



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF BRITISH COLUMBIA

The ALS Society of BC

A SPECIAL INFORMATION SUPPLEMENT

The McCuskers' fight with ALS

Hello, my name is Don McCusker. I am a 38 year old man born and raised in Burnaby, British Columbia. I have two older brothers Bob and Steve McCusker as well as my parents; Bob Sr and Marilyn McCusker who I am proud to say have been married for 46 years.

There is currently 3000 people in Canada that are living with Amyotrophic Lateral Sclerosis or ALS, commonly referred to as Lou Gehrig's disease. I am one of the 3000. I was asked to share my story and experiences about ALS. This is my story about the disease. This is a hard story to tell. This is a real story.

On January 28 2012 I along with my two brothers traveled to Courtenay BC to visit our parents. Under usual circumstances I am always excited and look forward to visiting with my parents, however on this occasion I was going to see them to deliver news that I knew was going to shatter their soul and being. This would be the hardest day of our family's life.

All my life growing up both my family members and I had been blessed with good health. I was always active and healthy spending most of time in my youth playing sports such as hockey, baseball, and golf. My dad played professional hockey for the Vancouver Canucks, so being inspired by him I was focused on hockey in my teens and twenties playing Junior A for the Surrey Eagles and was fortunate enough to receive an athletic scholarship from Northern Michigan University where I played hockey for four years and graduated with a Bachelors of Science degree. My life consisted of playing hockey in the winter and golf in the summer.

When I was done playing competitive hockey I followed another passion of mine; golf, and became a member of the Canadian Professional Golfers Association for the next five years.

Eventually I wanted to enter the corporate business world, and I became a licensed Insurance Broker in 2003. Over the next 8 years I enjoyed being a Commercial Insurance Broker with Axis Insurance Managers specializing in Commercial Property and Casualty Insurance. I was focused on my career and enjoying life when in the fall of 2011 I started to recognize things were not right with me.

I recognized on isolated instances I was having difficulty articulating words when speaking. I would get short of breath on the phone, or in a client meeting. After a couple of months of trying to dismiss the symptoms, the slurred speech was eventually getting worse and prompted me to see my physician. He referred me to a neurologist who did some preliminary tests, and once again referred me to another neurologist for further testing. At this point I was growing quite concerned. I received a test called an EMG which is used to record the electrical activity of muscles. Prior to the test I did some research on possible causes of my symptoms, but did not know what was wrong with me. After the EMG test the doctor met with me and informed me that she was virtually positive I had ALS. The doctor informed that we do not know what causes ALS and there is currently no cure or successful treatment for the disease.

ALS is a terminal motor neuron disease that is characterized by rapidly progressive weakness, muscle atrophy and fasciculations, muscle specificity, difficulty speaking, swallowing, and breathing. Eventually patients lose the ability of all muscles including arms, legs, and body. When muscles in the diaphragm and chest wall fail, patients lose the ability to breathe and die from respiratory failure. The diagnosis was extremely difficult to hear. I asked her what the long term prognosis was. She told me that I had between 3 and 10 years to live...

What do you say to that?
I thanked the doctor for her candor and went to a private area in the hospital to decompress emotionally.

I went home and looked up ALS on the internet. I soon realized that the doctor had actually given me an optimistic prognosis by telling me 3-10 years. I learned that 50 percent of people with ALS die within 3 years and 90 percent die within 5 years.

I had one final test to confirm that I had ALS. It was an MRI of my brain to rule out any other brain related illness that may be causing my symptoms. I remember walking to the hospital that morning praying that they would find a brain tumor on the MRI. What a thing to wish for.

The results of the MRI showed no irregularities on my brain and in January of 2012 my biggest fear became a harsh reality; I was diagnosed with Bulbar ALS.

Throughout the tests and doctors meetings over the last couple of months I had kept my two brothers apprised of the latest developments and eventually the diagnosis. They were both extremely supportive and came to a lot of the meetings with me. The day I was diagnosed Steve was with me and I spoke to Bob Jr on the phone who lives in Calgary. It was so hard for me to have to share that information with my two brothers.

My parents live on Vancouver Island and they knew that I had been going for tests regarding my speech, but I had yet to tell them the full diagnosis until it was confirmed. When it was, my two brothers and I agreed it would be best to tell them in person together so we traveled to their home on Vancouver Island in Courtenay, British Columbia.

It was hard for me to know I had ALS and even harder to tell my brothers.

But having to let my parents know that their youngest son has an aggressive terminal disease was something that I knew would be absolutely devastating to them. Just the thought of telling them broke my heart.

We went to my parents home and sat in their living room with them. I began to attempt to explain my situation but I could not get any words out of my mouth. This wasn't because of the ALS affecting my speech, it was because my heart hurt so much looking at my parents and thinking about how I was going to hurt them I simply couldn't speak. My brothers spoke on my behalf and explained to my parents that the tests I had been taking over the past two months have confirmed that I have ALS. Both my parents are intelligent individuals and knew that ALS was a possibility, but to hear it confirmed and knowing the repercussions that diagnosis included hit them immediately and hard. I could see that they were both



Don McCusker with parents Marilyn and Bob.

literally crushed. My parents reacted as I had expected.

