



Multiple  
Sclerosis  
Society of  
Canada

Société  
canadienne  
de la sclérose  
en plaques



**Written Submission for the Proposed  
British Columbia Accessibility Act**

**Multiple Sclerosis (MS) Society of Canada**

**BC & Yukon Division**

**November 2019**

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## Introduction

The Multiple Sclerosis Society (MS) of Canada is pleased to provide this submission to the Ministry of Social Development and Poverty Reduction as part of the provincial accessibility consultation process. We applaud the BC government for showing leadership and engaging with British Columbians about accessibility legislation. This leadership, coupled with the multiple vehicles for consultation, is a positive step forward to improving awareness and attitudes about accessibility and disability in the province, and to ensuring that the final legislation be broad-based and comprehensive.

There are considerations in discussing accessibility and determining what the proposed legislation should include. The MS community is particularly qualified to advise in this regard, as many of the issues surrounding the broader themes of accessibility and disability are everyday experiences for people living with MS and their families.

In order to respond to how BC's accessibility legislation can begin to address the everyday challenges faced by the MS community, this submission will use the British Columbia Framework for Accessibility Legislation as an outline for discussion.

## Federal Motion M-192 (Episodic Disabilities) and Complimentary Federal Accessibility Legislation

The British Columbia Framework for Accessibility Legislation document released as part of ongoing consultations notes that various sources guided the creation of the framework document and formed the foundation of accessibility consultations. These sources including the United Nations Convention on the Rights of Persons with Disabilities (UNCRDP), the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), the Accessible Canada Act (Bill C-81), and existing accessibility legislation from other provinces.

However, there exists other policies and legislation outside these sources that would be critical to developing accessibility legislation in BC. One such piece is federal Motion M-192 (Episodic Disabilities). Private members' motion M-192 was tabled to Parliament in June 2018 by MP David Yurdiga (Member of Parliament for Fort McMurray-Cold Lake) and was passed in November 2018 with support from all parties. The motion was developed in order to acknowledge and fill the many gaps in federal legislation that fail to address the needs of Canadians living with *episodic* disabilities (periods of wellness followed by periods of disability). *"In Canada,"* Yurdiga noted, *"support for persons with disabilities is built on a binary switch, either you can work or you cannot. However, life with episodic disabilities is not that black*

### ***Canada has one of the highest rates of MS in the world!***

MS is a chronic, often disabling, disease of the central nervous system. Since that includes the brain, spinal cord and optic nerve, MS can affect vision, memory, balance, and mobility.

Over 77,000 Canadians, including 12,000 British Columbians, live with MS. Approximately 1 in every 385 Canadians live with MS. Women are three times more likely to be diagnosed with MS than men.

MS is the most common neurological disease affecting young adults in Canada. 60% of adults diagnosed with MS are between the ages of 20 and 49 years old. On average, 11 Canadians are diagnosed with MS every day.

*and white. Special requirements must be considered for people with episodic disabilities.*"<sup>1</sup> At the federal level, this means that Canadians are denied much needed supports such as Employment Insurance (EI) Sickness Benefits and Canada Pension Plan- Disability (CPP-D) benefits due to the on-and-off nature of their disease.

The motion resulted in the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities (HUMA) Report "[\*Taking Action: Improving the Lives of Canadians Living with Episodic Disabilities.\*](#)" The report proposed a wide-array of policy changes needed in order to ensure that Canadians living with episodic disabilities are adequately protected. While the report's recommendations were complimentary to the Accessible Canada Act, Bill C-81 was not itself adequate to ensure the protection of Canadians living with episodic disabilities. The report provided a list of recommendations to Parliament framed around developing supports so that people with episodic disabilities can stay in the workplace longer and are able to access much needed supports.

In the context of BC's Accessibility legislation, it will be important to build in and incorporate the groundwork laid by Motion M-192 in order to ensure the adequate protection of British Columbians living with episodic disabilities so that additional legislation to do this is not needed.

