

Grant 1 Tony Simpson & Dawn Henderson May 2019

ADDOR is pleased to announce their first grant in support of the continued fight against Huntington's disease (HD), by providing financial assistance to help an HD sufferer Tony Simpson.

Tony Simpson



Tony 31 December 2012

Tony is 50 years old. He inherited HD from his father, who had kept his condition secret, until 3 years before his death in 2005. Following the disclosure that their father had HD, Tony and his elder sister Jane decided, in 2003 to be tested together on whether they had inherited Huntington's disease (HD), sadly they were both diagnosed positive.

Tony is one of 4 siblings, 3 have inherited HD. Tony's sister Jane sadly passed away in March 2016 aged 49 leaving two children, who may develop the HD condition in time, we pray not. It was extremely difficult for Tony watching his older sister struggle with this crippling disease and die, so young, knowing that this is his fate, unless a medical breakthrough is made soon.

The third sibling Mike, who lives in Wales, is 10 years younger, he is now struggling with the onset of the HD symptoms.

Tony worked hard all of his life, never being late or off sick from work. He was super fit, rock climbing, cycling and running. He completed the London to Brighton bike ride in just over 4 hours. He still tries to keep fit on his home exercise bike, completing 10 miles in 31 minutes.

Tony lives in Weymouth with Dawn, his partner of 26 years. As Dawn, who is also his carer says "we're not married because he doesn't want to rush into things", "He loved to ride his motor bike with me being a very bad passenger on the back". She added "his balance, co-ordination and speech are now on the decline, but he still does his best".



Tony & Dawn, North Wales, November 2018

The couple had planned to go on holiday to the Canary Islands, at the end of January this year. However, whilst travelling to Gatwick airport, they were caught up in a major incident on the M25 motorway, delayed for over 4 hours and missed their flight. The insurance company refused to compensate them, as they were travelling by taxi to the airport. Unbelievable!!!! For a couple living on benefits it was a catastrophe, not only emotionally, from missing out on a long-awaited break together, but financially. They are still fighting that decision, which is now with the Financial Ombudsman. Let us hope they are successful in their fight for compensation.

Dawn in a message to ADDOR, said “We love each other now as much as the first day we met. In my eyes he is being extremely brave and strong. This is breaking my heart to see him like this, but he's stuck with me, through thick and thin.”

Two years ago IONIS, the pharmaceutical company, spent two days with Dawn and Tony, filming their day to day life with HD. IONIS were given permission to show the video at lectures and drug conventions. With Dawn and Tony’s permission ADDOR hopes in the future to be able to provide a link to that video to share their experience.



Tony Today

ADDOR is very pleased to provide £500 to Dawn and Tony to share time away together.

Dawn & Tony's responded "Thank you so much for your call. From a complete stranger, it comes as a wonderful surprise".

If you would like to help in the fight to defeat HD, fund research and help others like Tony and Dawn

Please donate at addor.co.uk