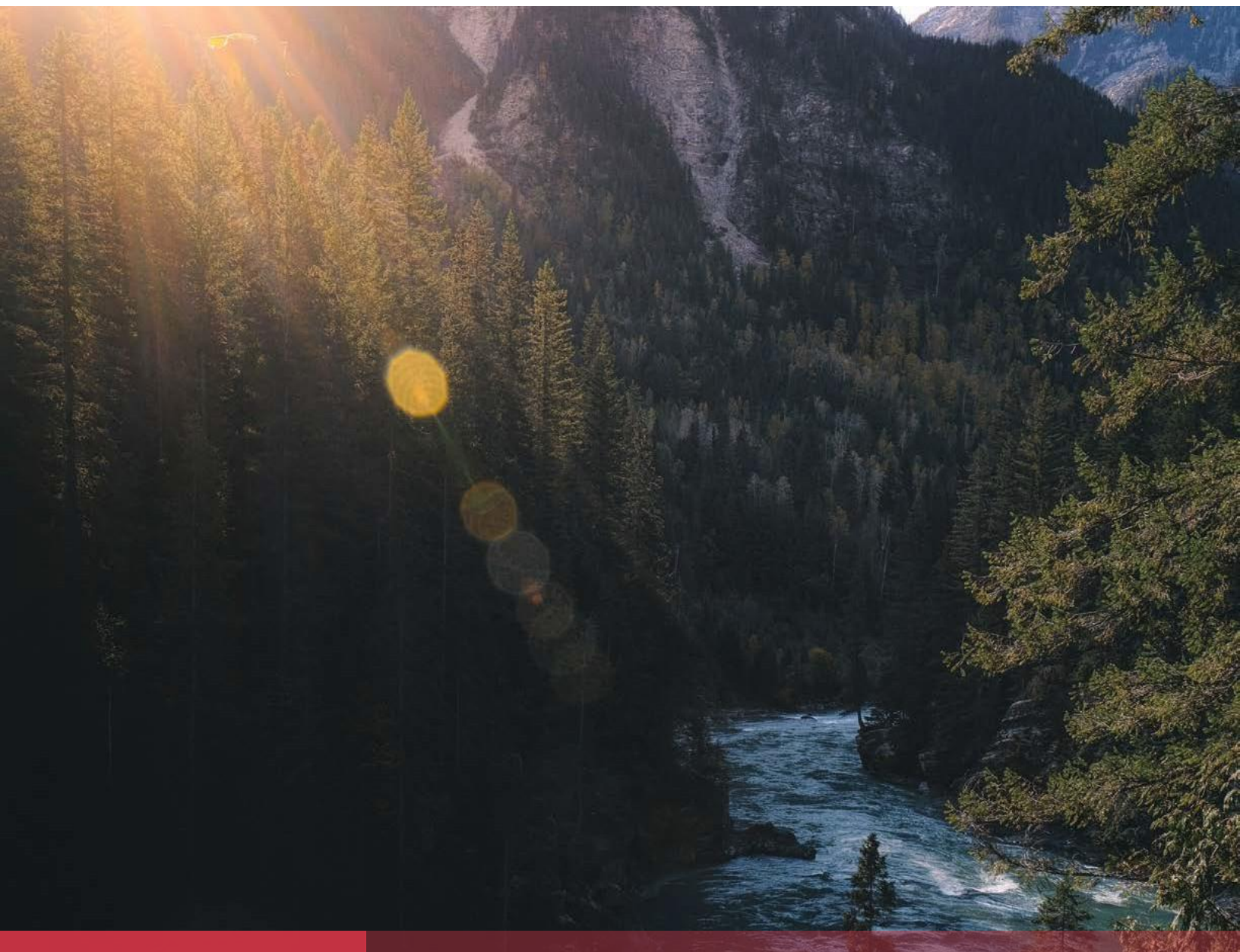


BRITISH COLUMBIA ROUNDTABLE REPORT

| Parkinson Canada



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ROUNDTABLE SERIES SUMMARY

The 2021 Parkinson Canada Roundtable Series consisted of eight regional roundtables, followed by a national session, over the course of three months. This effort brought together more than 150 voices from the Canadian Parkinson's community to gather understanding, insight, and clarity to support Parkinson Canada's advocacy efforts.

