



Submission to Provincial Budget Consultation for 2020-2021

Friday, June 26, 2020

Lengthy waitlists for critical Parkinson's treatments put patient health at risk

**Decrease waitlists and increase access to therapies for
Advanced Parkinson's Disease:**

1. Deep Brain Stimulation (DBS)

2. Duodopa Therapy

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Recommendations:

Deep Brain Stimulation

1. Support the interprovincial reciprocal agreement and allow people to access DBS in other provinces until a second neurosurgeon is in place in BC.

We also recommend travel assistance be provided to patients as although some care can be provided through telehealth pre and post-surgery, at least several trips to the appropriate clinic would need to take place.

2. Provide a second DBS clinic in Fraser Health Authority

Duodopa Therapy

Remove the 'cap' or quota system of five patients per year.

Overview

There are 13,300 British Columbians who have heard the words “you have Parkinson’s disease” from their doctor. Although there is no cure, most patients are able to maintain a decent quality of life with assistance from medical and non-medical treatments.

Unfortunately for some, as the disease progresses, symptoms become unmanageable and without access to additional treatments, it can result in death.

Deep Brain Stimulation (DBS) and Duodopa Therapy are therapies that can be used to manage these progressive symptoms, alleviating pain and severe disablement for a number of years and saving lives.

DBS is a surgical procedure used to treat a variety of disabling neurological symptoms—most commonly it is used to treat the debilitating symptoms of Parkinson’s disease (PD) such as tremor, rigidity, stiffness, slowed movement and walking problems.

DUODOPA® is a levodopa/carbidopa intestinal gel delivered through a pump similar to an insulin pump. It is known by its brand name DUODOPA®.

In comparison to other provinces in Canada, in BC, only limited access is available to both of these therapies for those who need them. Long waitlists exist. Patients face excruciating pain, deterioration of their already fragile health, make repeated trips to emergency services as they experience difficulty with breathing, swallowing, pain, movement and balance. Patients end up hospitalized, sometimes until their end of life, or enter long term care sooner than wanted or necessary.

During these experiences, caregivers watch helplessly, knowing that if they lived in another province in Canada, they would receive the care without the excessive wait. We know one person who moved to Alberta to receive care. We know another, an elderly Alberta man on Duodopa therapy, who wants to retire to Kelowna where his family lives. He cannot because he would have to go in the quota waitlist for BC Pharmacare coverage.

The situation causes great caregiver stress and often breakdown of caregiver health. The caregiver may become ill themselves, quit work to take care of their loved one or to have to consider hospitalization or long term care for their family member, an estimated 8 to 10 years earlier than necessary. These costs to the healthcare system are much greater than providing access to therapy, whether it be DBS or Duodopa.

It is not right that it matters that these people live in BC and cannot receive the same care they would receive elsewhere in Canada.

We urge the province to provide the funds for the BC Minister of Health to move forward on the Premier's expectation that he will "reduce wait times and implement province-wide co-ordination to manage and actively monitor waitlists" to provide more timely access to these therapies and give people their lives back.

Recommendation - Deep Brain Stimulation

The Parkinson's community is very grateful that the province increased access to Deep Brain Stimulation (DBS) in the 2019-20 budget, doubling funding to increase the number of procedures from 36 to 72 per year.

The province also promised to further increase access and reduce waitlists by hiring a second neurosurgeon trained in this very specific procedure. However, this has not yet occurred and we understand that it is unlikely to occur until June 2021 at the earliest when a new graduate **may** be available. Once recruitment is complete, there will likely still be a number of months before the new surgeon begins treatments.

We are grateful that once a patient is on the surgical waitlist, the time to receive DBS is now down to months from a former two year wait.

However, the surgical waitlist is not the only waitlist for this procedure. Dr. Chris Honey is the only neurosurgeon in BC providing this life saving and life changing procedure for British

Columbians with Advanced Parkinson's disease; the waitlist to see Dr. Honey to be assessed for the procedure is still **up to three years**.

An Interim Solution for DBS:

The wait to be assessed is untenable. However, there is an interim solution – BC has a reciprocal interprovincial agreement to pay for treatment in other provinces. Clinics in both Saskatoon and Toronto have indicated willingness to accept patients from BC and that their wait times, including assessment are six months or less.

We know of patients who have accessed DBS in Calgary because of their geographical proximity to Alberta and who have been accessing movement disorder specialists in Calgary for their ongoing care. So there is already a framework for other patients to be given the same access to earlier care.

However, patients who have more recently contacted BC Health have been told by the Minister of Health and department staff the financial coverage would not be honored for receiving this care outside of BC, even though the wait time in BC is so excessive.

We urge the province to support the reciprocal agreement at least until a second neurosurgeon is in place in BC.

We also recommend travel assistance be provided to patients as although some care can be provided through telehealth pre and post surgery, at least several trips to the appropriate clinic would need to take place.

