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GADA

Genetic Aortic Disorders Association Canada

L'Association Canadienne des Maladies Génétiques de l'Aorte

In the spirit of the season,

we want to share a few inspirational stories from our members that demonstrate how your generous contribution helps GADA develop it's new programs, like facilitating integrated aortic clinics across Canada and supporting the MAC International Registry research to establish critical differences between various rare and deadly genetic aortic disorders. These are just a few of the GADA initiatives that impact the lives of our members like ...

Nico (unknown mutation)

I am not certain that I can describe in words a sentiment that has accompanied me for most of my adult life. Namley, what it is to spend a lifetime being weary of a condition that one may or may not have, but what I can say, is that associations such as GADA provide relief by their effort to uncover the complexities of aortic disorders and narrow the scope of research to define individual problems.

Both my paternal grandfather and father have suffered from aneurisms and aortic ruptures – my father having been specifically diagnosed with Marfan syndrome – but until GADA had a role in deciphering and highlighting the distinctions in aortic disorders, I felt as though I was living under an umbrella of fear.

I am thus thankful for the distinguished effort they are making to create an open registry for clinicians, scientists and doctors to have a clearer understanding of the disorder and its implications on individual patients. ■

From everyone here at GADA,
we wish you and your family a wonderful,
safe and happy holiday!

Ulyana (MYH11)

At 29 years of age, my birth father (I was adopted at birth) informed me that I had a 50/50 chance of having inherited a possible genetic aortic mutation. He, along with his mother and brother, all had an aortic aneurism and/or dissection. Luckily, everyone survived. They were working with a geneticist in Ontario and were all part of a study out of Texas. I also contributed a DNA sample to the study.

At the time, the gene causing the mutation had not yet been identified. I was informed that most doctors would likely label it Marfan syndrome but it was better described as TAAD because it specifically affected only the aorta.

I began seeing a cardiologist and had echocardiograms twice a year. When I got pregnant in 2011, I was monitored as a high-risk pregnancy and had regular echocardiograms.

I was 33 weeks pregnant when I got a strange and sudden pain in my throat that persisted through the night. Next morning in the ER, my vitals were normal and I was sent home diagnosed with a cold. The pain subsided and I carried on. A week later I got an abrupt and sharp pain in my back. I called my cardiologist who sent me to the ER and scheduled an echo for the following week. In the ER the pain in my back grew excruciating and I was given a strong painkiller. I explained my aortic condition and the risks but the doctors hesitated to do an MRI to protect the baby. They did an ultrasound of my stomach instead and found gallstones, which combined with my heartburn was determined to be the source of my pain, and I was discharged. The following week I went for the scheduled echo where the technician immediately spotted a dissection of my ascending aorta. My aortic aneurism was about 6 cm wide!

At 35 weeks pregnant with a progressing aortic dissection, I was immediately scheduled for a surgery. An MRI confirmed the dissection and my husband and I were faced with a decision – either repair the dissection followed by the delivery or the other way around? We felt that leaving the baby in the womb during surgery was too risky for the child and it was the best decision we ever made. What I remember next, was being woken up by my husband, Daniel, and a nurse showing me images of our baby girl, Nina.

Since that episode the genetic mutation has been identified as that of the MYH11 gene, which includes disease of the aorta without any outward signs of other bodily abnormalities. We are very happy to share that Nina tested negative for the MYH11 mutation!

GADA's programs to support the MAC International Registry research is extremely crucial to keep medical professionals updated of the many new gene mutations that cause fatal aortic disorders and their distinguishing features. Having an organization such as GADA to provide support and education is also reassuring to Canadians experiencing the precariousness of these disorders. ■

Nevaeh (TGFBR2 – LDS)

When Sandra's grand-daughter, Nevaeh, was born in 2006 she had an inclination that there was more going on other than what the doctors described as 'typical clubbed feet'. Sandra repeatedly noted the little one's long slender fingers, hyper-extensible joints, low muscle tone, mild craniofacial features and pectus excavatum. Along with the waving of research documents that she'd whip out of her hand-bag, Sandra finally managed to initiate a referral to a geneticist. Could it be Marfan, Beals, or Ehlers-Danlos syndrome? Two years later in 2010, Nevaeh was diagnosed with Loeys-Dietz syndrome (TGFBR2 mutation) and in Nevaeh's case her mutation is random with no familial link.