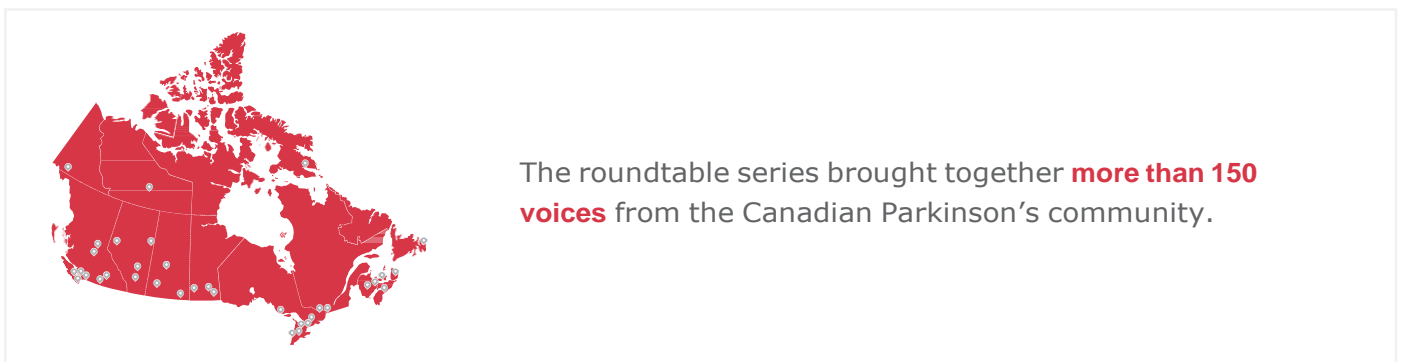
The purpose of the roundtables was to listen to the realities and unmet needs of the Parkinson's community and capture the key issues surrounding Parkinson's healthcare from provincial, territorial, and national perspectives. To support validation of the findings, Parkinson Canada strove for diverse participant representation. People living with Parkinson's, care partners, healthcare professionals, and regional Parkinson's organizations were all invited to participate in the roundtables.

Each roundtable was approximately three hours long and included, speakers, large group discussions, and smaller breakout conversations. Moderators facilitated the conversation and note-takers were present to accurately capture input and insights from the participants. For the purposes of privacy and encouraging an open dialogue, these roundtable sessions were not recorded, and quotations used within this document are anonymously attributed.

This regional report has been created to summarize the unique realities faced by members of the Parkinson's community in British Columbia. Following the in-depth discussions from the National Roundtable and building off the eight regional roundtables, Parkinson Canada has identified key priorities for the Parkinson's community to consider to better improve the overall health and quality of life for those living with Parkinson's in Canada.

- Identify and address gaps for additional training and knowledge transfer to qualified healthcare professionals about Parkinson's, which will allow for earlier diagnosis and treatment of Parkinson's.
- Examine the systemic issues and barriers throughout the healthcare system to determine what steps can be taken to increase the number of healthcare practitioners available to support people with Parkinson's.
- Advance equitable access to care and improved treatments for all Canadians living with Parkinson's.

These priorities will provide a roadmap to the organization in developing our future advocacy work in supporting Canadians affected by Parkinson's.



INTRODUCTION

UNDERSTANDING PARKINSON'S

Parkinson's is a chronic, progressive neurodegenerative disease caused by a loss of dopamine-producing neurons in areas of the brain associated with movement. Individuals with Parkinson's may experience a resting tremor, slowness of movement, muscle rigidity, and balance problems. While Parkinson's is typically thought of as a movement disorder, non-motor symptoms such as anxiety and depression, sleep issues, difficulty swallowing, and cognitive impairment, including dementia, can also occur. The average age of diagnosis for Parkinson's is 60 years old, but some people are diagnosed prior to 60 and referred to as having early onset Parkinson's.

Currently, there is no cure for Parkinson's or treatments that can stop or slow the progression of the disease. There are only therapies to help manage the symptoms. Most Parkinson's medications work to maintain levels of dopamine in the brain, a neurotransmitter that supports the execution of movement as well as other functions controlled by the brain. The gold standard medication for Parkinson's, Levodopa, helps to make up for the dopamine lost due to brain cell degeneration. Levodopa was developed in the 1960s. Surgical procedures like deep brain stimulation (DBS) and the insertion of a Duodopa® pump can also be options for people living with Parkinson's.

In addition, the following therapies can help manage Parkinson's symptoms, physical therapy and exercise for mobility, flexibility, and balance; occupational therapy for daily activities; speech therapy to help with voice and swallowing; and mental health services for depression and anxiety.

