



Since 2001, Joanne Stark's friends and family have helped her raise almost \$80,000 via the annual Walk to End ALS.

B.C. woman has raised almost \$80,000 to support people living with ALS

By Joanne Stark

My name is Joanne Stark and I am 63 years old. I was diagnosed with ALS over 20 years ago in September, 2000. Three years before that, I began experiencing slurred speech, choking, tripping and dropping things.

At the time, I was living and working in the Lower Mainland as a human resource specialist for a high tech company. I relied on words to do my job. Some people thought I had a drinking problem. It was very frustrating and upsetting because we didn't know what was wrong.

I saw multiple neurologists. Eventually, doctors ruled out serious diseases like Multiple Sclerosis. They even ruled out ALS. The doctors advised me to get on with my life; they would continue to monitor me every six months. Then, two days before I was moving to Massachusetts, USA for a job promotion, I received news that drastically changed my plans. My most recent

tests showed that I did have a variant of ALS.

I remember that day vividly, but the following months were a blur. I had a breakdown and stopped work immediately. Friends and family rallied around me to help. Eventually, I realized that I wasn't going to die tomorrow, and I had to get back some sense of normalcy. I joined the ALS Society of BC and started attending Patient Support group meetings, where I made some lifelong friends.

In 2005, when I could no longer live safely on my own, I moved to Parksville into a wheelchair accessible suite that my parents added to the side of their rancher home. The positive in that was more time spent with my immediate family living on Vancouver Island, especially my beloved mother Glenna and late father Joe.

My progression with ALS has been very slow, but is picking up speed. My mobility has declined to the point where I'm confined to a wheelchair or bed. I'm still

strong enough to transfer with help from equipment and some human support, and a few times each week, I walk down the hall in my home using a walker, assisted by a care aide. I wear ankle-foot-calf orthoses all day. The muscles in my face, throat, neck and torso are getting weaker, making breathing shallower, eating more challenging and choking more frequent. I've gone from being articulate to speaking haltingly, breathlessly, slurred... and sometimes, not being able to speak at all. The effort needed to function with a failing body causes much fatigue, made worse by stiffening limbs and muscle spasms.

Although my hands and arms don't work very well, I can still use a computer/iPad to read, communicate and entertain myself. I can still feed myself, drink from a mug (or wine glass), brush my teeth and write a bit. And I can still think, feel, laugh and cry, although my smile is a little crooked.

Many thanks go to the people and organizations that support

me being able to live at home: Island Health Home Support Services, Sue's Seniors Care, ALS Society of BC, ALS Centre @ GF Strong, and friends and family, especially my mother Glenna, who turned 88 this April.

The annual Walk to End ALS raises critical funds for community-based support services and research. Last year, my friends and family raised \$4,000 in my name. Since I started participating in 2001, they've helped me raise almost \$80,000! Much thanks to all who have donated.

ALS is expensive and is not covered by B.C. MSP. The ALS Society of BC provides crucial services to people living with ALS — 60 per cent of all money raised by the Walks to End ALS goes directly back to patients in the form of equipment and support. The Loan Equipment Programme has provided me with many pieces of vital equipment: walker, shower chairs, hospital bed and specialty mattress, safety rails and poles and a power wheelchair.



The 2021 Walk to End ALS
50/50 Raffle
PURCHASE TICKETS: **\$5.00 PER TICKET**
www.walktoendals.ca/BC
FOR MORE INFORMATION:
1-800-708-3228 OR ADMIN@ALSBC.CA
4,000 TICKETS AVAILABLE
CHARITABLE #: 10670 8985 RR001
BC GAMING LICENSE #: 128255
DRAW: JUNE 21, 2021 @ SAN ALS SOCIETY OF BC OFFICE
1228-1331 COMMERCE PARK, RICHMOND, V6V 2X7


Although the end of my ALS journey is looming much nearer than the beginning, I consider myself lucky to have lasted this long with a good quality of life. I decline, then plateau for a couple of years, decline again, and plateau again. Unfortunately, lately the declines have become more frequent, making the plateaus shorter.

ALS is a relentless thief. It can rob you of your mobility, your voice, your breathing, your independence, your dignity and, ultimately, your life. So, let's find a cure for ALS!



Fly Away Raffle
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win:
WestJet Voucher Trip for 2
(valued at \$2,900)
Buy Tickets: ALSBC.CA
Proceeds benefiting ALSBC Equipment Loan Program
Some restrictions may apply.
DRAW: August 13, 2021, 5pm at The Big Horn Golf & Country Club, 1000 Clubhouse Dr, Kamloops, BC V2H 1T9

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