

You never know what to expect in life.

You never know what to expect in life. Usually that means good things will happen, like meeting my wife Michelle. We met at a Kamloops Dairy Queen as teenagers and married two years later. I stopped in to get a milkshake and met my future wife.

I studied electronics at Cariboo College and that led to a position with BC Tel in 1979. Michelle and I found ourselves starting out in the small town of Dawson Creek. Building the telephone network was satisfying and interesting work. That little farming town really grew on us and that's where we brought our two beautiful daughters into the world. Besides work, I spent my time coaching the girls' sports teams and camping and fishing with the family. But eventually the cold winters made us look for warmer climes and I took a transfer to Nanaimo in 1997. It was here that my two hobbies, fishing and golf, really took off. We especially enjoyed our time boating on the ocean. I continued to coach the girls' softball teams until they both graduated high school.

In early 2005 I noticed I had a nervous muscle twitch in my right bicep. I didn't think much of it, but after some time I went to my family doctor. Not a guy to mince words, he gave me the worst case scenario; "Lou Gehrig's disease". I didn't expect that. I was well aware of the story of Sue Rodrigues and the fear ballooned inside me. Naturally I denied the entire visit, but after a few more months with my biceps thighs and stomach twitching uncontrollably like a total body-itch, I went to a neurologist. But the progression of the disease, at this point, was very slow and the neurologist said I was merely "stressed".

So, with no real answers, I tried to ignore what was happening. I went to the gym and took up yoga with Michelle. I tried to relax and make it go away.

Two years later, in 2007, as I was approaching my 50th birthday, my left foot started to droop. Walking itself became a strenuous effort.



Michelle and Frank Novakowski

The weakness throughout my body was becoming more apparent and I was no longer in full control of my physical actions. I began compensating for my weakness. I gave up cycling and bought a Honda scooter. Walking 18 holes of golf changed to renting a cart. Even mowing the lawn became difficult. What was happening to me? My 50th birthday was approaching, was this getting old felt like? I needed to find real answers and consulted a different neurologist. This time the symptoms had progressed so that a diagnosis of ALS was unofficially made. A few weeks later I was in the GF Strong ALS Centre and the diagnosis was confirmed.

No more hiding, no more excuses. However, it was still several weeks before I could say the words out loud.

The crushing reality of the situation was overwhelming, and we lived in a state of shock for several weeks. Slowly we began to share the news with relatives and friends. We knew that I was weakening and didn't know how much time we had to deal with the practical things that needed attending to. We put our beautiful house up for sale, sold our boats, and prepared to move closer to family in the interior.

The diagnosis of ALS doesn't mean the end of everything, life does go on. A

few months later, we walked our eldest daughter down the aisle at her wedding. And, now walking with two canes, we were determined to take the trip of a lifetime to Egypt.

As difficult as walking was, we walked with a sense of wonder, stepping on the same stones people had walked 5,000 years ago, and this was somehow comforting. I knew my ability to walk would soon end and we enjoyed the trip to the fullest.

Just when you think you can't progress any more I had a shock last year. My weakened chest muscles combined with a severe cold almost asphyxiated me if not for the quick attention of my caregiver and my wife. I was taken to hospital by ambulance. The only solution to sustain my breathing was a tracheostomy, which I chose to do, and I now use a ventilator most of the day. Even though I find myself quadriplegic, I am still able to get out every day including disabled sailing in the summer where I control the boat through a sip and puff system.

We have been fortunate to receive support from our entire family especially our precious girls. The ALS Society and Interior Health have helped us immeasurably, by providing the support we need to live our lives to the fullest. The Disabled Sailing Association here in Kelowna

has given us back the joy of being on the water.

It's been 8 years since this all started and I'm not giving up. I still look forward to years to come, time with my family and being on the water again this summer.

What is ALS?

Amyotrophic lateral sclerosis (ALS), often referred to as "Lou Gehrig's Disease," is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body.

The progressive degeneration of the motor neurons in ALS eventually leads to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, patients in the later stages of the disease may become totally paralyzed.



Join thousands of Canadians from across Canada for fitness, fun and the fight against ALS

For more information:

Register online www.walkforals.ca

or contact the ALS Society of British Columbia & Yukon
1-800-708-3228 | info@alsbc.ca



"ALS is a devastating disease that affects the person living with ALS, their family and caregivers. There is no known cause or cure, yet. Your participation will help us to raise funds to support people living with ALS, and research to find the cure."

- Wally Buono, GM & Vice President of Football Operations BC Lions Football Club, Official Spokesperson for the WALKs for ALS in B.C. & Yukon

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