## Scope of Legislation and Definition of Disability

BC's accessibility legislation should establish clear, broad, inclusive definitions of "disability" and "barrier." The Accessible Canada act defines disability as:

*a physical, mental, intellectual, learning, communications or sensory impairment – or a functional limitation – whether permanent, temporary, or episodic in nature, that, in interaction with a barrier, hinders a person's full and equal participation in society.*<sup>2</sup>

Notably, this definition is inclusive of Canadians with disabilities that are both visible and invisible, as well as disabilities that are permanent or episodic in nature. Like the Accessible Canada Act, BC's legislation needs to include the notion of the changing dynamic of disability which is the case for individuals living with progressive neurological diseases like MS.

"Accessibility" means "barrier-free." An accessible workplace or goods or services are ones in which people with disabilities can fully participate to the extent of their individual abilities. "Barrier" is defined in the Accessible Canada Act as:

*anything – including anything physical, architectural, technological or attitudinal, anything that is based on information or communications or anything that is the result of a policy or a practice – that hinders the full and equal participation in society of*

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<sup>1</sup> Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities. 2019. "Taking Action: Improving the Lives of Canadians Living with Episodic Disabilities." Available at <https://www.ourcommons.ca/DocumentViewer/en/42-1/HUMA/report-15/>

<sup>2</sup> Employment and Social Development Canada. "Proposed Accessible Canada Act." Accessed November 2019. Available at <https://www.canada.ca/en/employment-social-development/programs/accessible-people-disabilities/act-summary.html>

*persons with a physical, mental, intellectual, learning, communication or sensory impairment or a functional limitation.*<sup>3</sup>

As mentioned previously, there are a number of barriers relevant to British Columbians living with MS which we explore below.

## Barriers and Improving Accessibility Standards

As the Framework for Accessibility Legislation notes, one of the goals of the proposed legislation is to support the development, implementation, and enforcement of accessibility standards in several areas where barriers currently exist.

### Built Environment

MS is a complicated disease that has a major impact on quality of life of all those affected by it. The day-to-day uncertainty that many people with MS experience often causes a significant loss of quality of life. To maintain independence, people affected by MS must be able to participate fully in their communities and have access to public buildings, housing and transportation. Accessibility issues are a significant factor in maintaining and ensuring a positive quality of life for people affected by MS.

The MS Society hosted the *Listening to People Affected by MS* quality of life initiative/survey in 2013 and heard from 6000 Canadians affected by MS. This was followed up in 2018 with the *Listening to People Affected by MS 2.0* survey. In both these surveys, we heard that accessibility to the built environment

“Our environmental scan as part of the Listening to People Affected by MS initiative found that many buildings and spaces are not accessible to people with disabilities. Building codes govern this accessibility through minimum standards that are not highly specific so many issues ‘fall through the cracks’ such as the height of sinks, towel and soap dispensers, and the location of wheelchair accessible doors and ramps which may not be convenient.”

continues to be an urgent priority issue. We heard that accessible buildings, particularly for programs and services such as restaurants, fitness programs, and recreation centres, is another area that presents gaps for Canadians living with MS. This issue was discussed by the focus group participants in *Listening 1.0* who indicated that many of these programs/services are not available to them because the buildings are not fully accessible.<sup>4</sup>

Additionally, these codes only apply to new buildings and larger renovations, leaving many existing structures inaccessible. Considerations such as the use of interlocking brick, uneven walkways, and poorly designed stores create daily challenges for those with restricted mobility.<sup>5</sup>

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<sup>3</sup> Ibid.

<sup>4</sup> MS Society of Canada. 2013. “Listening to People Affected by MS Findings Report: Focus Groups”. Accessed November 2019. Available at <https://mslistening.ca/pdf/Focus-Group-Findings-Report.pdf>

<sup>5</sup> Ibid.

All these issues have a significant impact on a person's daily life, their ability to get around and stay active in their community; ultimately, having a negative impact on their quality of life. As one participant stated *"These architects do not really know what accessible means. It is about more than the size of the stall in the bathroom."*<sup>6</sup>

One concern in BC is that accessibility standards will be 'downloaded' to municipalities who may not have the expertise to inform those standards, or who may not have made the proper consultations when making those decisions. One recent example of this is the province's decision last year to shift accessible parking requirements for residential and commercial buildings to local governments in an attempt to improve accessibility to those areas. However, both disability advocates<sup>7</sup> and municipal officials<sup>8</sup> have since raised their concerns that municipalities were both unprepared and ill-equipped to formulate those standards on their own. The province should play a role in setting standards and leading municipalities in accessibility, rather than merely passing that responsibility on.

