

# Living for Today

## Clayton's journey with ALS

At 31, Clayton Smailes was living the life of anyone that age would dream of. He was a few years into his chosen career as a TV news cameraman and editor for CFJV-TV in his hometown of Kamloops. Married for five years to wife Colleen, a fifteen month old son Nolan and five months pregnant with second son Justin, Clayton was in the process of purchasing his first family home. Playing hockey in the winter and slow pitch in the summer, volunteering time to 4-H and always making time for a good get together with great friends, Clayton was always busy and enjoying life to the fullest. Always the life of the party with a twinkle of mischief in his eye, Clayton enjoyed each day. Life continued that way until June 2003. Here is Clayton's journey with ALS...



The Smailes Family

### Info on 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



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Peoples Drug Mart is a Cornflower Gold Level Provincial Sponsor for the ALS Society of BC.

## in his own words....

I had an annoying twitch in my left shoulder that would not go away. I saw my family doctor about it and he referred me to a neurologist, who asked a bunch of questions, including was I having any trouble speaking. After being asked I thought "come to think of it, I am having trouble enunciating." I think that he was surprised at that because he referred me to another neurologist who did the tests. It was that day in late August 2003, I learned I had ALS. I went back to work in a daze and said I needed the rest of the day off. I went home to tell my pregnant wife that I had an incurable disease. Who does that at 31? We sold our house we had bought and redone with the help of friends and family, realizing the renovations that would be needed to make day to day living possible as the illness progressed would be too much. We made the decision to build a new home, that would accommodate a large power wheelchair and other equipment I would need. Once again, friends and family came to help.

ALS moved from my left arm and hand into my right arm and hand. Within a year it had travelled to my legs and walking was becoming difficult and after a couple of bad falls and broken bones, the reality of having to use a wheelchair

was here. As if losing the ability to walk was not enough, I was also losing the ability to eat independently, having to be spoon fed and eventually not being able to eat at all due to swallowing complications from the ALS. In addition, my voice became unrecognizable as my own, and eventually disappeared altogether.

However, I am very fortunate to still be able to communicate, which provides me with an increased quality of life and ability to be involved with my sons. Through research of a good friend and the support of the ALS Society of BC, I am able to use an eye gaze computer system to partake in daily conversations and let my needs be known. Without this tool I would be lost. I am even able to control the lighting and the TV with this system, an invaluable small measure of independence.

ALS is an illness that not only changes the life of the patient, but everyone else in your life as well. Not only have I had to completely change my life, but my family and friends have as well. I was an independent person who was more used to helping than needing help. I have to watch my boys grow without being able to teach them how to throw a ball or ride a horse, or even wrap

them in a hug to cuddle. My wife has gone from being an equal partner in a marriage to being a primary caregiver to a shadow of the person she married, a full time mother and continue her career as a teacher as well. My boys have had to watch their dad lose the ability to answer even the simplest questions, and learn patience beyond their ages, waiting for mom's attention while she helps dad.

On the positive side, my having ALS has brought into perspective the value and importance of friends and family. I have been very fortunate to have tremendous support from my family and the most amazing group of friends that a person could ever find. I never have taken any friendship for granted, but I now value them even more. We have learned to appreciate every day and be thankful for all the good things in life. A good friend of mine has often said that he "doesn't see me as someone dying from ALS, but rather as someone who lives with ALS."

I have tremendous support from the community, many people and businesses have donated materials and time to help my family. Some of whom I don't even know. It is an overwhelming feeling to know people are helping to do

the things that I can no longer do.

An example of the level of support I have had can be seen with the ALS walk in Kelowna last year. Coincidentally, the walk fell on my birthday and we intended to celebrate the day with family and a few friends. We ended up having over 100 people making the trip to Kelowna and smashing our intended fund raising goal. My family and I would not have made it this far without the incredible support from the ALS Society of BC - equipment loans being first and foremost and the staff at Interior Health.

ALS is a debilitating disease that without the support of the ALS Society of BC would be impossible for anyone to live with. It is possible, especially with such tremendous support, to beat the odds of ALS. I have been living with ALS for 5 1/2 years, longer than I was told when diagnosed.

Awareness of this disease needs to be promoted and research continued - a cure is there somewhere - it just needs to be found.

thank you!  
have a great day!  
Clayton Smailes



Everyone is welcome. No registration fee. Contact ALS BC for more information at 1-800-708-3228 or [www.walkforals.ca](http://www.walkforals.ca)

Okeover Inlet in Powell River, BC - April 4, 2009  
Coordinator: Frankie Kellner, [afkellner@telus.net](mailto:afkellner@telus.net)  
OVER \$7,200 RAISED

Richmond-Vancouver - June 6, 2009  
Coordinator: Karen DiVenanzo, [Karen.DiVenanzo@sunlife.com](mailto:Karen.DiVenanzo@sunlife.com)

West Kootenays in Nelson, BC - June 7, 2009  
Coordinator: Gord Shannon, [gordshannon@shaw.ca](mailto:gordshannon@shaw.ca)

Mid Island in Parksville, BC - June 7, 2009  
Coordinator: Al Stevenson, [alrstenenson@shaw.ca](mailto:alrstenenson@shaw.ca)

Surrey, BC - June 13, 2009  
Coordinator: Manpreet Dhillon, [mdhillion@exchange.ubc.ca](mailto:mdhillion@exchange.ubc.ca)

Fraser Valley in Abbotsford, BC - June 13, 2009  
Coordinators: Carole Sinclair, [carolesinclair@shaw.ca](mailto:carolesinclair@shaw.ca)  
Leanne McNeil, [ninmcneil@shaw.ca](mailto:ninmcneil@shaw.ca)

Okanagan in Kelowna, BC - June 20, 2009  
Coordinator: Gerry McNeil, [oktyson@shaw.ca](mailto:oktyson@shaw.ca)

Prince George, BC - June 28, 2009  
Coordinator: Helene Rohn, [hrohn@shaw.ca](mailto:hrohn@shaw.ca)

Victoria - September 21st, 2009  
Coordinator: April Reym, [aprilreym@yahoo.ca](mailto:aprilreym@yahoo.ca) • 778-285-5222

Whitehorse, BC - September 27, 2009  
Coordinator: Donald Watt, [whitehorsewalkcoordinator@alsbc.ca](mailto:whitehorsewalkcoordinator@alsbc.ca)  
Phone: 876-332-3669

### 23rd Annual Memorial Golf Tournament

Date: Wednesday June 17, 2009  
Location: Northview Golf & Country Club, Surrey BC  
Proceeds to support the George "Sonny" Williams Endowment to support Caregivers and patient services.

### 1st Annual ALS Tournament of Hope, Kamloops

Date: Thursday, September 17th, 2009  
Location: The Dunes Golf Course, Kamloops BC  
Proceeds to support the development of enhanced communication equipment and patient services.



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For more information on sponsorship or to advertise on this page, contact Wendy Magee, Executive Director, ALS Society of BC at (604) 685-0737 ext 222 or email to [wendy.magee@alsbc.ca](mailto:wendy.magee@alsbc.ca). Donations of cash, real estate or securities are tax receiptable and greatly appreciated.

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