

Alex raising funds for Scottish Huntington's Association

Alex Wilson from Edinburgh is on a major fundraising drive this spring. Last month the 59-year-old completed the London Marathon with his daughter Kate, and is now shining up his dance shoes in readiness for the next challenge.

That challenge will be the Dance 100 – a five hour sponsored dance to be held in George Square in Glasgow on 14 May.

The semi-retired surveyor was accompanied on the marathon by one daughter and now the other, his 25-year-old daughter Chloe will dance with him, along with his sister Sharon.

Alex said: “The London Marathon was amazing, especially because I was running with Kate who first suggested that we do it together. It was her idea and without her I don't think I would ever have done it.

“We loved the atmosphere and the music, and the crowds went wild when they saw our Mario and Luigi outfits. We got lots of high fives as we ran.

“We wanted to stand out for Scottish Huntington's Association, and Kate went above and beyond with her fundraising. We raised more than £4,000 and most of that was by Kate. I'm extremely

proud of her for doing so much and for training so hard. At one point she had an ankle injury that needed physiotherapy but even that didn't stop her.

"I hadn't run a marathon for more than 30 years and it was my first time in London so it was an adventure for both of us. We were both very emotional crossing the line with a time of just over five hours."

His connection with the charity is a very personal one as his own father died from the disease. Alex said: "I've seen first-hand how Scottish Huntington's Association supports families and the way the charity is working to raise awareness and reduce the stigma that even today continues to surround the disease. Too many people don't know about Huntington's and that only adds to the challenges families face.

"I was 14 when I found out about the disease and it was difficult to watch it overtake my dad. He became more reclusive and had significant physical and mental health symptoms. As the oldest of four children, I felt it was my responsibility to help Mum care for my dad and my siblings. Unfortunately, Dad was only 47 when he passed away."

Huntington's disease is caused by an inherited faulty gene that damages the brain, leading to complex physical, mental health and cognitive symptoms. People with the disease can lose the ability to walk, talk, eat, swallow, and make rational decisions, resulting in the need for 24-hour care.

Alex does not know if he has the faulty gene, although his brother Graham has Huntington's. Each child of an affected parent is at 50% risk of inheriting the disease. Instead of opting for a Huntington's test Alex had an operation to replace his knee and explained: "That was enough to deal with, so I chose to have the surgery and leave the test. Now I have a titanium knee and I can run, keep fit – and dance – without being in pain."

A loss of control over movement causes repetitive jerky movements and impairs balance and mobility. Early onset dementia, behaviour changes, and reduced ability to make rational decisions, plan and organise is also common, while serious mental illness such as depression, anxiety and, in some people, psychosis, can develop.

Scottish Huntington's Association is the only charity in Scotland dedicated exclusively to supporting the Huntington's community. It does this through a network of Huntington's Disease Specialists, Youth Advisors and Financial Wellbeing Officers in addition to working towards improved specialist services for families, regardless of where in Scotland they live.

hdscotland.org









Alex Kate and Chloe