

Help and hope to all



Jim Williams

“But there’s a story behind everything. How a picture got on a wall. How a scar got on your face. Sometimes the stories are simple, and sometimes they are hard and heartbreaking. But behind all your stories is always your mother’s story, because hers is where yours begin.” —Mitch Albom, *For One More Day*

Thanksgiving has passed us by, and Christmas looms in just a few weeks. Many of us scurry to prepare for what we hope will be a glorious holiday season, full of laughter and joy. Time spent with friends and family can be a great time in our lives, creating memories to last a lifetime.

Thanksgiving is always a good time with my immediate family, but also carries with it a bittersweet memory as well. It was in 1996 on Thanksgiving Day that my mother

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passed away after a seven-year period of suffering from Huntington’s disease. I still remember when she received the diagnosis. While not a surprise, it was devastating for her and our family. Huntington’s had been in my family for many generations but only recently had been accurately diagnosed.

Huntington’s disease (HD) is a neurodegenerative genetic disorder that affects muscle coordination and leads to cognitive decline and psychiatric problems. It typically becomes noticeable in mid-adult life. HD is the most common genetic cause of abnormal involuntary writhing movements called chorea, which is why the disease used to be called Huntington’s chorea.

Symptoms of Huntington’s disease commonly become noticeable between the ages of 35 and 44 years, but they can begin at any age from infancy to old age. In the early stages, there are subtle changes in personality, cognition and physical skills. The physical symptoms are usually the first to be noticed, as cognitive and psychiatric symptoms

are generally not severe enough to be recognized on their own at the earlier stages. Almost everyone with Huntington’s disease eventually exhibits similar physical symptoms, but the onset, progression and extent of cognitive and psychiatric symptoms vary significantly among individuals.

So why am I writing about Huntington’s disease? It is not one of those covered by the umbrella of the Muscular Dystrophy Association. The answer is found in the mission of MDA to provide help and hope to those with muscular diseases.

One of the ways MDA works to fulfill its mission is to support research toward finding therapies and cures for muscular disease. The doctors and researchers working every day to provide breakthroughs are incredibly generous in sharing the results of that research. That is why I can write about Huntington’s disease. My family has had a direct positive impact from the work done by MDA researchers.

Genetic scientists meet every year at conferences and scientific symposiums to talk about their work and share the information openly with those in other fields. The best example of the benefits being shared was when MDA researchers, working with scientists with the Human Genome Project, were successful in mapping the human genome. That breakthrough has been instrumental in other genetic research.

When branches spend their time raising funds for MDA, they also contribute to the knowledge base for all genetic diseases. Your work helps those with Parkinson’s disease, cystic fibrosis, Down syndrome and many others.

Since 1952, NALC has had one charity we sponsor nationally. That is, of course, the Muscular Dystrophy Association. The wisdom of that choice has been proven over the years. Periodically, resolutions come to the national convention asking to add to our list of national charities. It may be that after a cure for MD is found that we will consider another option.

But our consistent position has been to focus on MDA. That doesn’t mean we are uncaring about those afflicted with other tragic diseases. It does mean, though, that by concentrating on MD we have indirect yet real impact on many. The generous way in which MDA shares its knowledge and research with others is proof that we chose the right national charity.

I hope that no letter carrier family will ever have to face the reality of a genetic disease. If you do, you’ll know you have a champion in your corner. Thanks to your work, MDA gives help and hope to all those suffering from genetic illnesses.