Muir Maxwell Trust to be wound up

One of Edinburgh’s independent charities with perhaps the highest profile, and the highest fundraising too, is to be wound up.

The charity, Muir Maxwell Trust, was founded in 2003 by Ann and Jonny Maxwell to help those affected by epilepsy.

Their son Muir has Dravet Syndrome, a severe form of the condition which resists treatment.

It has been run by Ann and two members of staff, organising huge and spectacular events in Edinburgh and London. Recently the charity has had to direct itself towards applying to trusts and foundations for funding.

It has been challenging, particularly for Ann who recently required brain surgery during the last twelve months.

Ann, who was awarded an OBE in 2015 for charitable services to the Treatment and Care of Epilepsy in Children, said: “We have concluded it is better to leave the stage on a high and celebrate all of our successes, including the wonderful legacy of the Muir Maxwell Epilepsy Centre (MMEC) at Edinburgh University and also our Muir Maxwell Research Fellow, Dr Simona Balestrini whose pioneering work in the genomics of complex epilepsies at the Epilepsy Society will continue for another year.

“We are proud to have played a key part in the delivery of a transformational genetic diagnosis at Yorkhill Children’s

Hospital for many of the severe childhood epilepsies, and also the arrival of the first NHS approved cannabidiol, Epidiolex, as a new treatment option for more complex epilepsies. We have also delivered more epilepsy alarms to families managing their child’s epilepsy at home than any other UK charity, a legacy that will be continued by the Daisy Garland charity who, in line with our own criteria, will be distributing Muir Maxwell Trust epilepsy alarm vouchers to families for some months to come.

“It has been an honour and a privilege to work with so many eminent physicians, committed supporters, businesses and indeed celebrities too. We leave the stage immensely proud of our contribution and especially our partnership with Edinburgh University which will be the continuing legacy of the work of the Muir Maxwell Trust. These are challenging times for us all but with the strength of the University behind the MMEC we are confident the Centre will continue to make a pioneering contribution, in Muir’s name, to the field of epilepsy for generations to come.”

Ann and Jonny, who is Chairman of the Trust, live in Edinburgh and are parents to Connor (26), Muir (23) and Rory (21). As a five-year-old, Muir was not expected to survive his second decade. He is now 23 years old and lives full-time at the

David Lewis Centre in Cheshire, a world class residential centre caring for 90 adults with complex epilepsy.

Ann added: “Although I am sad that the time has come to wind up the Trust, I am proud of all that we have achieved and the legacy we leave behind in Muir’s name. The work of the Trust has always followed the experience of raising Muir but that journey has changed now from a journey through childhood epilepsy to one focused on living as fulfilled a life as possible in adulthood. Improved treatments and better understanding of complex epilepsies, including Dravet Syndrome, has meant that many children are surviving long into adulthood. My focus has already turned to campaigning to ensure the needs of adults with complex epilepsy are properly recognised and supported allowing them to enjoy a quality of life that is as rich as any other.”

“I know I can speak for the world of epilepsy when I say it is indebted to all those who have supported us over the past 17 years. Together we have made a transformational contribution, and now it is time to pass the baton and move on to our next chapter.”

Professor Sir John Savill, Regius Professor of Medical Science at the University of Edinburgh, said: “Inspirational support from the Muir Maxwell Trust allowed the University of Edinburgh to establish the Muir Maxwell Epilepsy Centre. The Centre is making remarkable research contributions that will benefit children and families affected by epilepsy for many years to come. I anticipate that the Centre will go from strength to strength, providing one of many positive legacies for the Trust’s remarkable philanthropic work led by Ann and Jonny Maxwell.”

Shona Campbell at MHA Henderson Loggie has been engaged to assist in the wind up of Muir Maxwell Trust.

She said: “Muir Maxwell Trust has been a successful charity that has been at the cutting of progress in understanding complex epilepsy for over 17 years. It leaves an impressive legacy of achievement that has helped children and families across the country to live with the consequences of epilepsy, and Dravet Syndrome in particular. All staff and creditors will be paid in full.”


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