Every Parkinson's experience is unique, with symptoms and progression varying from person to person. Living with Parkinson's requires a holistic approach to care, which includes all aspects of an individual's life.

KEY PARKINSON'S TERMINOLOGY

Movement Disorder Specialist (MDS): A neurologist who has completed additional fellowship training in the area of movement disorders.

Wait time: Time an individual must wait to see a healthcare professional.

Care partner: Another term for caregiver.

Multidisciplinary care: This term can have wide-reaching definitions but for the purposes of this report, it refers to accessing a diverse range of healthcare professionals as part of the management of Parkinson's. Multidisciplinary care models can also involve components such as care coordination, education, and self-management support.

Integrated care: A healthcare model where healthcare professionals from different specialities communicate

and interact in the joint management of care. There can be many different degrees of integration from simply exchanging notes to more in-depth collaboration.

Deep Brain Stimulation (DBS): A neurosurgical procedure where electrodes are implanted deep into the brain and electrical stimulation is delivered through a pacemaker-like device. This electrical stimulation impacts dysfunctioning brain circuits and helps in the management of Parkinson's symptoms.ⁱ

Duodopa®: A gel mixture of levodopa-carbidopa (Parkinson's medications) administered continuously through a pump into the small intestine. It allows a constant and more consistent amount of levodopa to be present in the body.ⁱⁱ

AN OVERVIEW OF PARKINSON'S IN CANADA

Parkinson's is one of the fastest-growing neurological diseases in the world and Canada has one of the highest prevalence rates compared to other countries.ⁱⁱⁱ

It is estimated there are more than 100,000 people in Canada living with Parkinson's in 2021.^{iv,v} That number will grow by about 30 people tomorrow and the day after that until we reach 50 new diagnoses per day within 10 years.^{iv, v}

One in five people living in Canada with Parkinson's wait a year or more to receive a formal diagnosis after reporting their symptoms to a medical professional.^{vi} Prolonged wait times to receive diagnosis have serious implications for an individual's quality of life and increase the likelihood for both physical and mental health deterioration.

In 2018, the national wait time average to see a Parkinson's specialist, also known as a Movement Disorder Specialist (MDS), was 11 months with some regions reporting wait times of more than two years.^{vii} It is estimated that there is only one MDS for every 1,400 people living with Parkinson's in the country and most of these specialists are in major urban centres within the provinces, posing a geographical barrier for rural Canadians with Parkinson's.^{viii}

Currently, there are no MDSs in Prince Edward Island or in any of the territories. Furthermore, there are also no general neurologists in the territories. People living with Parkinson's in these regions must see travelling neurologists who visit intermittently, or they must attend appointments with clinicians in other provinces.

According to a 2018 IPSOS poll conducted by Parkinson Canada, many Canadians living with Parkinson's pay a portion of healthcare expenses out-of-pocket.^{vi} This includes critical healthcare services like medications and physiotherapy. Furthermore, nearly 75 per cent of survey respondents report paying a portion of exercise class expenses out-of-pocket.^{vi}

AN OVERVIEW OF PARKINSON'S IN BRITISH COLUMBIA

There are over 15,000 people living with Parkinson's in British Columbia. Nearly 25 per cent of people with Parkinson's in the province waited one year or more to receive a formal diagnosis after first reporting their symptoms. The provincial average wait time to meet with a Parkinson's specialist is six months to one year.

British Columbia has seven Parkinson's specialists – six are in the Greater Vancouver Area and only one is on Victoria Island. It is estimated that there is one Parkinson's specialist for every 2,206 people living with Parkinson's in British Columbia, which is one of the poorest ratios in comparison with other provinces that have specialists.

Compared to other provinces, many medications require special authorization for coverage by the provincial formulary, resulting in access barriers.

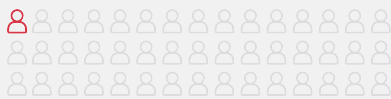
When surveyed, 65 per cent of people with Parkinson's in British Columbia had to pay out of pocket for a portion of their medications. Furthermore, 72 per cent had to pay some portion out of pocket for physiotherapy and 88 per cent for exercise classes - both forms of physical activity that are critical to Parkinson's care.



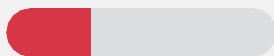
There are over **15,000** people live with Parkinson's in British Columbia.



The provincial average wait time to meet with a Parkinson's specialist is **six months to one year**.



There is **one** Parkinson's specialist for every **2,206** people with Parkinson's in the province.



Nearly **25%** of people with Parkinson's in B.C. waited **one year or more** to receive a formal diagnosis.



