

June is the month to remember those with ALS

By **David Tilson**

Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, is an immensely debilitating disease, which at present, is a terminal diagnosis for those affected by it. It eventually robs those suffering from the disease the ability to speak, walk, eat, swallow, or breathe. This relentless and unbelievably cruel disease is a death sentence, as 80 per cent of those diagnosed with it die within two to five years of being diagnosed, according to ALS Canada. This is not a reason to give up hope for making ALS a treatable disease. We can all do our part during ALS Month to increase awareness, support those suffering with ALS, as well as the outstanding organizations who diligently work towards finding effective treatments.

ALS is the most common cause of neurological death in Canada with approximately 2,500 to 3,000 Canadians over 18 currently living with it, according to ALS Canada. It doesn't discriminate based on age, sex, ethnicity, or socio-economic standing, as it can affect anyone. It's also a disease which has a considerable impact on families since costly equipment and care is needed for ALS patients (with 80 per cent of the burden of care falling on the shoulders of family members), according to ALS Canada. This undoubtedly creates physical, emotional, and financial pressures on caregivers while they try to support their loved ones.

Symptoms of ALS can vary from person to person. In the early stages of the disease, the symptoms can often be overlooked or viewed as typical signs of aging. Some of the potential early signs of ALS include: tripping, dropping things, slurred or thick speech, difficulty swallowing, weight loss, decreased muscle tone, shortness of breath, increased or decreased reflexes, and uncontrollable periods of laughing or crying. Potential early symptoms of ALS include: feeling weak, fatigue, muscle cramping or twitching, and muscle stiffness or rigidity. As the disease progresses over time, the muscle weakening spreads throughout the body leading to difficulty breathing, chewing, swallowing, and speaking. However, the senses of touch, taste, smell, sight, and hearing remain intact and for many suffering from the disease, the muscles of the eyes and bladder continue to work until very late in the disease's progression.

ALS has touched my family. My father was diagnosed with this disease and suffered from it for four years before passing away. I know, firsthand, the tremendous impact it has on both the patient and their family. After going through this experience with my father, I wanted to do my part to help increase awareness of this terrible disease, while also encouraging crucial support for research and resources to help other families affected by ALS. This is why I re-introduced my Private Member's Bill C-205 (An Act to designate the month of June as ALS Month), also known as the ALS Month Act, in the House of Commons on December 10, 2015. If this Bill were to pass, it would officially designate June as National ALS Month.

We can all play a role in increasing awareness of ALS and support the much-needed efforts for resources and research. For example, you can purchase a cornflower in June to support those suffering with ALS. You can also join a "Walk for ALS" event. I'm pleased to be participating in the Orangeville "Walk for ALS" event taking place on Sunday, June 02, 2018. Registration will take place at 8:30 a.m. and the walk will start at 10:00 a.m. at the Island Lake Conservation Area. For more information, please contact Lee Pettit at leepettit1@yahoo.ca or Laurie Laxer at llaxer@als.ca Registration information may be found at <http://walkforals.ca/find-a-walk/ontario/>

I would like to take this opportunity to congratulate ALS Canada and all of the provincial ALS societies who perform the critical role of being the voice of those affected by ALS and their families. Your tireless work to provide support and your dedication to finding effective treatments is greatly appreciated. We also thank you for the important work you do during ALS Month and throughout the year. Your extraordinary efforts inspire all of us to do our part to make ALS a treatable disease and not a terminal diagnosis.

For more information on ALS Canada, please visit www.als.ca