My Dad is an extremely strong, stable, controlled, and dependable individual. He immediately wanted to be supportive. Although I saw the complete concern and anguish in his eyes and body language, he remained composed and his leadership was amazing. My Dad always has been, and always will be my hero.

My mom is like me. She is outwardly emotional, and wears her heart on her sleeve. My mom was heartbroken and angry. She was extremely emotional and wanted answers for why her son was sick and why this was hurting our family. She wanted to protect me from this illness but she didn't know how and it was killing her. It was the worst feeling I have ever experienced seeing my mom in so much pain.

After an hour of tearful emotion and trying to console my mom and I, I witnessed something I will never forget for the rest of my life. I was watching my mom crying and sobbing when she did the following; she took one big breath in, literally breathing the tears back into her body, and with total composure and calmness looked at me and said; "well, as a family we need to come together and fight this". To this day, nor ever again will I see a person have as

much courage as my mom had in that moment. That statement allowed us to move forward as a family. Just thinking about it still inspires me today.

It is now approximately one year since my diagnosis. I feel extremely fortunate and blessed with how I feel today. My slurred speech has gradually become worse, and I do have a number of physical issues related to the disease, however generally speaking I do feel pretty good physically, and I am still capable of being able to do many of the things I enjoy such as golfing and skating with my friends.

I know how lucky I am because over the last year I have had the opportunity to meet a lot of other ALS patients from across the country, and many of them are a lot worse off physically than I. However, the spirit, determination, and positive attitudes of the ALS patients I have had the privilege of meeting would never let you believe for one second that they are disadvantaged in any way. ALS patients are some of the toughest people I have ever met, and I draw great inspiration and strength from their determination in fighting ALS.

Since my diagnosis the support my family and I have received has been incredible. It has given me an opportunity to strengthen and build many of my current friendships such as my high

school friends in Burnaby, my hockey friends, fellow members and staff at The Vancouver Golf Club, friends in the golf and insurance industries, friends of my brothers and my parents, friends and colleagues at The ALS Society of British Columbia, and old and new friends alike.

ALS is a terrible disease that has taken the lives of thousands and thousands of fellow Canadians. The good news is we are making huge strides in research for ALS and there is a strong possibility of a cure or tangible treatment being available in the near future. One thing that has become extremely clear to me in the last year is that no person is unblemished. We all have shortcomings, we all have challenges. My challenge is ALS. I have told my family and friends that I will remain positive, I will fight, and I will endure until a cure is found. I will not waiver from that promise. I hope in some way you can use this as an inspiration to overcome the challenges you may have in your life.

I sincerely thank everyone for all your support and love you have shown to my family and I. For that I consider you all family. Remember; "we need to come together and fight this".

Regards,
Don McCusker, Director ALS Society of BC

Fly Away Raffle

to help fight ALS

Win
a return trip for two to any scheduled WestJet destination!

Prize value \$2,200
Only 1,000 tickets printed

Grand Prize Courtesy of
WESTJET

Valid until April 9, 2014. Draw will take place on Tuesday, April 9, 2013. Some restrictions may apply. Employees and direct family members of the staff of the ALS Society of BC are not eligible. Ticket purchasers must be 19 years of age or older. Winners consent to the release of their names by licensee.

Tickets are just
\$20

BENEFITING

ALS Society of BC
1233 - 13351 Commerce Parkway, Richmond, BC V6V 2X7 Tel: 1-800-708-3228
Charitable # 106708985 RR0001 BC Gaming Event Licence # 47970
Call: 1-800-708-3668 or 604-278-2257 Email: support@alsbc.ca

2013 DATES AND LOCATIONS

APRIL 6TH	OKEOVER - POWELL RIVER
MAY 25TH	RICHMOND-VANCOUVER
JUNE 2ND	WEST KOOTENAY (NELSON)
JUNE 9TH	MID ISLAND (PARKSVILLE)
JUNE 15TH	OKANAGAN (KELOWNA)
JUNE 15TH	FRASER VALLEY (ABBOTSFORD)
JUNE 22ND	SURREY
JUNE 23RD	PRINCE GEORGE
TBC	KAMLOOPS
TBC	VERNON
JUNE 22ND	WILLIAMS LAKE
TBC	TRI-CITIES (COQUITLAM)
SEPTEMBER 7TH	DAWSON CREEK
SEPTEMBER 15TH	VICTORIA
SEPTEMBER 29TH	WHITE HORSE

Wally Buono,
GM and VP of Operations of the BC Lions, and official spokesperson for the BC & Yukon Walks for ALS.

We need your help. Please donate.

Name: _____ Phone Number: _____

Address: _____

Donation Amount: _____ Payment: Cheque MC VISA AMEX

Card Number: _____ Expiry: _____

Security Code: _____ Signature: _____

To make an on-line donation, please visit www.alsbc.ca

CHARITABLE # 106708985 RR0001

WWW.ALSBC.CA WE NEED YOUR HELP.

To learn more about ALS or to make a donation online visit www.alsbc.ca

Phone: 604.278.2257 | Email: info@alsbc.ca

ALS Society of BC: 1233-13351 Commerce Parkway, Richmond B.C. V6V 2X7



Ad paid for by BC Gaming Grant