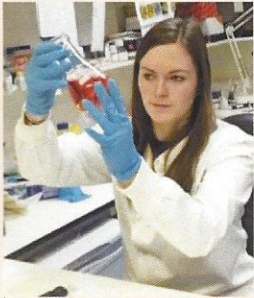




A Scientist's Perspective on Huntington's Disease



Hello! My name is Emma and I am a scientist with a special research interest in Huntington's disease (HD). I began my first degree at Cardiff University, Wales in 2009 and studied Biochemistry. During my degree I had a great time, exploring a new city and learning to look after myself after leaving

home for the first time! But, my degree made me realise that what I was really interested in was diseases. What makes diseases happen? How do diseases impact upon the people who have them and their families? What can be done to help people living with and at risk of developing these diseases?

I wanted to get a greater understanding of HD, it is a disease that has been known about for a long time and it is a disease that has affected my family. I was really excited to be offered a three year PhD to study a pre-clinical mouse model of HD in the Brain Repair Group, at Cardiff University. My PhD looked at a mouse model of HD to see how accurately it reflected the human condition.

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This was a great opportunity as I had three years to really explore HD as a disease and answer some fundamental questions, which are tremendously important for better understanding HD in people. I really enjoyed my PhD, it was hard work but definitely worth it. I was in a tremendously supportive environment with a wonderful group of knowledgeable and talented work colleagues who were world leaders in their research fields.

During my PhD I was lucky enough to be invited to the HD patient clinic by Prof. Anne Rosser. Initially I was very nervous, I had always worked with cells and animals in the laboratory and although I had met people with HD before, I wasn't really sure what to expect. I was made to feel very welcome and the clinicians really appreciated the knowledge that I brought to clinic with an understanding of the science of the disease.

The people visiting for their clinic visits were also very accommodating and kind in allowing me to sit in on their visit. This was a great turning point in my career, as it really reinforced the fact that the research I was doing in the laboratory was tremendously important, but I really liked talking and interacting with patients and I realised that I wanted to become involved in research with people. I am very grateful to the families I met that day, who allowed me to appreciate how important it is to do research into this horrible disease.

Meeting people with HD also made me realise that more can be done to communicate science and research to people with HD, family members and the general public. Because of this, public engagement and outreach activities are a particular passion of mine and something that I feel really strongly about. I am a Science, Technology, Engineering and Mathematics (STEM) ambassador and in this role, I go out into schools and colleges to help children understand science, research and HD. We play with jelly brains and put their teachers in the brain scanner to give them an idea of what a brain looks like. I am also a member of Speakezee, a national organisation which puts on talks and events for the general public about science. I also try to write science communication articles, a bit like this one, for people who may not be able to get out and attend events. You can find my article called 'James and the Giant Gene' on the Biochemical Society website (<https://www.biochemistry.org/Portals/0/Education/Docs/Emma%20Yhnell.pdf>), it is a story about a man with HD. I think social media is also a great way of communicating and I am a keen user of twitter (@EmmaYhnell). There is a great HD community on Twitter, that everyone can get involved in, it is how I was invited to write this article! Finally, I was invited to the UK Parliament in Westminster in March 2016 to present my research to parliament. This was really exciting, I got to meet members of Parliament and talk to them about HD and the food was nice too! I want to do all I can to raise awareness of HD and help people to understand the condition.

I hope you agree that engagement with HD families and the general public is so vitally important to raise awareness of this disease and promote further understanding of it. I hope it is something that HD families can ask for more, to encourage more scientists and clinicians to talk about their work and their research. Honest, open communication between HD families, scientists and clinicians is really important, so please ask us for more information, or to explain ourselves in plain English. Sometimes we get a bit caught up in our science words and medical jargon, so just let us know, communication is key to helping people and families who are affected by HD.

Dr. Emma Yhnell