

Grant 3 Mick & Mary Johnston August 2019

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

Mick & Mary Johnston story

Mick Johnston, 66 years old, lives with his wife Mary in Killeel, a fishing village, as Mary put it "in the beautiful Mountains of Mourne, area of Northern Ireland". Mick was diagnosed with HD in 2001, although Mary said "certain signs were there before, but were not at the time attributed to HD".



Mick, Mary & Margret arriving at the share centre in Lisnaskea

He inherited HD from his mother. His grandfather, an uncle and an aunt, also had HD. There were two siblings in Mick's family, fortunately both his brother and sister did not inherit this cruel disease.

Mick joined the Army Junior Leader's at the age of 15, serving for 24 years, with much of that time spent in Germany. He was an extremely fit active man, who was a keen swimmer in his younger years. Both Mick and Mary share a love of the great outdoors.



Mick & Mary dining together

On leaving the Army in 1993, Mick and Mary moved to the Lothian area of Scotland, where Mick worked in the motor trade, until retiring through ill health in 2005. During their time in

Lothian they were active members of the Lothian Family Branch of the Huntington's Disease Association (HDA), Scotland, with Mary being the Branch Treasurer for eight years.

In 2016, with the worsening progression of Mick's HD, they decided to move to Mary's birth place, Newry, where more family support is available to them. Since starting to live in Kilkeel, they have joined and are active in the Newry Support Group of HDA, Northern Ireland

Mary is the main carer for her husband Mick who is now in a wheelchair, has lost his speech and relies on 24 hour care, mostly from Mary, although more recently, there is additional carer support provided, 4 times per day.

Mary drives a van fully adapted for the wheelchair, which enables them to get out together.



Mick & Mary enjoying the great outdoors

Mick and Mary do not have any children, they decided, because of HD in the family, not to risk having children. As Mary said "although there is disappointment in not having children, we are blessed, because, from my brothers and sisters, we have an extended large family of 24 nieces and nephews in the UK and America, which more than fills that void.

Mary has been hoping to take Mick away for a few days for a short break, somewhere he can enjoy being outdoors, but also has wheelchair accessibility, which has been a huge barrier to lots of their planned outings. A few days at the Share Centre (a registered charity outdoor adventure centre in Co Fermanagh) seemed ideal. She would like to take her sister Margaret with them for extra support. However money is very tight, for them to be able to afford this break.

HDA Northern Ireland (HDANI) Chief Executive, Sorcha McPhillips in response to ADDOR's offer to help, said "We have a lot of very deserving cases, but the offer is timely to provide a respite break for Mick and Mary. Northern Ireland is very limited in terms of wheelchair accessible, affordable holiday options and the vast majority of the families we work with are benefit dependent. This couple would be ideally suited to a grant to help them enjoy safe, quality respite time together. We would be most grateful if you would consider them for assistance".



Mick & Mary enjoying the great outdoors

ADDOR was extremely pleased to provide a grant of £500 to Mick and Mary to spend quality respite time away together.

In early August Mary and Mick enjoyed a lovely few days away, in Lisnaskea, Co Fermanagh, on the edge of Lough Erne, with Mary's sister Margaret.

Mary during one of our telephone conversations said "you are a guardian angel". Their Specialist HDA Adviser Angie wrote "thanks again to yourself and all the trustees, what you are doing for HD families is incredible, this lovely gesture of support will make a positive difference to Mick's quality of life".

These gracious words of praise give us at ADDOR great pleasure, to know we are helping, but really belong to you, our donors, for your continued financial support, without which, none of this is possible.

ADDOR applauds and supports the tremendous work of the HDA Support Groups and the HDA Specialist Advisers, which is of such extreme importance to HD sufferers and their families.



Mick & Mary on another trip out

If you would like to help in the continuing fight to defeat HD, fund research and help other sufferers and their families, like Mick and Mary

Please donate at addor.co.uk