Sandra Topper is on the Board of Directors for GADA Canada. She was one of the original co-founding members of the Loeys-Dietz syndrome Foundation of Canada and remains dedicated to fostering awareness and being a supportive advocate to several members of the Canadian LDS community. ■

Jan (FBN1 – Marfan)

I was diagnosed with Marfan syndrome only a few months after my birth and my family was fearful of what it meant for my future. Throughout my childhood my mother was ever-watchful of the dangers around me and despite her best attempts, I did realize there was a difference between myself and the other children. They all ran around the soccer field for an hour while the gym teacher told me I had to sit out after merely half the class. I didn't suffer any trauma from sitting outside of the class but I was clearly treated differently. I learned that I excelled in every academic subject I tackled. I am interested in the etymology of many languages; I have worked hard in the sciences and math and I am currently pursuing a degree in business managment. Through my studies into academia I found others like myself, unable to perform physically – albeit by choice – but excelling in their education. I persevered past the restrictions of my feeble bones and broken heart. It doesn't matter if you can walk or run, it matters what you choose to do with what you have.

I've trained in archery, been part of a walking club and even learned to swim. I don't particularly enjoy swimming but it keeps me healthy until further advancements can be made to help Marfan syndrome and related disorders. GADA Canada (formerly The Canadian Marfan Association) is here to do just that. Through them, we all have the chance to do everything we want to do and more, both before and after a cure is found. The entire GADA Canada community has always been kind to my family and I know if ever I was in need of something, they would always be willing to help. ■

Lisa (ACTA2)

In 2010, six days after giving birth to my beautiful daughter, Lauren, my life took a drastic turn when I was diagnosed with an aortic dissection. I underwent highly complex surgery of a dissection that ran from the root of the aorta, through the arch, and down through the descending aorta. The arteries going to my head and neck were tearing from the aorta and there was very little healthy tissue to work with. I had been bleeding internally and suffered two strokes before the operation had even begun.

The surgery was a tremendous success but I had a long recovery ahead of me. One stroke had taken part of my vision, another had caused paresis in my right side. It was truly a disaster of epic proportions for our little family. We found out later, that all of it could have been avoided. In 1991, after my father passed away at the age of 45 from complications related to a surgical repair of an abdominal aortic dissection, we were told that aortic dissection was not heritable except in carriers of Marfan syndrome which he didn't have. What happened to my father was likely not preventable, but we didn't have the medical knowledge regarding aortic health that we have now.

Now, 24 years later, we know that Marfan syndrome isn't the only path to genetically-based connective tissue disease affecting the cardiovascular system. Other diseases such as Loeys-Dietz syndrome (LDS) and ACTA2 carry the same risks of aortic disease. We went on to discover that myself, my sister and my little Lauren all carry a genetic mutation known as ACTA2, as did in all likelihood my father. This places us at an inordinate risk for thoracic aortic diseases such as aneurysms and dissections that are related to connective tissue disorders.

What happened to me was preventable, had my family physician been more knowledgeable about the sizeable risk of family history as it relates to aortic dissection. What happens from here with my health and that of my sister and my daughter is now something that we can actively manage. We are all being monitored closely so as to prevent any acute aortic events. Prevention is the key. Although I have some residual vision loss as a result of the stroke, I've been fortunate to be able to return to my life as a mother/ wife/ daughter/ sister/ relative and friend.

We need to continue with research efforts to help us understand ACTA2 and other genetic aortic disorders better. They are complex and multi-systemic but most of all they can be deadly.

Please help us to improve the odds by contributing to the efforts of GADA Canada to support research and promote knowledge of aortic health in our community. ■