.

Hello folks, My name is Irene Wilson, thank you for inviting me to speak from a patients perspective

I was diagnosed with NMO Spectrum disorder at the Western General Hospital Edinburgh in January 2013 and positive for Aquaporin 4 antibody with a spinal cord lesion involving more than 3 segments from T1 - T6.

I was a swimmer, swimming at least 50 lengths 5 days out of 7 for many years. I have Systemic Mastocytosis and was on Interferon Alfa 2b for over 12 years to treat this condition. I also have Systemic Lupus but I was fit. I am The UK Mastcytosis Charity Leader working many hours a day.

What is interesting is about two months before my NMO diagnosis, with my Haematologist's agreement because my mastocytosis condition was stable I stopped my Interferon Alfa injections. Whether there is a tie in with stopping this and NMO developing I do not know. Also since 1980 I have had every few months over the years what seemed to be shingles affecting a different nerve every episode. I was on constant Famacyclovir it did not stop the attacks. Although it presented like Shingles the PCR tests were always negative and these recurring attacks were always on a different nerve each time. These attacks baffled my consultants. My last attack was around a month before NMO was diagnosed and I have not had one attack since NMO diagnosis. Is there a tie in with this as well I wonder.

It was Christmas 2012 and the first thing that I noticed my legs seemed un coordinated and I was falling over my own feet. I had a tight swollen feeling under my breasts all the way around from back to front as though my bra was too tight and I had a tight band around me. My toes on both feet were numb. When I look back I had noticed my toes being numb for several months. I did speak to my GP about this but because I had had an accident in the summer of 2012 falling off a ladder and breaking a vertebra in my lower spine my GP thought the numbness was because of the broken vertebra and I accepted this.

By Hogmonay I was much worse and could hardly walk from A - B without falling. I got an urgent appointment with my GP. She tried for almost an hour to get through to neurology at Edinburgh but Hogmonay in Scotland is a busy time and no one answered. She sent me home and said if I got worse to phone NHS 24.

Within a few days I was much worse. My son is an intensive care consultant with many years experience. He realised something was seriously wrong and got me straight to my local hospital. They sent me in an ambulance to the Western General in Edinburgh. An immediate MRI scan was requested. It showed a tumour (so the doctors thought) on my spinal column. They would have to operate. The operation was on my birthday 10th January 2013 not a very welcome birthday present.

Looking back I wish I had questioned this diagnosis (I mean the neurologist saying it was a tumour) From what I have now learned I wonder why they did not suspect a Myelitis and if they had, an operation on my spinal column might not have been necessary causing the serious complications I have to day. I do not know anyone with NMO where neurosurgeons had to operate.

After the operation I was told it was not a tumour as they thought but a lesion covering several vertebras and no one had any idea what it was. Biopsies were taken at the time of the op and sent

.

away for testing. I was started on high dose steroids. Results took 3 weeks to come back. After the op I was able to walk very cautiously with a walker but gradually over a couple of weeks became paralysed and had no feeling from the chest down. Deep lesions appeared my legs and my feet and they were very swollen. It was like looking at someone else's legs and feet. My bladder and bowel were also paralysed and I had to deal with this manually which was not at all pleasant.

The pain in my legs was unbearable. The only way I could describe this was like motorbikes inside my legs. None of the pain meds including Ketamine helped and at times I was screaming the pain was so difficult to deal with and the doctors despite trying different meds were unable to find a way to control the pain. They suggested Plasma Exchange and I had 4 rounds of this which made a big difference and the pain gradually subsided. I was in hospital for four months. The day I was being discharged from hospital I fell with my walker. The pain in my upper back was unbearable. It was to be several months of me pleading with my neurologist to do an MRI scan. I knew something was very seriously wrong . Then the MRI results went missing and did not turn up for a month. Eventually when my neurologist found the results he was horrified. The scan showed a complete collapse of my spine which you can read part of my report on my slide. My Neurology surgeon was unable to operate it was too complex and operating could cause complete paralyses. The alternative at the moment is that I am receiving pain relieving injections regularly into my spine.

I absolutely hate the way I look, the shape of my upper back, the weight gain, my bladder and bowel issues, and the numbness I have to contend with. I find it very difficult from day to day to accept this.

Despite all this I have worked extremely hard at physiotherapy and I am now back in the water swimming. My knees and lower legs and feet and parts of my spine are still numb and my bladder and bowel remain paralysed but I am walking even if ungainly and here to day to tell you this. I am currently on Azathipoprine. This was started after the Plasma Exchange.

This workshop is about controlled drug trials. From my own point of view I would be very worried starting on a trial just in case out of the blue a relapse occurred especially as so far 'touch wood' no relapse.

It must be extremely difficult for the drug companies as trialling new meds is the only way to know if there is a good outcome. From my own perspective I would be reluctant to take this chance. Maybe however, if a person has experienced relapses they would be more keen to join a drug trial hoping it would help.

NMO is life changing. There is no doubt about that and everyday is a struggle and I so hope meds can be found that can help make a big difference to a patient diagnosed with this and of course neurologists being more aware of the condition as in my own case the immediate diagnosis was a tumour on my spinal column and had they realised it was a myelitis I would not have required them to operate.

Thank you