## Service Delivery

The unpredictable effects of MS are physical, emotional, and financial and last for a lifetime. MS impacts all British Columbians - not only the affected individuals, but also their families who come together to manage the realities of MS. These realities make accessing services and supports particularly challenging throughout one's life. We heard during the *Listening 1.0 survey*, that when it comes to quality of life, accessing doctors, specialists, tests, treatment and services in a timely and convenient manner is difficult for many.<sup>9</sup> This was echoed in *Listening 2.0*, as the most important factor affecting quality of life for British Columbians with MS in their day-to-day lives continues to be access to comprehensive and effective treatments and care.<sup>10</sup>

Finding information about programs and services is also consistently problematic. We also heard that people with MS want to live at home and not be a burden on family and friends. They want to be active participants in their communities. However, we heard that accessing services to maintain this independence can be difficult. There were many barriers. Home care services and assistance with personal care vary significantly by region, have long wait times, and often limited access. There are few age-appropriate long-term care facilities for people with MS and life is very difficult for those living in facilities that do not provide the mental, recreational and social stimulation required to maintain good physical, mental, emotional and social health.<sup>1</sup> In *Listening 2.0*, over half (58%) of survey respondents currently in long-term care say that they live in a facility with people that are not close in age to them.<sup>11</sup>

Quality healthcare in the community for people with complex disabling chronic disease such as progressive MS is woefully inadequate. The current system offers community-based care to those who

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<sup>6</sup> Ibid, page 9

<sup>7</sup> Boynton, Sean, Hasegawa, Regan, and Nadia Stewart. 2018. "B.C government shifting accessible parking requirements to local governments." *Global News*. Available at <https://globalnews.ca/news/4692689/b-c-accessible-parking-local-government/>

<sup>8</sup> Bartlett, Keili. 2018. "Accessible parking not optional, councillor says after province removes regulations." *Victoria News*. Available at <https://www.vicnews.com/news/accessible-parking-not-optional-councillor-says-after-province-removes-regulations/>

<sup>9</sup> MS Society of Canada. 2013. "Listening to People Affected by MS." Accessed November 2019. Available at <http://mslistening.ca/>

<sup>10</sup> MS Society of Canada. 2018. "Listening to People Affected by MS Initiative 2.0." Page 57.

<sup>11</sup> Listening 2.0, page 232

The MS Society BC and Yukon Division's Equipment Provision Program (EPP) aims to provide equipment or financial assistance for people living with MS who have limited financial resources and no other agency or source available to them which could provide assistance. The program does this through acquiring new pieces of equipment or paying for repairs on current equipment (based on financial need). In 2018, EPP helped 246 individuals obtain the equipment they needed.

Equipment provisions covered by the program include mobility aids (manual wheelchairs, walkers, scooters etc.) personal care (bath lifts, safety rails etc.) and home care (hospital beds, air conditioners etc.).

Individuals who apply to EPP struggle to obtain the supports and equipment they need, even if they are receiving public or private financial support. In the MS Society's Listening to People Affected by MS 2.0 survey, British Columbians identified mobility as a top issue of concern. Only 29% of British Columbians living with MS felt that they had access to equipment and technology that they could afford to help them maintain their independence.

are terminally ill in the form of palliative care but leaves people with diseases like MS struggling to get support.

In addition to quality care, access to treatments remains a high priority. It is important to ensure that British Columbians living with MS have access to all currently approved disease-modifying therapies (DMTs) approved for multiple sclerosis (MS) as they appear to work by blunting the destructive autoimmune response that targets tissues in the central nervous system (CNS). For many individuals living with MS, DMTs offer measurable therapeutic benefits by suppressing MS relapses and, in some cases, *delaying the accumulation of disability*. Access to these medications is key to maintaining quality of life including employment and income. Despite this, in Listening 2.0, only half (54%) of British Columbians with MS felt that they had access to DMTs or medicine to manage their symptoms.<sup>12</sup> It was also concerning when Ocrelizumab (Ocrevus®) a highly effective, safe treatment for MS patients approved by Health Canada was recently listed for intended coverage by every other province *except* British Columbia.<sup>13</sup> Ocrevus is indicated for treatment of adult patients with Relapsing Remitting MS (RRMS).<sup>14</sup> Perhaps more significantly, it is the first, and only, DMT for Primary Progressive

MS (PPMS) in Canada and provides hope for those living with this debilitating form of MS<sup>15</sup>, with some calling it a game changer.

