

Grant 6 Bill & Christine Bateman December 2019

ADDOR is pleased to announce a further grant in support of the continued fight against Huntington's disease (HD), providing financial assistance to help a family living with the impact of HD.



Bill & Christine

The Bateman Family story

Ann Pathmanaban Specialist H.D. Adviser for Dorset & Wiltshire, recently contacted ADDOR with the following request for help. "I recently met a gentleman, his daughter and grandson, who have a very sad story. They have given me permission to tell you about it. He met his wife when she was fifteen and he was sixteen. They were together for many years until she died two years ago, having had HD. They moved to Dorset five years ago and he coped with her at home alone with NO HELP! I am so sad for them. His GP has only just referred him to me now to try to offer him some help (why not before I don't know) because he is not recovering at all from his grief at losing her and medication/counselling have not worked. He also had two other close bereavements recently.

One thing that I feel is preventing him from moving on at all is his deep sorrow that he can't afford a headstone for her grave. He had to stop work at fifty to care for her and he is now sixty seven and living on a state pension.

I know this is not a usual request but would your Trust Committee consider paying towards a headstone for his wife? He managed to pay for her funeral with a struggle, but I really think it will help him to heal a bit. At the moment he can only focus on feeling he has let her down by not getting the headstone. The rest of the story is also very sad but I won't go into it. I managed to obtain a small grant towards it from the Dorset Branch of the HDA, but it is going to cost around £800 so it will not be enough on its own.

He lives alone in Wimborne and his daughter and grandson live in another rented flat not far away. She cannot help much for reasons she may divulge at some point if she wishes. She said she has managed to save £100 towards it in two years, and it costs around £800. I see this being a long haul and one through which he will struggle to cope.

It is devastating that they could have had support from the Specialist HD Adviser in their previous area and I could have supported them for the three years when they moved here

until she died, and got them the help they needed, if only I knew about them. They have had a really rough deal.

I totally understand if this is not something that you can support, but thought it worth asking. If you feel it is, I will let you have their contact details, which they have also given permission for me to do”.

Although outside of the normal request received by ADDOR, the Trustees felt they should try and help, agreeing to do so and with the feeling there was more to this story and sadly there is.

Bill Bateman lives alone, finds it difficult to talk about the loss of his beloved wife and so it was requested that I contact his daughter Michelle. What I thought was going to be problematic for me in asking personal questions turned out, not to be, as Michelle was articulate, spoke freely and showed a loving concern for her family, desperately wanting to fulfil the need for some closure by erecting a headstone in memory of her mother Christine.

So to continue the story. Bill and Christine were childhood sweethearts and were together for 49 years until Christine died in 2018, from complications associated with Huntington’s disease (HD) at the age of 64. Christine was diagnosed with HD in 2004 and as was explained by Ann’s request, received inadequate support, particularly when they moved to Wimborne, Dorset for the last few years of her life, where she finally succumbed to this cruel relentless incurable disease.



Christine a lovely Lady, Wife, Mother & Grandmother

However as suspected the story does not end there. The family has a history of HD through the mother’s side of the family. Michelle’s grandmother had HD, she had six children, three of whom inherited HD and three did not. Her great grandmother is also thought to have had HD, which is a logical supposition, with the family history. As a result two of Michelle’s cousin’s inherited HD which manifested itself for Theresa at the age of 21 and for Shane at the age of 25. Theresa is now 50 years old and Shane is 40. It is also thought that one member of the family, who was committed to an Institution in the past, was actually an HD sufferer.



Michelle

Michelle then talked about her immediate family. Michelle (46) was herself recently tested and sadly has been diagnosed as inheriting the Huntington's gene. She has three children Charlotte (26), who decided to have the test and has thankfully had a negative result. There are two boys Martin (23) and Luke (15) but neither have been tested for the gene. It is always a difficult decision to make, to have the test or not, but if they do go ahead we all pray they have a negative result.

Michelle went on to say "she cannot go out to work, as she regularly suffers severe migraines, therefore money is extremely tight" and thus the difficulty, with her father only receiving the state pension and Michelle unable to work, for the family to save sufficient money to buy a headstone.

ADDOR is pleased to provide a grant of £350 to Bill, Michelle & the family to complete the funding needed to purchase that much needed headstone for Christine.

There may be others in the UK and certainly worldwide living with inadequate support and financial help. We at ADDOR are humbled, as we listen to the stories. ADDOR acts as a conduit, to help HD people in need, but without the support of you our donors, we could not carry out our work.

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