A Second Recommendation for DBS

Currently, the DBS program is part of Vancouver Coastal Health Authority's (VCHA) annual budget; however, three-quarters of the patients live outside the VCHA region.

Dr. Honey has trained another neurosurgeon, Dr. Zurab Ivanishvili, who currently works out of Royal Columbian Hospital for Fraser Health Authority doing non-DBS neurosurgeries. Therefore, Dr. Zurab already has a surgical team that could support him for DBS surgery.

We understand Fraser Health Authority was exploring providing DBS, in 2024 when their new tower will be available. However, we understand the province has given a directive that DBS be kept centralized in Vancouver Coast Health Authority.

As a majority of the patients come from this health region, we recommend that funding be provided to set up a second DBS clinic.

Duodopa Therapy

One of those lifesaving treatments, a levodopa/carbidopa intestinal gel known by its brand name DUODOPA®, is being withheld from those who need it most. Although the province of BC announced February 14, 2017 that they would begin providing coverage for this therapy, they instituted a cap or **quota system of five individuals per year**. It is estimated that an additional 10 to 20 individuals per year would be eligible for the treatment here in British Columbia.

DUODOPA® is delivered through a pump similar to an insulin pump. Although the drug is currently expensive to administer, it is only suitable for a very small number of patients. The cost of the drug is approximately \$60,000 per year; however, in the interim, while individuals are waiting for this therapy, patients estimate that their frequent trips to the emergency room, struggling to breathe and manage their pain, have far outweighed the yearly cost of the drug.

Aside from the medical costs, this takes an incredible emotional toll on patients and their families while they live with the constant looming fear of death. It simply does not make moral or financial sense to deny this therapy to the few other individuals that would greatly benefit from this therapy any longer. We, as a province, can do better; none of the other provinces have this limit in place.

The province's own Ministry of Health website cites that it has an "overall responsibility for ensuring that quality, appropriate, cost effective and timely health services are available for all British Columbians". Right now, it is failing people with Parkinson's, and in denying them this therapy, risking their lives.

The only other option for some of these people is Deep Brain Stimulation (DBS). Although DBS is funded by the BC government, as described above, funding is not adequate for this therapy either, making it an unrealistic option for these patients.

We encourage you to read more about this situation on Parkinson Society British Columbia's (PSBC) (<http://parkinson.bc.ca/duodopa>).

Recommendation for Duodopa Therapy

Remove the 'cap' or quota system of five patients per year. None of the other provinces without this limit have seen the number escalate. Meanwhile the other medical costs have not been required for these patients receiving therapy.

Appendix A - Why DBS Remains an Issue:

- **Across Canada, there is at least one functional neurosurgeon for every two million people -- except in BC, where it is one for every five million people.**
In comparison, Saskatchewan with a much smaller population of 1,098,352 people has virtually no wait list with three qualified neurosurgeons; and Alberta, again with a smaller population than BC, has a waitlist of six months with two qualified neurosurgeons.
- **Parkinson's disease is a progressive neurological disorder that can be treated surgically only within a certain time period. A lost year of benefit may be devastating for a patient, condemning them to a life of disability with flailing limbs, debilitating tremors, and/or the inability to move, work or lead a normal life.**
Dr. Christopher Honey, MD, DPhil, FRCSC is currently the only stereotactic functional neurosurgeon in BC performing these very complex surgeries. The waitlist to see Dr. Honey is still 3 years for initial consult, although the doubling of surgeries from 36 to 72 per year has reduced the wait time for surgery after assessment.
- DBS is used only for patients whose symptoms cannot be adequately controlled with medications. DBS uses a surgically implanted, battery-operated medical device called a neurostimulator—similar to a heart pacemaker and approximately the size of a stopwatch—to deliver electrical stimulation to targeted areas in the brain that control movement, blocking the abnormal nerve signals that cause tremor and other PD symptoms.
- Unfortunately, even with the additional time for surgeries, it will take at least three years to reduce the waitlist – with new patients added all the time. The additional time is not enough to meet the current need, and with the worldwide incidence of Parkinson's expected to double by 2040, the waitlist continues to quickly multiply. It should be noted that follow-up appointments with those having received the surgery, as well as battery replacements every 4 to 5 years, must be added into Dr. Honey's workload.
- **Currently, all patients must travel to Vancouver for the procedure. The budget is held by Vancouver Coastal Health Authority (VCHA) and yet the majority of patients reside outside Vancouver in other health authorities.**
What should be a provincial program is being funded through the VCHA, resulting in considerable costs for patients as they must travel to Vancouver multiple times for pre and post-surgery follow-up appointments. Alternative, telehealth care for follow-up should also be put in place for patients outside Vancouver.

