

Grants 7-10 Christmas December 2019

ADDOR in the “Fight to Defeat Huntington’s Disease (HD)” made grants to the University College London (UCL), Huntington Disease Centre to support their research work in seeking to defeat HD and to help three families living with the impact of HD.

Grant 7 UCL HUNTINGTON’S DISEASE CENTRE



ULC Staff

UCL Website Statement

Our vision is a world in which Huntington’s disease is no longer something families have to worry about. UCL’s Huntington’s Disease Centre strives to achieve this future by combining world-class scientific expertise and the highest quality multidisciplinary clinical care. Our research spans the full range from laboratory research to understand how the Huntington’s disease gene causes the disease and how it affects the living brain, through the development of innovative new treatments and leading the world in clinical trial design and execution. We are committed to training the next generation of future scientists and clinicians to contribute to the fight against HD.

A further £100 grant was made to the UCL Huntington’s Disease Centre to support their research work

Grant 8 Mick & Mary Johnston Story



Mick & Mary Johnston

Mick & Mary enjoying respite time together at the share centre in Lisnaskea

Mick, 66 years old, lives with his wife Mary in Kilkeel, a fishing village in Northern Ireland”. Mick was diagnosed with HD in 2001

Grant 9 Tony Simpson & Dawn Henderson Story



Tony December 2012



Tony & Dawn, North Wales



Tony 2019

Tony 50 years old, lives with his partner Dawn in Weymouth, Dorset, he was diagnosed positive with Huntington's disease (HD) in 2003

Grant 10 Alan & Dianne (Di) Pagett Story



Alan & Di

Alan, 65 years old, lived with Di in Axbridge, Somerset, he is now in a specialist care home. Three years ago Alan collapsed with a seizure and was diagnosed with a glioblastoma brain tumour. With surgery to partially remove the tumour, chemo and radiotherapy, the prognosis was, it would hopefully prolong his life for 13 months. When diagnosed with the brain tumour Alan, showed signs, which indicated he may have Huntington's disease, a subsequent blood test sadly confirmed he also had this cruel disease

These families live every day with the devastating impact of this cruel incurable disease. The ADDOR Trustees as a gesture of their continuing support, decided to make a further grant, in the sum of £100 each to the families, to use as they wish, to buy a special gift for their loved one at Christmas.

There are many others who need help throughout the world. If you would like to help ADDOR in the continuing "Fight to defeat HD", fund research, help other sufferers and their families, like Alan & Di, Tony & Dawn, Mick & Mary

Christmas Grant Update 23rd December 2019

The recipients on receiving the news of the £100 Christmas contacted ADDOR and expressed their appreciation of the unexpected gesture.

Mick & Mary Johnston

Thank you for your kind gift to treat Mick to something nice. I will make sure he gets something he will enjoy. It was so nice of you to remember us at this time, we wish you all at ADDOR a really Happy Christmas and Peaceful New Year. God Bless always.

Tony Simpson & Dawn Henderson

Dawn on behalf of Tony & herself said "we thank you very much for the Christmas gift. We've been looking at different rock concerts, Tony is making his mind up at the moment".

She went on to say "Tony's doing his best as always. He still uses the rowing machine 3 times a week and rides his exercise bike. However sadly he now struggles when walking and talking".

They also have other immediate difficulties, to deal with, the family are still in limbo trying to find somewhere new to live. The date on the present rental agreement has only been extended until the end of January 2020. They are also concerned about Tony's mother, who not only suffered the loss of a daughter from HD, is concerned for Tony's health but has to additional worry about her youngest son, also diagnosed with HD.

It is so sad that more is not being done to help this family, living with the tragic impact of HD.

Alan & Di Pagett

Di telephoned me on receiving notification of the grant. She was emotional, crying as she put it "tears of happiness". She had arrived home that night feeling desperate and alone, not sure how she was going to face Christmas. She had no money, Alan would be coming out of the hospice for Christmas day, how to put food on the table or buy a small present for each of the grandchildren. There would also be difficulties in caring for Alan at home for the day, which filled her with trepidation and added to her worries, but she wanted so much to do it for the man she loves.

Di was contemplating taking out a loan from one of the high interest loan companies, but was then further worried, how she would be able to pay back the loan.

As Di said "she was overcome with gratitude that help was at hand", we spoke at length of her concerns and I tried to help, I hope I brought some comfort to her.

When I contacted her Specialist HDA Advisor the following day, I said "I appreciate so much more having tried through ADDOR to help people, how much we owe to organisations such as HDA, the Samaritans and other organisations, they provide comfort in times of crisis, sometimes just by listening to people. This is especially relevant when taking care of families living with the tragic consequences of HD"