65% of people with Parkinson's pay out of pocket for a portion of their medications.

ROUNDTABLE DISCUSSION THEMES

Three major themes were focused on during the roundtables. Summarized under each theme are the commonly held perspectives of the participants.

DIAGNOSIS WAIT TIMES

When participants of the British Columbia Roundtable were polled, 100 per cent felt that diagnosis wait times are a challenge in the province.

The consensus amongst the group was that further education of Parkinson's for both family physicians and general neurologists is essential to receiving an earlier diagnosis of the disease. Many in the group shared their personal stories on the length of time they had to wait for their general physician to be able to get them an appointment with a neurologist, and even greater wait times were reported for getting in to meet with an MDS.

“Getting a diagnosis sooner rather than later is key. I became a non-functioning person for 18 months. Disconnection between my brain and my hands. I cannot imagine if I had to wait two more years. There are people in our support group who have not received a formal diagnosis and they are waiting, and I understand their frustration.”

- Person living with Parkinson's, Vancouver, B.C.

Geographic location was then raised by several members of the group. With many people living in the remote northern island region of B.C., it can be time consuming and expensive for those residents who live with Parkinson's to have to travel down to see an MDS or neurologist on the lower mainland of the province.

The entire province of B.C. has only seven MDSs available to meet with Parkinson's patients and they are spread out at four movement disorders clinics that are all located within the populous urban centres in the province.

“The key is we need to get people living with Parkinson's who are newly diagnosed in to see an MDS sooner, not just a general neurologist. It is important that we have enough MDSs available to see people.”

- Care partner, Vancouver, B.C.

One member of the group who is living with Parkinson's shared that there are no MDSs who reside within the northern islands and his Parkinson's specialist will travel for two weeks a year to that part of B.C. to have in-person appointments with patients. Given the limited amount of time that his doctor will be in the region, there are very few patients that he has time to meet with for in-person consultations.

"I'm a year and half into a four-year wait for DBS surgery."

- Person living with Parkinson's, Victoria, B.C.

In addition to long wait times for diagnosis, members in the group also discussed the lengthy wait times for Parkinson's patients to get in for Deep Brain Stimulation (DBS) surgery. DBS is proven to be a successful form of surgery for treating symptoms of Parkinson's. The unfortunate reality is that many must wait three to four years (at times even longer) before being able to receive the procedure within the province.

ACCESS TO CARE

The next topic of discussion was access to care. Several members of the group began discussing the importance of exercise to help manage their Parkinson's symptoms. Organizations such as the Parkinson Society of British Columbia offer complementary exercise classes for people living with Parkinson's and there were multiple members in the group who discussed the benefits that they feel that exercise has had on both their physical and mental health in managing their Parkinson's symptoms.

"I work out a couple of days a week with a group of people who have Parkinson's. It is the most helpful thing for my disease, and it provides me with a sense of community."

- Person living with Parkinson's, Vancouver, B.C.

Physiotherapy was another crucial allied healthcare service that was discussed by members of the group. Several members in the group shared how they meet consistently with a physiotherapist who will assess their mobility and provide exercises that help with stretching out muscles and improve range of motion. It was then mentioned how important it is to begin seeing a physiotherapist initially after diagnosis to begin strengthening muscles and keep in shape.

One major barrier for people living in remote parts of the province who have Parkinson's is the out-of-pocket travel expenses to urban centres for their medical appointments. Whether by plane or by ferry, the cost of transportation and accommodation to the nearest major city becomes quite expensive. For those who must travel from remote northern parts of B.C. and do not have any form of insurance coverage or work benefits, this can be financially unattainable.

“It is expensive to travel. And now in the pandemic, airlines have been cancelling flights. People cannot get down to Vancouver for their surgeries. I must get a surgical procedure and it will cost me \$1,000. It is fine for a surgical procedure, but when it is just for a 15-minute appointment it is not worth it.”

- Person living with Parkinson’s, Quensel, B.C.

A couple of members in the group then discussed how the province does offer some medical travel benefits, depending on how far north you live. In addition, care partners can also have their travel costs covered by the benefits program, so that the person living with Parkinson’s does not have to travel alone. Unfortunately, this travel subsidy program is not offered to residents of midland B.C. or for those who live close to major cities. To qualify for this coverage, an individual must live at least 100 kilometers from the nearest medical facility where their appointment is scheduled.

