# Michelle Mitchell – CEO, Multiple Sclerosis Society, UK



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*Michelle Mitchell, CEO of the Multiple Sclerosis Society in the UK since 2013, discusses her charity's aims; their focus on research and development; funding in the face of Brexit; and policy changes in the future.*

**Could you please start by introducing the Multiple Sclerosis (MS) Society?**

We were set up 65 years ago by Richard and Mary Cave. Back then there was no understanding of the biology of MS and there were no treatments. People were told that they could not have children and that they should go home to their families and suffer. Thankfully the world has moved on quite considerably since then, but the enduring mission and the enduring values of the MS Society remain the same. Our mission is to see a world free from the effects of MS and until that day comes, we will support people in living the best lives they possibly can, while making sure that nobody has to face MS alone.

We developed a new strategy four years ago, which sought to root our goals in the needs and aspirations of people living with MS. We followed a rigorous process of assessing our own goals and priorities based on what people with MS had said. Through that process the number one objective became increasing access to effective treatments. That means increasing access to treatments that are currently available on the National Health Service (NHS). However, our focus is also on the development of treatments in the future. Although the MS community is fairly small, the science is

telling us that with a fair wind, smart focus, good innovation and global collaboration, we should be in a position to stop MS, as we understand it today, in seven to ten years. So our overall goals are to stop MS, slow down and stop the accumulation of disability and eventually be in a position where we can reverse the effects of MS.

We achieve our social impact in three key areas. The first is through research, which we describe as ‘hope for tomorrow’. The second is through services support, friendship and peer support; we describe this as ‘help for today’. Finally, we believe a critical role for our organization is in changing laws. We aim to influence policy, regulation and public attitudes while also improving the commissioning of services. Underpinning all of that work are our efforts, alongside people living with MS, to make sure that there is an honest and powerful story that is being told and that the reality of living with MS is being communicated effectively.

**The organization has channeled USD 215 million towards research. What are your greatest achievements?**

Charities contribute over £1.6 billion towards research in the UK. Our research is focused on what people with MS say is important. Currently, we are funding, along with the National Institute for Health Research (NIHR) and the MS Society in the US, a phase three clinical trial for secondary progressive MS, which Dr. Jeremy Chataway is leading, focusing on a re-purposed drug: simvastatin. We are collaborating globally and with different partnerships to achieve our aims as quickly as possible.

We also fund a range of research infrastructure. The tissue bank, which we co-fund with Parkinson’s is globally leading and used by people from around the world to conduct research. We are particularly pleased to be funding younger researchers, although we make sure that we have a stream of highly effective fellows. We also work globally with our research program through the Progressive MS Alliance (of which we are founding and managing members, along with the MS societies in Canada, Australia, Italy and the United States) to bring the major funders of research together in order to make urgent progress.

In the past we have had several important successes. We fund research because we believe in hope for the future and think this is one of the ways in which we can drive change. In 1976 we funded Professor Ian McDonald to set up a specialist MS center at the Institute of Neurology in London. He went on to develop the guidelines around MS and set up the world’s leading MRI-based programs, setting the gold standard around diagnosis. Our funding also saw the progression of

botox trials, which are now used in relation to bladder control.

**What are your interactions with pharmaceutical companies?**

At a global level we work with the Progressive MS alliance. We have an industry forum and industry partnerships whereby, on a non-competitive basis, we all have something distinctive to contribute to achieving our goal, which is finding new treatments for progressive MS. We see the solution as charities, industry scientists and researchers working together. Domestically we work, where appropriate, with industry. However, it is important that we have the right type of relationship and that our relationship is thoroughly regulated. It has to be transparent and there should be no conflict of interest. We have really clear guidance.

**What are the biggest challenges facing the MS Society today?**

Tackling health inequality and improving outcomes are very important goals for us. These are common aspirations among charities, the NHS and both public and private healthcare providers. We are currently developing a new MS service specification which would be a standard. However, we really need to tackle a number of important issues.

We have significant and unwarranted variation in access to treatments for MS in the UK. This ranges from around 49 percent in Wales to around 77 percent in Northern Ireland. These treatments have gone through a rigorous process and are cost effective. They help to slow down the accumulation of disability significantly and really affect people's quality of life. For people who lack access to treatment, the progression is often quicker, and as a result there are a number of interrelated factors from leaving work, becoming unemployed and receiving welfare to increased levels of divorce and family breakdown that affect quality of life. The caring responsibilities that fall on loved ones also significantly affect quality of life.