- **Increasing access to Deep Brain Stimulation for people with advanced Parkinson's disease will reduce the suffering endured by those with this neurodegenerative disease and provide them with the ability to live independently for 10 or more years.**

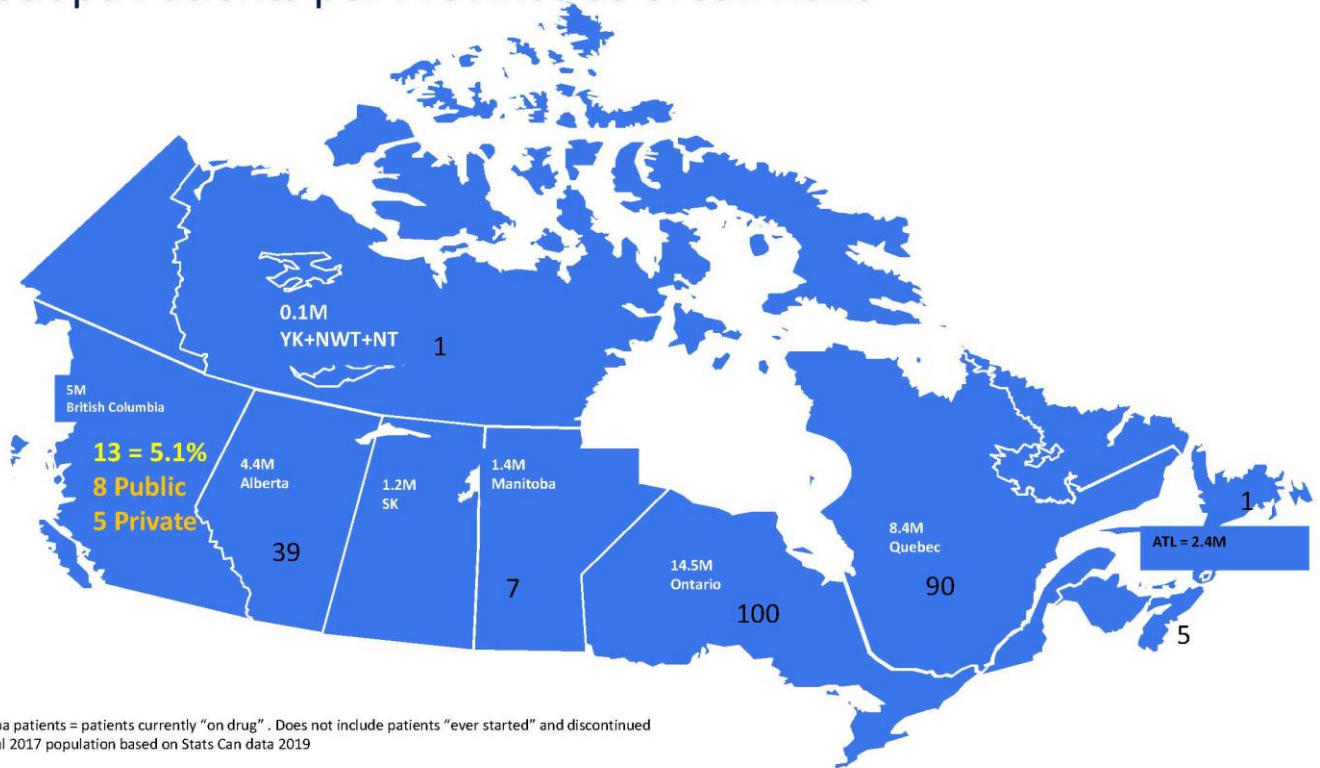
Helping people stay independent also has a strong economic rationale. Many people with advanced, disruptive symptoms of Parkinson's disease will end up in hospital beds or long-term care in the near future. The cost of this care is roughly \$80,000 to \$100,000 per person per year, or \$1 million per person over ten years. Thus, it makes moral and economic sense to provide DBS to those who need it, as soon as possible.

We encourage you to read more about this situation on Parkinson Society British Columbia's (PSBC) website at <http://parkinson.bc.ca/DBS>. Several videos on the website demonstrate the remarkable life-changing relief provided to two patients who have received DBS.

* Honey, C., Malhotra, A., Tamber, M., Prud'homme, M., Mendez, I., & Honey, C. (2018). Canadian Assessment of Deep Brain Stimulation Access: The Canada Study. *Canadian Journal of Neurological Sciences / Journal Canadien Des Sciences Neurologiques*, 45(5), 553-558. doi:10.1017/cjn.2018.268

Appendix B

Duodopa Patients per Province as of Jan 2020



*Duodopa patients = patients currently "on drug" . Does not include patients "ever started" and discontinued
 Provincial 2017 population based on Stats Can data 2019

Province	# Duodopa pts	Public reimbursement status
BC	11	C x C not on Formulary – Annual CAP = 5 pts
AB	35	AHS on Formulary - No CAP
SK	0	SK Health on Formulary - MDC opening soon
MB	6	MB Health on Formulary - No CAP
ON	102	OPDP on Formulary - No CAP
QC	87	Patient D'exception - No CAP
NS	4	On Formulary – No CAP
NB	2	Under review
YT	1	On Formulary - No CAP
Total	248	