My name is Martin Johnston. I am 47 years old and was diagnosed with Motor Neurone Disease (MND) in August 2018, aged 40. I am from Aberdeen, Scotland and live with my wife Jenny and two children, Calum (16) and Sophie (12).
Prior to my diagnosis, I worked as a Computer Aided Designer for various companies in both the Housing and Oil and Gas sectors. I was also a semi professional footballer until the age of 35, playing for Scottish clubs Cove Rangers, Peterhead, Elgin City and Brechin City.

At the beginning of my MND journey my son Calum had started playing football with a local team Dyce Boys Club, and having had a football background, I eventually became a coach of the team. It was around that time I began to feel something wasn't quite right with my body. My right leg just wasn't working the same as it used to. I couldn't run properly and couldn't kick the ball like before. Initially, I put the problems down to general wear and tear due to playing football since the age of 7.
Over time, things got gradually worse with my mobility with a few unexplained trips and falls. So, I decided at that point to get things checked with various Doctors and Physiotherapists. This led to an MRI scan of my lower back to see if there was any issue there. But still no conclusive answers were found.
The next symptom I encountered was the twitching of my calf muscles on both legs. I didn't at that point think that there was any link to my mobility issues. More Doctor appointments followed. But there was no indication that anything serious was going on, and the most probable explanation was it was stress related.
It wasn't until the twitching began in my thigh muscles that I first started to worry. I was checking my iPad late one night before bed, when I decided to search Google for answers. Straight away, the first result was an article about a terminal disease called Amyotrophic lateral sclerosis (ALS). Naturally I started to panic and couldn't sleep that night. But after speaking to Jenny in the morning we came to the conclusion that it couldn't be ALS, as I would have been in a lot poorer health than I was due to the rapid nature of ALS.

I had heard of Motor Neurone Disease due to some former professional footballers being diagnosed with the condition. But at that point I hadn't made the connection that ALS was the same condition and what it was referred to as in the USA.
The most notable footballer at that time diagnosed with MND was former Rangers FC player and cult hero Fernando Ricksen. I was aware of his bravery and courage fighting the disease for a few years. It was difficult to see a previously tough and talented footballer now unable to speak and confined to a wheelchair.
But it wasn't until Doddie Weir, the Scotland Rugby legend, was diagnosed with MND and spreading awareness that I started to see similarities between his symptoms and my own.
I made another appointment with my Doctor, and at this point it was decided that I would be referred to Neurology as a precaution and to rule out any Neurological involvement.
I had just started a new job a few weeks previous when my Neurology appointment arrived in June 2018. Jenny and I both went along but weren't too concerned about what we might get told. However, that's when everything changed. The consultant carried out a physical examination and asked various questions about the symptoms I had been having.

Following that we were told it was definitely a neurological condition and that I would be booked in for a series of tests to establish a diagnosis.
We left the hospital that day feeling numb and worried, but still hopeful that it could be something less serious than MND.
Over the course of the next few weeks I was booked in for an MRI scan of my neck, blood tests and a nerve conduction study before an appointment back at the hospital for a confirmed diagnosis.
Those weeks were filled with worry. I couldn't think of anything else at that point and the job I had just started suffered as a result of my mind being constantly elsewhere.

When the day of diagnosis arrived I knew within myself it was going to be the news I was dreading. Jenny on the other hand was still hoping for a miracle.
Unfortunately as I expected we were delivered a hammer blow of a Motor Neurone Disease diagnosis with a life expectancy of only 3 to 5 years.
On top of that we were told that there are no real treatment options other than a medication called Riluzole which can extend life by only a few months.
With the appointment over, we were then on our way home to see our children and try to act like nothing was wrong. But on the inside we were in turmoil.

The weeks that followed were tough. We decided to keep the news within our close family circle until we were able to come to terms with things ourselves and be in a position to tell the children without breaking down.
With the help of family we were able to book a holiday to Florida to make memories while I still could physically manage. So, we decided that we would tell the children in a diluted way about my MND diagnosis as they already knew their Dad's muscles weren't working properly. But then a week later we would tell them that we were going to Florida, and that would hopefully shift their focus to looking forward to an exciting holiday.
At that point Calum was aged 10 and Sophie aged 6. So they both didn't fully understand the seriousness of the condition and life got back to as close to normal as possible.
We had an amazing family holiday to Florida over New Year 2020, which we will never forget.

I was searching for clinical trials in the UK and found out one was about to begin in Glasgow called MIROCALS. Thankfully I was enrolled and although I eventually found out I was receiving the placebo, I was at least hopeful that efforts were being made to try to find new treatments and that I was able to contribute in some way to this.

After approximately a year since diagnosis and after we had told the children we decided now was the time to make the news of my diagnosis public.
Due to my footballing background we knew that the news would travel fast and would generate some press attention. But we felt ready to speak about it and wanted to use our story to raise awareness and to focus on the positive mindset I had been able to build over the previous year. Much of that positivity had only been possible due to the late Doddie Weir, who was a sporting hero of mine. Having a Scottish legend at the forefront and leading by example in the fight against MND was hugely inspiring to me.

Doddie had set up the My Name’5 Doddie foundation to raise awareness and vital funds for research into the condition which gave MND patients hope that one day soon a new treatment or ultimately a cure could be found.
Not long after I made my diagnosis public I received a call from a phone number I didn't recognise. On answering the call, it was Doddie himself getting in touch to ask how I was getting on. Which gave me such a boost at a difficult time.

The support we have received as a family since revealing the diagnosis has been amazing. Calum and Sophie decided that our first fundraiser would include the local schoolchildren, their families and the local community. The event was to be a 5km inflatable assault course, which was unfortunately canceled at the beginning of the Covid pandemic. But we still raised over £11,000 for the My Name’5 Doddie foundation.
Since then with the help of family, friends, work colleagues, former football teammates and opponents over £82,000 has now been raised for MND charities in roughly six years.
The work of charities such as the Darby Rimmer foundation, My Name’5 Doddie foundation, MND Scotland & the MND Association is crucial to the MND community. Funding research and providing grants to families to help with the challenges we face on a day to day basis.

As things stand, it is now over 7 years since my MND diagnosis. My progression has been relatively slow with my legs mostly affected. Although I can still manage to walk with the help of a rollator. My hands and arms are weakening and my speech is slowing. I can no longer work and earn a living which I have done since leaving school, and now have to rely on government benefits which is a challenge trying to support a young family. I have had many falls and injuries including falling down a full flight of stairs and knocking myself unconscious. But I still remain positive with the help of my amazing wife and children. We tackle this as a family and try not to let it interfere with a normal family life. Of course, I miss playing football with Calum and Sophie in the garden and even going for a walk down the street unaided. But the most important thing is that I am still here today watching my children grow up. That is what makes me fight this disease every day.