



ENVIRONMENTALLY RESPONSIBLE DRIVING

CARBON NEUTRAL EVENT

ACE awareness cure exercise JSMA

JULY 2ND 2022

ACE IN MOTION

TOUR 2022

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ACE IN MOTION DRIVING TOUR TO SUPPORT THE ACE-SMA CHARITY

ACE, which stands for Awareness, Cure and Exercise, was set up by Sophie and Mike Howes, after their daughter Anouk was diagnosed with the debilitating condition. One of its key aims is to raise £500,000 to help fund a two-year clinical trial with the University of Oxford to collect enough data to prove the effectiveness of regular physiotherapy alongside drug treatment. Once proved, this will create a long-term impactful outcome.

SMA, Spinal Muscular Atrophy, is a rare genetically inherited neuromuscular condition. It is caused by a mutation in a gene called the survival motor neuron 1 (SMN) protein. The loss of this survival motor neuron causes cells in the spine called motor neurons to die. Over time, the breakdown of these neurons leads to a gradual decline in muscle size and strength. The symptoms of SMA can vary depending on age and disease severity – but they usually include muscle weakness, delayed gross motor skills and difficulty with crawling and walking. Breathing and swallowing are also affected. Once a motor neuron is lost there is no way of retrieving it – using muscles and keeping motor neurons active is essential for people living with SMA to maintain their strength, mobility and independence. The devastating effect on families coping with the condition is one thing, but perhaps the most sobering statistic is that the disease is the most common genetic cause of death in children under two.

On the 2nd of July this year, the ACE in Motion Tour will depart from Bicester Heritage taking in tour highlight, Williams F1 Heritage Experience Centre, organised by HERO-ERA in partnership with the ACE-SMA charity. ACE-SMA is a charitable body concerned with raising awareness of and improving the treatment of Spinal Muscular Atrophy, here in the UK. The charity is aiming to raise £500,000 to finance a clinical trial, in partnership with the University of Oxford, that could change the lives of children and families affected by this terrible disease which is a major genetic cause of infant mortality.

“Anouk was diagnosed with SMA in 2019 and there was no access to any sort of physiotherapy to help her with the treatment she was receiving. We were told she would be in a wheelchair by the age of three. With the help of Professor Servais and Charlotte Lilien, we want to create a clinical trial that will prove that physio is as important as the medical treatment.” Sophie Howes



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Sophie also states that, “the type of physiotherapy is vitally important as well, as many physios focus on soothing the effects of being confined to a wheelchair, rather than actually helping children to walk.”

Their journey though is one of hope and achievement, as Anouk has made incredible progress with cutting edge physiotherapy in conjunction with the medication. After facing up to the news that Anouk would be in a wheelchair from the age of three, their daughter who is now four, is able to walk independently and do the things young children like to do, like jumping in muddy puddles! It’s a remarkable achievement and is testament to Anouk’s hard work and her parents’ commitment to getting Anouk the right help which spearheaded parents Sophie and Mike into forming the charity. “The initials for the charity actually come from Anouk’s name” says Mike, “but what they stand for – Awareness Cure Exercise – those are the key parts to fighting SMA.”

The clinical trial will be run under the stewardship of Professor Laurent Servais, Professor of Paediatric Neuromuscular Diseases at MDUK Oxford Neuromuscular Centre Department of Paediatrics, University of Oxford. Professor Servais has been involved in the treatment of SMA in his native Belgium, which pioneered the use of the three drug-based treatments available today. His work also saw the implementation of a screening programme in southern Belgium with incredible results, that has seen SMA all but disappear. Professor Servais; “Screening at birth allows us to begin treatment before symptoms appear, and in this case, we can stop symptoms appearing at all, currently we have begun doing this in Oxford and we hope to extend this to the rest of the UK.”

There is a but though, as a nationwide screening programme will come too late for those that are already symptomatic. The treatments available are successful at slowing down the progression of the disease, but according to Professor Servais the most important aspect of any treatment is administering it in tandem with effective physiotherapy, on this subject he said, “we have to provide weekly treatment to help these patients with physiotherapy, from a respiratory perspective and an orthopaedic perspective.” Charlotte Lilien, Senior Paediatrics Research Physiotherapist, specialising in neuromuscular diseases at the MDUK Oxford Neuromuscular Centre, University of Oxford, who is also a key part of the trial team, expands further on the importance of bespoke care, “Each patient has unique needs, there



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are some care standards, but each case is individual and so the physiotherapy solution is quite complex. But with this level of physiotherapy in place, we can have a positive impact on the huge burden that these children and their families face.”

The team at the University of Oxford want to provide this cutting-edge physiotherapy to 20 children during the clinical trial; children like Esme Needham who at five years old is wheelchair bound and needs constant care from mother and father Stacie Swell and James Needham, and Esme’s 10-year-old brother Kyle. Theirs is a typical story of a family coping with the impact of this condition. “It’s a tough deal” says James, “You have to just get on with it out of necessity, through the good times and the bad.” Mum Stacie tells of some of the difficulties, “winters are hard, a cough or a cold isn’t just something Esme gets over, a child with SMA will usually end up in hospital.” They also speak of the difficulties of attaining any kind of regular physiotherapy for Esme, and the distance involved to get to the right kind of physio.

So how will the ACE in Motion Tour help? First and foremost, it will raise much needed funds for the charity, to enable the trial with the University of Oxford to go ahead, and of course raise awareness. The tour, which is the brainchild of HERO-ERA Chairman Tomas de Vargas Machuca, is a non-competitive event that will start and end at Bicester Heritage, with some opportunities for some ‘brisk’ driving on site at Bicester, as well as an idyllic route through the surrounding countryside and an event highlight; a visit to the Williams F1 Heritage Experience Centre.

All of HERO-ERAs Arrive and Drive cars will be available for the event, from Triumphs to Jaguars, with all hire fees going straight to the charity. Tomas de Vargas Machuca had this to say, “It was a very easy decision to try and bring the classic car world together to do something to help children with SMA. We have many partners onboard, including Bicester Heritage and Williams F1 Heritage, so we will be doing everything we can to help with ACE-SMA’s £500,000 fundraising target. We would love to be able to contribute to half of that goal, and that is our own personal target, it won’t be easy but there is no price really when it comes to helping children suffering with SMA.”

There is a thread of hope for the families and children dealing with SMA, children like Esme. The example set by brave little Anouk shows just what an incredible impact the right treatment can have on the quality of life for these children and their families, and Sophie,



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Mike and everyone connected with the efforts of ACE-SMA and the proposed clinical trial will be hoping that the ACE in Motion Tour is the incredible success that they deserve. More information is available on the ACE-SMA website and HERO-ERA website, and entries are available online and are open now.

More information on the ACE In Motion Tour here –
<https://heroevents.eu/event-schedule/ace-in-motion-2022/>

Sign-up for the ACE In Motion Tour here –
<https://heroclub.eu/event-4816850>

Learn more about ACE here –
<https://acesma.co.uk>

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Follow the link below to watch a short video on Ace and The Ace In Motion Tour
<https://youtu.be/PHzxcfOyoc>



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