It was then mentioned how important it is to have care partner support when it comes to managing Parkinson’s symptoms and attending various appointments. A member in the group living with Parkinson’s shared how when he initially was diagnosed, he would attend appointments with doctors and healthcare providers alone, but it was not until after his spouse started to go with him that he felt much more supported and helped lower his anxiety.

The conversation then shifted towards virtual healthcare. Several members of the group agreed that since the beginning of the COVID-19 pandemic, virtual medical appointments have been incredibly convenient and have spared people a lot of time and financial costs with not having to travel. Particularly for those living in more remote parts of the province.

“For things such as asking about their medication, a phone call works fine, and it streamlines things a bit. However, a person who has not been in a year and they have a problem with their walking, but they cannot articulate it - I need to see them in person.”

- Movement disorders specialist, Vancouver, B.C.

On the other end of the spectrum, a movement disorders specialist who attended the roundtable felt that virtual care and telemedicine can be challenging for him to accurately assess his patients. He then elaborated on how some of his patients will not log on for their ZOOM appointments on time, or have trouble accessing the meeting, or they do not know how to properly work their computer’s camera if they are not savvy with technology. As an MDS, he stressed how important it is to be able to see a patient in person, so that he can see how their mobility and range of motion are doing.

He then shared his opinion that Manitoba has a great model for telehealth that has a dedicated technician who runs all the audio and video for patients who use the service. This is a service that is available in the province’s hospitals and other medical clinics.

MODEL OF CARE

The final topic of the roundtable was on a model of care for Parkinson's. One member in the group shared her belief that it is crucial to receive support right from the moment you are diagnosed. There are so many resources online to read that she felt initially overwhelmed and would have found it beneficial to have a care coordinator or nurse to sit down and provide the most valuable information and resources, such as local support groups.

“The more information given to each healthcare practitioner, the better. Having them all be aware and working together. Even if it is just cc'ing each other on emails. It would give them an idea of what I am working on and keep an ongoing record of my health.”

- Person living with Parkinson's, Vancouver, B.C.

This sentiment was then echoed by another member in the group with Parkinson's. He shared that when he was first diagnosed, he was given a prescription by his general practitioner for the drug Levodopa. After receiving the prescription, he was then sent off on his own without any further guidance from the doctor or provided with a list of resources to review about the disease.

It was suggested that an organization, such as Parkinson Canada, could potentially develop a “diagnosis kit” that would be offered at medical clinics and contain accurate information about Parkinson's and other important resources for a newly diagnosed individual. This would help people avoid referencing misinformation about the disease that is found on the internet.

It was then mentioned how there are many Facebook groups that exist for Parkinson's support, since there is a lack of information that is provided to patients upon receiving their diagnosis. However, it was also cautioned that those online groups tend to have a tremendous amount of incorrect information.

“As the disease has progressed for me, what I would call a ‘plan for personal care’ has become important. At no time in the eight years that I have been diagnosed has someone come along and said, “you need this, and we are going to get it set up for you.’ I recognized that I would need to set things up for myself.”

- Person living with Parkinson's, Vancouver, B.C.

A care partner in the group discussed with the group how she took a geriatrician course offered through a local university that taught her cognitive tests and the signs for if her partner is experiencing delirium. She went on to suggest that it would be beneficial for more certificate courses to be offered that care partners could take in areas of physiotherapy, occupational therapy, speech therapy, etc., and reduce the need to rely on the healthcare system as often.

The next topic raised was on the excessive wait time for deep brain stimulation (DBS) surgery. One member in the group expressed his frustration with how long of a wait time it is in the province to receive this procedure, in comparison to other parts of the country.

A member in the group who works at a Parkinson's community organization explained how DBS is considered an elective surgery, which poses as a big challenge. She went on to explain how there is an appetite from other provinces to bring patients over from B.C. to perform the surgery; however, the ministry will currently not fund the travel costs associated with this medical procedure. It was then added by a movement disorders specialist in attendance that the ministry will in fact cover the cost of surgery, but not the cost of the equipment. Provincial governments cannot agree on who should be responsible for paying for the equipment expenses.

CONCLUSION

KEY PRIORITIES

During the Parkinson Canada Roundtable Series, members of the Canadian Parkinson's community spoke honestly about their current challenges and were both enthusiastic and hopeful that their shared insights will move towards meaningful action.

Upon concluding its roundtable series and after months of engaging with people living with Parkinson's, care partners, healthcare professionals, and other Parkinson's community organizations from across the country, we have gathered insights and have identified the following key priorities for improving the quality of life for people living with Parkinson's in Canada.