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<sup>12</sup> Ibid, page 90

<sup>13</sup> Provinces that have already added Ocrevus to their formularies include Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, and Newfoundland & Labrador.

<sup>14</sup> Among the approximately 77,000 Canadians living with MS, RRMS is the most common form and is characterized by unpredictable but clearly defined relapses (also known as attacks, exacerbations or flare-ups) during which new symptoms appear or existing ones get worse.

<sup>15</sup> PPMS characterized by a slow accumulation of disability, without defined relapses. It may stabilize for periods of time, and even offer minor temporary improvement but overall, there are no periods of remission.

## Employment

The published 2018 report, *MS in the Workplace* by the Conference Board of Canada, states:

*The unpredictability and episodic nature of MS make it particularly challenging in the workplace. As symptom types and severity vary greatly, individuals with MS can find it difficult to manage their treatments, let alone maintain a daily routine and meet work commitments within the traditional employment space.*<sup>16</sup>

This aligns with the MS Society's findings from the Listening to People Affected by MS Initiative, where we heard from thousands of Canadians affected by MS about factors that impact their quality of life which included employment.

A review of literature published between 2002- 2011 estimated that the average unemployment rate for individuals with MS is almost 60 per cent.<sup>17</sup> Data from the US indicate that people with MS experience some of the highest unemployment rates among groups of individuals with severe and chronic disabilities and have disproportionately high unemployment rates given their educational and vocational histories.<sup>18</sup> Yet people with MS want to work and struggle to continue to work.

The Institute for Research on Public Policy (IRPP) report "*Leaving Some Behind: What Happens When Workers Get Sick*," cited as the Mowat Centre's top public policy paper in 2015, asks how Canada is doing in supporting Canadians who experience a major health issue with their employment and income needs. It points to the "*need for a comprehensive re-examination of how Canadians are able to balance*

There are solutions to remove barriers and improve accessibility for employment and income support programs which need to be a part of the legislation to ensure changes ensue. The PWD payment is an important financial support for people living with disabilities who are unable to work or who are burdened with treatment or equipment costs – with over 100,000 British Columbians relying on the payment for their living essentials.

However, it is important to note that a single person living on the current PWD payment rate still falls below the official poverty line, which was recently defined in BC's Poverty Reduction Strategy (\$18,585 per year for a population center less than 30,000, \$19,976 per year for the city of Vancouver) (Market Basket Measure, StatsCan 2015). In our *Listening 2.0* survey, only 29% of British Columbians with MS felt that their disability benefits (public or private) allowed them to maintain a good standard of living

The strategy highlighted the increased financial pressures faced by British Columbians, including high housing prices, and increased basic utility, childcare and food costs – in 2017, British Columbians spent more on essentials than any other province except Alberta<sup>1</sup>. Yet despite these rising costs the PWD payment remains unindexed to inflation.

In line with the summary of ideas shared from BC's Disability Consultation Report<sup>1</sup> and in order to keep up with costs of living and ensure disability assistance rates do not erode their value over time, the province should take immediate actions to raise the rate of the

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<sup>16</sup> Thy, Dinh, Philip Astles, and Karen Turpin. 2016. "Multiple Sclerosis in the Workplace: Supporting Successful Employment Experiences." *The Conference Board of Canada*. Available at [https://www.conferenceboard.ca/temp/889edbb2-7c33-4788-9142-f6d39cdec36/7921\\_MS-in-the-Workplace\\_RPT-EN\\_Accessible.pdf](https://www.conferenceboard.ca/temp/889edbb2-7c33-4788-9142-f6d39cdec36/7921_MS-in-the-Workplace_RPT-EN_Accessible.pdf)

<sup>17</sup> Ibid.

