

MY TIME WITH AMEND

Earlier this year, I made an accidental discovery that would eventually land me in England, although I never imagined that it would go that far!

I have MEN2a, and this winter I was doing some research on the effects of MEN2a on children. My searching led me to the AMEND website, where I found a host of great information that my parents would have loved to have fifteen years ago when I was diagnosed, through genetic tests, with MEN2a. The AMEND website was so well put together that I decided to search through all of the sections, two of which would lead me to England. While exploring, I found the “Volunteering” section and the “Start A Patient Group” section. I was very interested in the idea of volunteering with AMEND, as I already volunteer extensively in my home province of Newfoundland and Labrador in Canada, so why not volunteer for a worthy cause abroad? It was my mother, who also has MEN2a, who became the driving force behind my voyage to England. When we looked at the AMEND patient groups from around the world, we saw that there is no AMEND branch in Canada, and after a short debate, we decided that we would like to take on the challenge of creating an AMEND patient group in Canada. To get our idea off the ground my mom, Donna, emailed Jo Grey, who was just as excited about the prospect of expanding AMEND to Canada as we were. And since I was still keen to volunteer with AMEND, my mother and I arranged a period of time in May and June when I would leave Canada and travel to England, to take a position as AMEND’s summer intern for 2015, and here I am!

During my time as an AMEND intern, I have been given so many amazing opportunities to see the range of MEN care in the UK. Along with AMEND CEO Jo Grey, I took part in Great Ormond Street Hospital for Children’s MEN clinic, where we counselled several families with children who have MEN conditions; we visited Professor Neil McDonald and visited his research lab at the Francis Crick Institute where we learned a lot about his current research, which has won an AMEND MTC Research Award. We were also visited by Dr Jane Green, a geneticist and professor of genetics at Memorial University of Newfoundland, who studied my family extensively when our RET mutation was trying to be found. In our further adventures, we attended the Addison’s Disease Self Help Group’s annual general meeting, where we heard a great lecture on Addison’s disease given by Professor Wiebke Arlt of the University of Birmingham. In the last few days of my internship, Jo and I will be attending the International Thyroid Forum on June 12th and 13th, where we will be acting as patient representatives for AMEND. And last but certainly not least, we will be heading to Oxford on my last full day in England to meet with Professor Rajesh Thakker of AMEND’s medical advisory team, and Kate Lines, who was awarded AMEND’s MEN Research Award for 2013, and to receive a tour of the University of Oxford’s MEN1 laboratories.

Although these excursions to meetings, events and forums in London and Oxford are a large part of my time here with AMEND, most of my time was spent with Jo Grey and Helen Blakebrough at the AMEND office in Tunbridge Wells, Kent. While at the office, I helped with the 2015 updates to the MEN2a and MEN2b Patient Information Books, including the addition of a glossary of scientific terms to the end of the books. I also helped the AMEND team with the creation of a Patient Information Book for MEN4, which is a new, and very rare, disorder that has joined the MEN family. The patient information book on MEN4 will (hopefully) be available online later this year. I also did some searching for the research being done on MEN disorders, and as I found out, there is quite a bit of

research going on, it's just not all open to the public as of right now. And my final job as an AMEND summer intern was write some wonderful articles for the upcoming August newsletter 😊

Along with all of these great office projects and out-of-town events, I also learned a lot about how to run a charity during my time with AMEND, which will be very useful when I return to Canada and attempt to start up AMEND Canada with my mom.

My time in England with AMEND was a once in a lifetime opportunity, and I am extremely grateful to Jo Grey, her family, Helen and everyone who I met while in the UK for making this internship idea a reality. Hopefully the next article I write for this newsletter will be about the successful creation of AMEND Canada!!

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