We have been working with commissioners to try and understand why there is such significant variation. We launched an award-winning campaign called 'Treat Me Right', where we worked alongside the Association of British Neurologists and the MS Society in the US to build a scientific consensus, while making sure the guidance and behavior reflects the science. Equally we have been tracking the prescribing data in the UK and comparing it with the lived experiences of individuals with MS. This used a survey of around 14,000 participants, one of the largest surveys of its kind, enabling us to develop a really thorough understanding of the experiences of individuals

living with MS in the UK.

Additionally, because the landscape regarding the quantity and quality of new treatments has changed so quickly over the past five to ten years, we find that many people in the MS community have not had informed discussions with their neurologists in consideration of the innovations that have been made. One of our roles, through our ‘Treat Me Right’ campaign, has therefore been to build the level of education and information about what the treatment landscape looks like and equip people with the tools, techniques and information they need to have informed discussions in order to help drive that change through the healthcare system. We are seeing substantial increases in access to treatments, although certainly not as high as we would like.

We also play a crucial role in supporting MS nurses, general practitioners and neurologists, so they can support people with MS to make informed decisions about the treatments that are best for them. We believe that each individual needs to make the right choice based on great information and informed discussions with their specialist. We are continuing to develop that and are going to launch a major report, coinciding with MS day in May, which will build our capacity and capability to support people in changing their behaviour.

**What are going to be the impacts of Brexit on the MS Society?**

Firstly, it really is quite unclear as to what is going to happen. We have a resolute focus on access to effective treatments and innovation. We will forge ahead as a country and as a society in ensuring that access is not compromised. There are a number of issues that we are watching very closely, however. One of them is whether or not we opt out of our agreement with the European Medicines Agency (EMA). This will be especially important if the EU’s licensing fails to match that of the UK. The possibility of delays in access to treatment will be a particular point of focus for us.

The UK has also historically contributed and received significant research funding through the EU. However, UK researchers are feeling that the world is changing quite quickly around them, even before anything has actually happened. Thus, we need to continue to invest in research and display the partnership qualities whereby people want to continue to work with us. Watching that funding is going to be really important. Of course, we will take up global opportunities as they are presented.

In terms of us as an organization, there are a number of issues. One of these is the effect that Brexit may have on the economy. Since the 2008 recession we have gone through a sustained

period of very modest levels of economic growth and significant cuts in public expenditure. We have also seen, for the first time in a generation, rising health inequality among parts of the population and the lowering of life expectancy in some of the most deprived areas. Furthermore, large proportions of welfare benefits have been taken away from people with MS at an unbelievable rate. There have hence been quite significant challenges. But the fear is, if there is another slowing down of growth, those factors will continue.

As for donations, our advantage is that we have a very loyal community who live with MS for a long period of time. We have high levels of trust and loyalty. However, undoubtedly, we will be considering the affect that Brexit may have on both donations and legacies in relation to property values.

**What is your position on the use of cannabis for the treatment of MS?**

For people living with MS, particularly with pain and spasticity, where the evidence is strongest, we believe that cannabis should be legalized for medicinal purposes. We have had a very powerful and personal response from the MS community. Many are working in the devolved parliaments, particularly in Scotland and Wales. Overall there is a great sense of ‘why not when I can’t afford licensed treatments?’

**Do you see any policy changes on the horizon in regards to cannabis legalization for MS treatment in the UK?**

Never say never. We are waiting for a response from the Home Office. We were one of the first charity to take this policy position in relation to the legalization of cannabis for medicinal purposes for pain and spasticity. When we launched our position, the media and community responses were incredibly positive. There is an appetite among politicians to look at this issue, certainly in Parliament. There is a real appetite for change out there. We will continue, with people with MS, to make that case for change. We are one of the few charities to take a position and we expect many of the other health charities to follow suit.

**A few words to conclude?**

I strongly believe that this is an incredibly exciting time in the field of MS research. We have a once in a generation opportunity to stop MS. And we have that because we have some of the world's best researchers and scientists conducting some phenomenally promising research. Working together with an active, engaged MS community, we're driven by a resolute focus on changing the world – quickly – and partnering with whoever we need to make steps to stop MS. You can see this urgency in everything we do. And we'll continue to keep an open mind and good collaborative skills, so that we can work with the right people internationally and locally, to make the changes that people with MS are demanding.

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