- Gaps have been identified in the support of the development and promotion of Parkinson's curriculum and awareness for family physicians and allied healthcare professionals. **Work needs to be done to address these gaps and provide additional training and knowledge transfer to qualified healthcare providers, which will allow for earlier diagnosis and treatment of Parkinson's.**
- Systemic issues exist within healthcare across Canada, which means people living with Parkinson's are underserved given the limited number of Parkinson's Nurse Specialists and Movement Disorder Specialists. **Systemic issues and barriers throughout the healthcare system need to be examined to determine what steps can be taken to increase the number of healthcare providers available to support people with Parkinson's.**
- **Equitable access to care and treatments for all Canadians living with Parkinson's is essential.** This includes exploring the availability and wait times for life-changing treatments and access to Health Canada approved medications.

These priorities will help provide a roadmap to the organization in developing our future advocacy work in support of Canadians living with Parkinson's.

NEXT STEPS

The roundtable series was an opportunity to hear from the Parkinson's community and get direction on advocacy needs to help inform the development of an advocacy strategy for the organization. These roundtables and reports are the first step in this process and will be the foundation of future advocacy efforts.

The next step is the development of a Parkinson Canada Advocacy Strategy based on these key priorities, which will outline how the organization, along with all Canadians, can play a role in advocating for those affected by Parkinson's.

We will continue to build relationships with key stakeholders and government officials to raise awareness about the gaps that currently exist in Parkinson's healthcare. In addition, we will continue to collaborate with community organizations across the country to address these advocacy issues and work towards our mission of transforming the lives of people living with Parkinson's in Canada.

ACKNOWLEDGEMENTS

PARKINSON ADVISORY COUNCIL (PAC)

Parkinson Canada is grateful to Parkinson Advisory Council members Bob Kuhn and Joe van Koeeverden, who participated in all roundtables.

COMMUNITY ORGANIZATION COLLABORATION

Parkinson Canada recognizes we are stronger together and appreciate the support for the roundtables from the following organizations:

Parkinson Association of Alberta

Parkinson Society British Columbia

Parkinson Society Newfoundland & Labrador

Parkinson Society Southwestern Ontario

Parkinson Quebec

U-Turn Parkinson's

ABOUT PARKINSON CANADA

People with Parkinson's are at the centre of everything we do. Our mission is to transform the lives of people living with Parkinson's.

Parkinson Canada funds critical research, provides information and support, increases awareness, and advocates for improved health care outcomes for people living with Parkinson's across Canada.

<https://www.parkinson.ca/>

APPENDIX

ⁱ Deep Brain Stimulation. (n.d.). Sunnybrook Health Sciences Centre. Retrieved January 7, 2022 from <https://sunnybrook.ca/content/?page=deep-brain-stimulation>

ⁱⁱ Duodopa® Therapy. (n.d.). University Health Network Krembil Brain Institute. Retrieved January 7, 2022 from https://www.uhn.ca/Krembil/Treatments_Procedures/Duodopa_therapy

ⁱⁱⁱ Dorsey, E. R., Elbaz, A., Nichols, E., Abd-Allah, F., Abdelalim, A., Adsuar, J. C., ... Collado-Mateo, D. (2018). Global, regional, and national burden of Parkinson's disease, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Neurology*. doi:10.1016/s1474-4422(18)30295-3

^{iv} Public Health Agency of Canada. Canadian Chronic Disease Surveillance System (CCDSS), Data Tool 2000–2016, 2018 Edition. Ottawa (ON): Public Health Agency of Canada; 2019.

^v Neurological Health Charities Canada (NHCC), Health Canada, Public Health Agency of Canada (PHAC), Canadian Institute of Health Research (CIHR). MAPPING CONNECTIONS: An Understanding of Neurological Conditions in Canada. Sept. 2014. pg.68.

^{vi} People with Parkinson's Face Gaps in the Availability of Health Services [Data Set] (March 28, 2018). IPSOS Public Affairs. Retrieved December 17, 2021 from <https://www.ipsos.com/en-ca/news-polls/parkinson-canada-stakeholder-survey-2018>

^{vii} Parkinson Canada National Environmental Scan conducted in Fall 2018

^{viii} Mathematical estimate based on ^v, ^{vii}

^{ix} R-1 March Interactive Data. (May 13, 2020). CaRMS. Retrieved December 15, 2021 from <https://www.carms.ca/data-reports/r1-data-reports/r-1-match-interactive-data/>

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