



AMYOTROPHIC LATERAL SCLEROSIS  
SOCIETY OF BRITISH COLUMBIA

# Living for Today

## With the support of each other

When Jerome attended his first ALS Support Group, he met Ian. They became friends from that point onward. Both men are living with Amyotrophic Lateral Sclerosis, ALS (Lou Gehrig's Disease).

The odds of being diagnosed with ALS are pretty slim, approximately one in a hundred thousand, but the odds of someone else with ALS living less than half a block away - are truly staggering. The two live close to the Davie Village in Vancouver's West End. Here is their story as told by them...



Jerome Best and Ian Quinn

My name is Ian Quinn, I am 44 and single. I walked to work every day for 23 years at St. Paul's Hospital. My work colleagues are extremely supportive, holding fundraisers to help support my homecare and other expenses.

An avid motorcyclist, I did a lot of touring and belonged to a club called the Border Riders Motorcycle Club, who has also been very supportive.

I am truly blessed with the support of friends and family (none of my family live in BC) since my diagnosis in January 2008. With the support of my friends who live in my condominium building, it is possible for me to continue to live independently.

I'm lucky to have Jerome close by, so we can continue to support each other in a way that only two friends with the same rare disease can.

What I would like people to know about ALS is the only real alleviation we have at the moment

is the love and support of family and friends. I feel I would be pushing daisies by now were it not for all the good, positive people in my life. I thank you all.

My name is Jerome Best, I am 54, married, and with the help of my wife Gay, ran a small mechanical contracting firm here in Vancouver. Having ALS these two years has revealed to me what a compassionate society we are, from the embrace of friends and family, to the wonderful support of the ALS Society of BC, to the incredibly skilled visiting health care workers from Coastal Health, to the Team at the ALS Centre at G.F. Strong; all these kind hands helping to make this bearable!

Ian has been an inspiration. Though he is much younger, he is a braver man than I, unwaveringly stoic and always upbeat. Ian wheeled with me down to the seawall on English Bay my first day with a power wheelchair. He showed me the

ropes, making sure my first day was a happy one. I still smile as I recollect us laughing our heads off, drag racing our power wheelchairs along the pathway, pedestrians stepping around us, dogs straining at their leashes, puzzled eyes.

It's a great neighbourhood for anyone facing mobility issues, or in a wheelchair. The people you meet on the street here are genuinely helpful, and in every single store, restaurant, café, bar, bakery and deli, they absolutely bend over backwards to look after you, to make you happy, to keep you safe.

One fine sunny day in August we decided to have lunch at Moxie's on Davie just to celebrate it being such a fine sunny day in August. We arrived a bit before the noon rush and got a nice table right by the window. When the food arrived the health care worker, Ana Lea, put on our bibs. Mine was a bit on the large side, actually it was

a towel. The sight of me girded for dining room action struck Ian as funny, and he burst into laughter, coughing food onto his bib. He managed to do this gracefully, and I burst out laughing, promptly spitting up too.

Through lunch we could barely stop laughing, I doubt either of us held anything down. Ana Lea vaulted between us to keep up. The image of us in our power wheelchairs in that nice dining room with food all over our bibs was so rich in irony that we had only to make eye contact for uncontrollable laughter.

Rene Descartes once said "I think, therefore I am". These few elegant words sum up for me the condition of living with ALS. Yes our bodies become quite weak over time but when it comes to living, and what it really means to be a human being, we are absolutely undiminished.



## 2nd Annual Awards for Excellence in Engineering Design to Improve Quality of Life of People Living with ALS

### 1) The Principal Award (\$5,000)

Project Title: Automated Speech Recognition and Intelligibility Enhancement System for PALS with BiPAP Assisted Breathing

Student: Samuel Chua, MSc Candidate; (Philippe Kruchten, Supervisor)

UBC Electrical & Computer Engineering

This project was selected for the Principal Award because of its obvious potential to significantly improve Quality of Life for ALS Patients. As well, Samuel's personal commitment to the needs of PALS stood out.

### 2) Award of Distinction (\$2,500)

Project Title: Motorized ALS Neck Brace

Students: Anmy Ho (Project Contact), et al; (Michael Van der Loos, Supervisor)

UBC Mechanical Engineering; Emily Carr University of Art and Design

This project is recommended for its group's achievement in support and mobility of the head, incorporating motorized assistance. The UBC Mechanical Engineering Team collaborated with an Emily Carr student on this impressively designed project, which people living with ALS on the Judges Panel actually tried on themselves.

### 3) Innovation Award (\$1,000)

Project Title: Automated Communication Board  
Students: Manijeh Ghafourian & Mazian Tabarestani; (Bruno Jaggi, Supervisor)  
BCIT Biomedical Engineering.

The Automated Communication Board was recommended for the Innovation Award. This is a well thought-out project addressing some significant limitations with existing "Low-tech" communications systems.

### 4) Honourable Mentions

(\$500: Three projects are nominated equally for Honourable Mention awards)

Project Title: Text to Speech Program  
Students: Michael Neufeld, UBC ECE

Project Title: Remote Controlled Retractable Footrest  
Students: Gregory Kryshatopa, Anthony Abila (Cyrus Rafouli, Supervisor)  
BCIT Mechanical Engineering

Project Title: Single Click Communication System  
Students: Jennifer LeRoy, Stephanie Nilsson (Bruno Jaggi, Supervisor)  
BCIT Biomedical Engineering

## What is ALS?

ALS, Amyotrophic Lateral Sclerosis, also known as Lou Gehrig's Disease, is a neurodegenerative disorder that affects the person's motor neurons that carry messages to the muscle resulting in weakness and wasting in arms, legs, mouth, throat and elsewhere; typically the person is immobilized or deceased within two to five years of the initial diagnosis.

ALS demands urgent attention. It's devastation is wreaked on the person diagnosed with ALS, the family, the caregivers and the health care system. When ALS hits a family, the focus turns to provision of care, equipment, and emotional support to the person who will die in horrific circumstances. In the later stages of the disease the person with ALS often cannot speak, swallow or move anything but his/her eyes; however, the mind remains alert.

The ALS Society of BC has helped thousands of patients and their families, by providing direct services including equipment loans, information and support.

### The ALS Society of BC:

- PROVIDES information to build awareness;
- SUPPORTS people affected by ALS to serve immediate needs;
- FUNDS research to provide hope/ to search for a cure

Your help provides hope. Please donate.

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