<sup>18</sup> Sweetland, J., Howse, E., & Playford E. "A systematic review of research undertaken in vocational rehabilitation for people with multiple sclerosis," in *Disability & Rehabilitation*, 2012; 34(24): 2031-2038.

*work and income during periods of receiving or giving care.”* The report notes that each year, six per cent of the Canadian workforce adjust its work status for some length of time in order to deal with a health condition.<sup>19</sup>

While we applaud organizations like the Presidents Group, a network of 25 change-driven BC business leaders, whose stated goal is to make BC the province with the highest employment for people with disabilities by 2030<sup>20</sup>, the current reality remains problematic. In terms of support that is provided by employers, in *Listening 2.0*, only 14% of British Columbians with MS said that their workplaces makes changes so that they can work despite their MS,<sup>21</sup> while only 12% of caregivers in BC said that their employer gives them time off as needed so that they can take care of the person with MS in their life.<sup>22</sup>

In general, people with disabilities face barriers in the employment context. Research conducted by the Conference Board of Canada identifies Canadians with disabilities as an under-represented group in the Canadian labour force.<sup>23</sup> There are, however, substantial numbers of Canadians with disabilities that are willing and able to work. If not full-time, then at least on an intermittent basis.

The HUMA report on Motion M-192 notes that of the 3.7 million individuals between the ages of 25 and 64 that reported having a disability in 2017, 1.6 million stated that their disability was either periodic or fluctuating (i.e. episodic).<sup>24</sup> This represents almost half of working age Canadians living with a disability. Often policies and programs targeted at income or employment support focus narrowly on “disability,” assuming a health condition that is either continuous or progresses linearly through time.<sup>25</sup>

People with MS who can not work have trouble getting by on the limited financial assistance offered under current government programs. Many British Columbians with MS cannot qualify for disability-related public or private insurance programs because eligibility is obtained through employment or is a workplace benefit, and many people impacted by MS in the prime of their lives are no longer able to maintain employment.

## Information and Communication

As the HUMA report on Motion M-192 notes:

*many employment-related and income-support programs and services fall within provincial and territorial jurisdiction, ...[and] people with episodic disabilities often face*

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<sup>19</sup> Meredith, Tyler and Colin China. 2015. “Leaving Some Behind: What Happens When Workers Get Sick.” *Institute for Research on Public Policy*. Accessed November 2019. Available at <https://irpp.org/research-studies/leaving-some-behind-what-happens-when-workers-get-sick/>

<sup>20</sup> Presidents Group. Accessed November 2019. Available at <http://accessibleemployers.ca/>

<sup>21</sup> *Listening 2.0*, page 91

<sup>22</sup> *Listening 2.0*, page 119

<sup>23</sup> Brisbois, Richard. 2014. “Business Benefits of Accessible Workplaces.” *The Conference Board of Canada*. Available at [https://www.conferenceboard.ca/temp/ee3b9f92-fd89-436f-b805-1bc131659140/6264\\_AccessibleWorkplaces\\_BR\\_AV.pdf](https://www.conferenceboard.ca/temp/ee3b9f92-fd89-436f-b805-1bc131659140/6264_AccessibleWorkplaces_BR_AV.pdf)

<sup>24</sup> HUMA Motion M-192 report

<sup>25</sup> Furrie, Adele. D. 2010. “Towards a better understanding of the dynamics of disability and its impact on employment.” *Adele Furrie Consulting Inc.* Available at [http://www.adelefurrie.ca/PDF/Dynamics\\_of\\_disability.pdf](http://www.adelefurrie.ca/PDF/Dynamics_of_disability.pdf)



*an 'arduous' task to determine what is available and how to access these programs and services.<sup>26</sup>*

Here in BC, the MS Society's Volunteer Legal Advocacy Program (VLAP) assists people affected by MS to address legal and advocacy challenges as it relates income/employment supports that they are qualified for but unable to access or navigate. This includes: Canada Pension Plan Disability Benefit (CPP-D), the Disability Tax Credit (DTC), long term disability (LTD), and the provincial Persons with Disability (PWD) payment. This program does this through the help of lay volunteers and lawyers who provide pro-bono advice or representation.

