy in infancy. Muir had his first seizure when he was 4 months old. As we rushed him to hospital that night we had no idea that we were about to embark on a journey that would alter the course of our lives forever, and that Muir would grow up severely learning disabled, with speech and language difficulties and a prognosis for a short life. Muir will never live independently, he will never work or marry. He requires care 24/7. Life for the whole family was a struggle, and as a consequence we established the Trust in Muir's name, to support other families struggling to cope with their child's epilepsy.

The work of the Trust has always followed the experience of raising Muir, providing services as we discovered they were lacking, but always finding a funding partner to continue that service once the need has been established. Our own lack of sleep while watching over Muir meant that we began by distributing essential and potentially life-saving epilepsy alarms that alert a parent or carer to a child's seizure during the night, and we are still doing that today. The use of an epilepsy alarm reduces the risk of sudden unexplained death in epilepsy (SUDEP) and provides peace of mind as well as restoring long lost sleep for families, including siblings. In the course of 10 years the Trust has distributed some 3,000 epilepsy alarms at an equivalent retail cost of nearly £2 million. In recent years alarms have been funded mainly by our successful applications to many charitable trusts and foundations. Despite early resistance to the quality of life benefits of epilepsy alarms for families, the medical profession now recognizes the need for such technology in the management of night time seizures, and I am in talks with both the Scottish and United Kingdom Governments about National Health Service (NHS) funding for alarms in the future.

Founder Ann Maxwell with son.

Other funds raised in the course of the past 10 years have provided the seed capital for many world-class state-of-the-art services under the Muir Maxwell Trust banner. The new Neville Medical Centre at Lingfield in Surrey, England, part of Young Epilepsy, a residential center and school for children, has a wing named after the Trust that accommodates state-of-the-art video telemetry, partly funded by us. We also made a significant contribution to the video telemetry service in the new Neuroscience and Neurosurgery Koala Ward at Great Ormond Street Children's Hospital (GOSH) in London, as well as many other pediatric centers of excellence across the United Kingdom. In addition, we have pro-

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Address correspondence to Ann Maxwell, Muir Maxwell Trust, Stuart House, Eskmills, Musselburgh, United Kingdom. E-mail: ann.maxwell@muirmaxwelltrust.com

Muir Maxwell
The Epilepsy Trust
for Children & Families

Ann Maxwell, Tesco Charity Mum of the Year 2013.

HRH The Princess Royal opening the Muir Maxwell Epilepsy Centre, February 2013.

vided numerous portable telemetry units enabling children's electroencephalography studies to take place in the comfort of their own home.

The early days also saw MMT launch ketogenic diet clinics in Scotland and fund the arrival of specialist nurses and dieticians at GOSH and Young Epilepsy. The Ketogenic Diet service has now been pioneered by another charity, Matthews Friends, and the ongoing funding of specialists has been absorbed by the NHS.

In 2005, Muir's consultant suspected a mutation in the *SCN1A* gene causing Dravet syndrome. We agreed to send his DNA to Australia at a cost to the NHS of ε2500, and 2 years later the diagnosis was confirmed. As a consequence, we decided to establish the United Kingdom's first dedicated genetic diagnostic service for childhood epilepsy based at the Royal Hospital for Sick Children in Glasgow, Scotland. The service initially focused on Dravet syndrome, and results took just 40 days. Today the service is aiming to test for a panel of epilepsy genes. More than 500 children and young adults in the United Kingdom have now received a confirmed genetic diagnosis of Dravet syndrome, and world class research has been published by our Muir Maxwell Trust funded Fellow, Andreas Brunklaus, on the serious quality of life issues in Dravet syndrome. A much unknown and misunderstood but severe epilepsy syndrome is now at the forefront of epilepsy research because of the cohort group the service has created, which in turn is now supported by a dedicated foundation of its own. MMT received a vote of thanks from the Scottish Government who has agreed to meet the future cost of developing this service.

More recently the Muir Maxwell Trust has formed a partnership with Edinburgh University College of Medicine and Veterinary Medicine to establish the Muir Maxwell Epilepsy Centre (MMEC), a collaborative research center focused on finding and addressing causes, cures, and quality of life issues in epilepsy. As part of the University's world class Neurosciences Service, head of MMEC, pediatric epilepsy consultant and epidemiologist, Dr. Richard Chin, together with his team, is leading the way on collaborative research across a variety of neurologic conditions also affecting children, including autism and fragile X syndrome. Collaborations have also been established with universities in Norway and Canada. Although MMT has provided the seed capital for this center, it is expected that it will go from strength to strength as research gathers momentum, and the contribution to research by the team will have positive implications around the globe for children with difficult epilepsy and their families.

All of these essential services are now established and thriving, and families around the world are benefiting from improved diagnosis, which enables earlier intervention, more effective treatment, and a better prognosis in epilepsy for our children. In the meantime, we continue to follow Muir's lead, and high on the agenda is the need for a new kind of residential living in the United Kingdom for our profoundly learning-disabled young adults leaving school, who will now live longer and deserve to thrive. Neither have we lost sight of the need for better control of Dravet syndrome and other complex epilepsies, and as the medical marijuana debate unfolds we are conscious that we may need to participate.

They say that an effective charity will eventually make itself redundant—in our dreams that would be our aim.

Disclaimer

Editor's Note: Epilepsia's Epilepsy Stories is a venue for non-profit organizations to educate our professional readership about their mission for people with epilepsy from around the world. Many organizations raise awareness about epilepsy including ILAE's sister organization, the IBE and its chapters. Epilepsia does not endorse one organization over another. If you would like your non-profit organization recognize, contact us at epilepsia@epilepsia.com.