NHCC 2019 Change-Maker Awards to two individuals ensuring voices of people with brain conditions are heard

Toronto, ON, May 12, 2020 – Two individuals determined to make the voices of people living with brain conditions heard by society are the winners of the 2019 NHCC Change-Maker Awards. Honoured are: Shirley Lee of Markham, Ont., who lives with dystonia, and Sprague Plato of Ottawa, Ont., who lives with Parkinson’s disease.

Neurological Health Charities Canada’s (NHCC) Change-Maker Award recognizes individuals who have made a meaningful difference in improving the quality of life for Canadians living with brain conditions. Organizations can also receive the award.

“The 2019 NHCC Change-Maker Awards go to two people who are making a real difference in the lives of Canadians with brain conditions. Thanks to them, others in their communities as well as decision makers know about how brain conditions impact millions of Canadians and what can be done to makes lives better. Shirley and Sprague are inspirations to us all,” said Michelle McDonald, NHCC chair.

NHCC is a coalition of organizations that represent millions of Canadians living with brain diseases, disorders and injuries (brain conditions). These conditions affect mobility and dexterity, while impairing memory and the ability to think. They can make it hard to see, speak and communicate. They can be painful and debilitating. See more information at: www.mybrainmatters.ca or www.moncerveaumovie.ca.

Shirley Lee of Markham, ON – Shirley Lee had to wait 15 frustrating years to get the appropriate diagnosis for her muscles that were out of balance, for her neck that was tilted to one side. It wasn’t until she read a magazine article about dystonia that she realized it was the condition she had experienced since a serious fall at age 15. A neurologist confirmed her suspicions; finally, she was able to get treatments that she needed.

Fortunately for other people living with dystonia, Shirley quickly became involved with the Dystonia Medical Research Foundation of Canada. She joined a Toronto-based support group, and in 2013, became its leader. Her vision to increase meetings and fellowship among people with dystonia helped many feel less socially isolated. Shirley also serves as a contact point for people who are newly diagnosed with dystonia, providing them with a calm knowledgeable voice in all the confusion of learning to live with dystonia.

Since Shirley spent a significant portion of her life without a diagnosis, she has made it her mission to increase awareness about dystonia and lessen stigma among the general public and the medical community. With more awareness, she hopes others won’t have to wait as long as she did to be diagnosed.

She did all this while working in the Ontario public service, often having to educate colleagues about the condition which caused her muscles to be out of balance and her head to turn. She is a proud member of the Ontario Quarter Century Club, recognizing 25 years of public service. Having lived with dystonia for more than 40
years, she is also grateful to her husband Patrick and children Michael and Jessica for their support.

Dystonia is a movement disorder that causes the muscles to contract and spasm involuntarily. The involuntary muscle contractions force the body into repetitive and often twisting movements as well as awkward, irregular postures. There are approximately 13 forms of dystonia, and many other diseases and conditions include dystonia as a major symptom. Primary dystonia affects an estimated 300,000 people in the United States and Canada and many more people have secondary dystonia, as a result of another brain condition.

Shirley was nominated for the award by the Dystonia Medical Research Foundation of Canada: https://dystoniacanada.org/home

“Shirley personifies the spirit of the Change-Maker Award through her positive, hopeful, and optimistic approach to life. Despite living 15 years without a diagnosis and a proper treatment plan, not only has Shirley persevered, but she has thrived. The way she positively leads the Toronto support group has provided hope and a sense of belonging to countless members of the community,” said Archana Castelino, Operations and Programs Manager, DMRF Canada.

**Sprague Plato of Ottawa, ON** – Newly retired as a school principal in 2005, Sprague then had to come to terms with a diagnosis of Parkinson’s disease. Loss of energy and walking issues took him to his family physician and then a neurologist, who made the diagnosis. He turned to a close family friend who also had the disease and although she was president of the local Parkinson Society, he hesitated to become involved – “it seemed so final,” he said.

But when he accidently ended up at the door of the Parkinson Society office on the way to his dentist, he decided it was time to find out what the organization could do for him, and importantly, what he could do for it. Within a year, he was president.

Since then, Sprague has held many volunteer leadership positions. He is currently on the Parkinson Canada Board of Directors. Before that he was chair of the Board of Directors of the Parkinson’s Society of Eastern Ontario. He served as Chair of both the Ontario Advocacy Committee and the Parkinson Canada Government Relations and Advocacy Committee and was a member of the Parkinson Society Canada Research Advisory Committee. He is proud of the role he played in consolidating a number of separate Parkinson societies into Parkinson Canada in 2016.

Another focus is his work as an Ambassador for Parkinson’s both at the federal and Ontario government levels. Through his speeches and presentations, he demonstrates his passion for bringing the voices of people who are living with Parkinson’s disease to politicians. This passion extends to his work with Parkinson Canada as well. He is Chair of the Ontario Provincial Council, which was created to ensure the voices of people with Parkinson’s are heard whenever decisions are made.

“I’m glad I can use the toolkit I had as a principal to be a leader in this other important area,” he said.

Parkinson’s is a neurodegenerative disease. Movement is normally controlled by dopamine, a chemical that carries signals between the nerves in the brain. When cells that normally produce dopamine die, the symptoms of Parkinson’s appear. Symptoms can include tremor, slowness and stiffness, problems with balance and rigidity of the muscles.

Sprague was nominated by Parkinson Canada: https://www.parkinson.ca/

“Sprague exemplifies what it means to be a change-maker. He uses his life experience and skills to improve the lives of people living with Parkinson’s and care partners both locally and nationally,” said Jacquie Micallef, Senior Manager, Public Affairs and Partnerships, Parkinson Canada.
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