It is common for our VLAP volunteers to hear of clients who struggle to understand the supports they are entitled to and need. Their clients include people living with MS, who, as a result of their episodic disability, are denied income/employment supports including the provincial PWD payment due to misunderstood eligibility criteria. In 2017, our program helped clients with their CPP-D applications and achieved an overall approval rating of 92% - this compared to the national approval rate which was 43% in 2015. Our VLAP program also assists with application appeals and had an 85% appeal success rate for CPP-D applications and 88% appeal success rate with PWD applications, indicating that client's applications are in many cases wrongly denied.

The difficulty encountered by clients in navigating individual programs is further complicated by the fact that clients are often confronted by barriers across the range of available supports simultaneously. This means that while a our VLAP volunteers and staff are assisting a client with accessing PWD, they are also working on a human rights or access to housing issue for that individual.

The MS Society's VLAP program is one of many run by non-profits aimed at assisting people with disabilities navigate programs that they are entitled to. Despite this, there remains a significant portion of British Columbians who are unaware or programs that can support them or are unable to navigate them. In *Listening 2.0*, British Columbians with MS identified an inability to access financial supports from government as one of their top four concerns.<sup>27</sup> One way to address this issue would be for the province to establish a provincial Disability Advocate as other provinces have already done. Much like BC's Seniors Advocate, the Disability Advocate would monitor and analyze disability services and issues in BC and provide regular reports and recommendations to the government on accessibility issues. More importantly, the advocate would be a one-stop shop for people with disabilities across the spectrum to access information and assistance as it relates to disability support programs.

## **Transportation**

Based on the results of our surveys, we heard that finding transportation services to allow people to function independently and participate in their communities is a challenge for some British Columbians. Access to transportation and mobility issues were a top concern from British Columbians living with MS.<sup>28</sup> There are many gaps in daily transportation services in cities and regions across the country. Although the nationally-regulated systems such as air and train travel are usually manageable, daily travel on provincially and municipally-run transit systems can be very challenging in and between many cities across the province. In many cities across BC these systems are fraught with issues such as

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<sup>26</sup> HUMA Motion M-192 report.

<sup>27</sup> *Listening 2.0*. page 64

<sup>28</sup> *Ibid*. page 64

inaccessibility for those with mobility restrictions. For example, for people living with MS, who often have to travel large distances at their own expense in order to see their MS neurologist, few if any of the hotel shuttle services at airports are wheelchair accessible. This leads to the person with MS having to pay to get to their hotel, whereas a person without a disability would not have to.

For services such as HandyDART, inconvenient booking requirements (i.e. having to book days or weeks in advance), limited service availability, constant delays in service provision, and limited hours of operation are also problematic. For those in rural areas accessible transportation is non-existent. This lack of day-to-day transportation has a significant impact on people's abilities to attend medical appointments, maintain employment, volunteer and participate socially in their communities, thus directly affecting their quality of life.<sup>29</sup>

## Looking Beyond Legislation – Seeking Cultural Change

Improving accessibility through policy changes is one step towards creating a cultural change towards people living with disabilities and truly creating a barrier-free province. Within government, improving accessibility and recognizing the unique needs of people with disabilities are not the responsibility of any one ministry, but rather requires a wholistic approach. Many of the recommendations in this submission address various aspects of lived experiences, and not only speak to the experiences of people living with MS but resonates with the wider community of people with disabilities.

We look forward to seeing the creation of this comprehensive and broad-based legislation which includes the proposals contained within this submission. This legislation along with effective implementation and enforcement will improve awareness and attitudes about accessibility and disability in British Columbia, and be inclusive of all people with disabilities including episodic which is key for people affected by MS.

## About the MS Society of Canada

The MS Society provides information, support and advocacy to people affected by MS, and funds research to find the cause and cure for the disease, bringing us closer to a world free of MS. We have a membership of 7,000 and are the only national voluntary organization in Canada that supports both MS research and services. The MS Society BC & Yukon Division continues to advocate for improved disability benefits and other income/employment supports, increased access to approved MS therapies, the creation of BC Disability legislation, and improved home and community care in order to empower British Columbians living with MS.

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<sup>29</sup> Listening 1.0