

WE ARE NOT ALONE IN OUR FIGHT ..

We've all come from somewhere different, arrived here for different reasons ... but why Canada, why have we chosen to make this our home? I believe it is a unique mindset that Canadians have that attracts those searching for a new life. Whether you are first, second, third, fourth, or fifth generation Canadian or perhaps you are new to this vast country we call Canada, our home, we all have the same drive to make it the best it can be.

We are a diverse country that has two official languages although some would argue after hearing all of our very Canadian slang and euphemisms that we actually have a third. We are a country made up of many cultures and ethnicities, which we openly embrace and celebrate. Canadians are known as kind, generous and proud individuals who respect the values and traditions of not only our own country but of those countries from which we emigrated. Canada affords so many opportunities to us its citizens but for many; just as important as what the country can do for us is what we can do for our country to strengthen it and make it stronger. That is the unique thread that is woven into the Canadian fabric.

One of the many ways Canadians strengthen our country and help its populace is through volunteering. There are many organizations that work endless hours to assist foundations and individuals, ensuring we are doing what we can to help. Whether the organizations goals are narrow or broad, the overall goal is the same, to make Canada and the lives of its citizens, better.

Recently an organization that is fairly new and coming into the foreground of those Canadians facing challenges and disease has come into my life. Founded in 2008 the Rare Disease Foundation is a Vancouver, British Columbia based organization helping to bring rare diseases effecting Canadians to the fore front in order to gain exposure and raise critical funding to find cures and controls. This organization has come to my attention because sadly I have two members of my family recently diagnosed as being affected by rare diseases.

My cousin, Alana, was diagnosed just over two years ago with Ehlers-Danlos syndrome (EDS). It is a disease of the connective tissue. For her it is primary effect is in her joints, skin and internal organs. She constantly battles chronic fatigue and pain. A situation that makes raising a young family even more trying. Sadly Alana isn't the only family member dealing with this rare disease and its little known affects. Her seven year old son, Mason, has recently been diagnosed with EDS as well, only in Mason's case the implications are far graver. Mason lives under the shadow of a potentially fatal heart condition. While in his mom, EDS affects the joints and skin, in Mason the connective tissue affected is in his heart. It's been identified that he has poor collagen in his aorta.

Alana and Mason have already had a roller coaster journey hindered by the fact that being so rare doctors don't always understand their disease. This is where the Rare Disease Foundation

joins our cast of characters. A rare disease is defined as a condition that affects less than 1 in 2000 people. With over 7000 rare diseases being diagnosed and more still undiagnosed it is believed that 1 in 12 people, nearly three million Canadians have a rare disease. These numbers show the important need for volunteers to continue supporting these organizations; donating their time and efforts to ensure studies can carry on so cures and controls can be found and improve the lives of our fellow Canadians.

As Kin, we are all too aware of how important it is to get our message out into the public forum. That is why for so many years our commitment to Cystic Fibrosis hasn't just been about fundraising but about awareness as well. The Rare Disease Foundation is no different. Public awareness and understanding is how every organization has to start. Cystic Fibrosis Canada is very fortunate to have the Kin Canada partnership, backing its fundraising and ensuring this cause gets out into the public forum.

How is a fairly new organization like the Rare Disease Foundation supposed to make it? Cystic Fibrosis, Heart and Stroke Foundation, Canadian Kidney Foundation, Crohns and Colitis Foundation are just a few of the many well established Associations and Foundations that are already out there, positively impact Canadians in many ways. How do they survive?

They do because of people like you and I, the Volunteers who through their donation of their time and efforts make them successful. Volunteering can come in many forms; making a monetary donation, spending time with seniors or the sick, teaching a child something new, or organizing a charity event are just a few ways Canadians can help many of these foundations. The many hours given towards raising monies to conduct research for many of the diseases Canadians suffer from have proven beneficial and so very important in the mission of finding cures and controls.

As we all move forward with our hard work, our uncountable hours and dedication to helping organizations, we as Canadians should be proud of what we have done, what we are doing and what we will accomplish in the future. As members of Kin, we certainly have reason to celebrate our accomplishments and the devotion to all that we are. I think Founder Hal and those first members were visionaries when developing our motto. Our motto of "Serving our Community's greatest need" really does say it all.

Submitted by Eileen George

Winner District One Quill Award 2018