

Registered Nurses' Foundation of Ontario
305-7270 Woodbine Avenue
Markham, ON L3R 4B9

November 10, 2023

To Whom It May Concern,

Re: Final Report to RNFOO

I am delighted to be the recipient of the November 2021 inaugural CCNEA. As per the contract, I am writing with a final report regarding the development of a Community Interprofessional Program for People with Parkinson disease (CIPPwP).

A team of five nurses and one physiotherapist have worked together over the past 2 years to complete and exceed the milestones as outlined in the proposal. Three specific areas that we proposed to focus on were Medication, Mobility, and Cognition. However, as our research and development progressed, the consensus among the team was to develop a broader and more comprehensive CIPPwP, an offering not currently available in Canada.

As PwP in Ontario are typically seen by a neurologist every 12 to 18 months, we have been told by physicians, physiotherapists, public health nurses, allied health professionals, PwP and their caregivers, that PwP need the support of PD specialized nurses in community care. Based upon models from the Netherlands and elsewhere, PD nurses help improve quality of life, address complex problems, and attend to top unmet needs, as identified in *The Voice of the Parkinson Customer*: (1) more self-management; (2) better interdisciplinary collaboration; (3) more time to discuss the future, and possible scenarios; and (4) a health care professional acting as a single point of access. We concluded that the strength and success of the CIPPwP would depend upon the ability of the nurse to address most, if not all, of the typical challenges PwP face, as well as help them to meet what is often their primary goal of living in their own home for as long as possible.

We have met and exceeded the deliverables enunciated in the proposal, and we addressed many more nursing diagnoses than originally intended. We have expanded the electronic health record and database to capture the various components of the program, including nursing care plans, protocols, assessment forms, questionnaires, research material, resource lists, and more. The remarkable area of expansion was the increase from 3 care plans (Medication, Mobility, and Cognition) to 37 nursing care plans, all fully researched, reviewed, and approved by two nurses knowledgeable in PD care, to meet academic standards for future publication. They are as follows:

General Health and Wellness

- Activity Engagement Deficit
- Anosmia
- ADL- Misc Challenges
- Advance Care Planning Neglect
- Driving Challenges
- Fatigue
- Nutritional Deficit
- Palliative Care Deficit
- Sexual Dysfunction
- Spiritual Distress

Motor Symptoms

- ADL- Dressing Challenges
- ADL- Hygiene Challenges
- Tremors and Dyskinesia
- Freezing of Gait
- Mobility Issues
- On-Off Episodes
- Oral Hygiene Deficit
- Swallowing Coles Notes
- Swallowing 1 Pre-Oral Stage
- Swallowing 2 Oral Preparation Stage
- Swallowing 3 Oral and Pharyngeal Stages

Non-Motor Symptoms (emotional/cognitive)

- Anxiety/Apathy/Depression/Suicide Risk
- Cognitive Impairment/PD Dementia
- Communication Impairment
- Hallucinations/Psychosis/Delusion/Delirium
- Impulse Control Disorder

Non-Motor Symptoms (autonomic)

- Constipation
- Drooling
- Orthostatic Hypotension
- Overactive Bladder
- Pain Management
- Sleep Deprivation
- Thermoregulation-Hyperhidrosis

Therapies

- Alternative Therapies Omission
- Cannabis Use Omission
- Complementary Therapies Omission
- Medication Non-Compliance

Having faced some common challenges in program development, there were many lessons learned, related to: time management, collaborative problem-solving, identifying roles/skills, template design, formatting, literature search guidelines, authorization for validated questionnaires, etc. The team embraced this as a growth opportunity.

Inconsideration of the extensive effort and the voluminous work that was produced by Registered Nurses with thirty or more years of clinical experience in geriatrics and advanced neurological nursing, the cost to do this was far greater than the CCNEA award.

Program Research and Development (incl. HST)	\$ 50,800
Administrative support	3,200
PwP (5) subsidy	1,000
Owner in-kind support (est.)	<u>20,000</u>
Total project cost	\$ 75,000
CCNEA Award	25,000
Nurse On Board investment	50,000

My team of nurse colleagues has demonstrated immense dedication in creating this exceptional program, designed to be sustainable and to accommodate new findings on PD management. While Nurse On Board is already caring for PwP, and is advertising the CIPPwP, ideally our efforts will lead to training of nurses across the province through an accredited education

program. Additionally, given an estimated 50,000 PwP in Ontario alone, and the “medical desert” for PwP living outside urban centres, there are many business opportunities for Nurse On Board to offset our significant investment. As we are growing our PD expertise among nurses in the Ottawa region, we are in discussion with potential industry and biopharmaceutical sponsors as they have funds designated for both patient care and nursing education. As PwP spend 70x more on their healthcare than those without a neurological condition, it is imperative that we pursue financial support on their behalf and facilitate the use of third-party insurance when available.

In consideration of the financial restraints of PwP, the CIPPwP has been designed as 12 weeks with 1 visit per week, for \$1,500. With sponsorship, or for those who have the means, we anticipate that many PwP would benefit from 2 visits per week, and 16 weeks of care management. This would allow more time to address and attain desired outcomes, as well as satisfy personal goals, for a fee of \$3,500.

Nurse On Board follows the structure below as a guideline and customizes the program to meet the unique needs of the PwP and their caregiver(s). Some may wish to continue beyond 12 weeks, exceed 1 visit per week, prefer to lengthen the program, and/or health issues may cause interruptions. Nurses will adjust the schedule and fees to align with patient-centered care.

Weeks 1 to 4	(\$1500 program)	Activity	Time	Fee	Comments
Intake		History	2.0 hours	\$250	PHIPA, MD, PT, etc.
Assessments		Scales	1.5 hours	150	RN and independent
Goals/problem list		Nursing Care Plan	1 hour	100	Priorities of care plan
Intervention		Per goals	1 hour	100	Unique
Weeks 5 to 8		Activity	Time	Fee	Comments
Interdisciplinary collaboration +/- medical appointment		Communication *GP or Neuro	1.5 hours	150	Resource List Advocacy role
Intervention/evaluation		Per goals/scales	1 hour	100	Unique
Advance Care Planning		Documentation	1 hour	100	Family meeting prn
Intervention/evaluation		Per goals/scales	1 hour	100	Unique
Weeks 9 to 12		Activity	Time	Fee	Comments
Self-Management techniques		Nursing Care Plan	1 hour	100	Review goals
Re-assessment/evaluation		Scales	1 hour	100	Ongoing plan of care
Medical appointment		Allied Health	1.5 hours	150	Anytime during program
Wrap-up/letter to Providers		Family meeting	1 hour	100	Future needs discussion

Throughout the development of the CIPPwP, Nurse On Board provided online preceptorship to three cohorts of Trent University students in the RPN to BScN bridging program. These practicums provided 12 nurses with an excellent learning opportunity regarding Parkinson disease management. While this was volunteer work for Nurse On Board, our effort supported our goal of nursing education as well as our dedication to improved community care for PwP.

At this time of immense stress and strain in healthcare, I'm delighted to work with senior nurses who take great pride in exemplary care; they are nurse leaders and lifelong learners who foster education as the most effective way to reduce barriers to quality healthcare. The CIPPwP is a valuable asset for Nurse On Board, and an important contribution to healthcare for PwP and nurses alike. We are making a difference and will continue to do our utmost to positively impact the lives of PwP and their caregivers. As the Owner of Nurse On Board, I am immensely grateful for the business recognition and for the forthcoming possibilities that winning the CCNEA and building the CIPPwP has ensured.

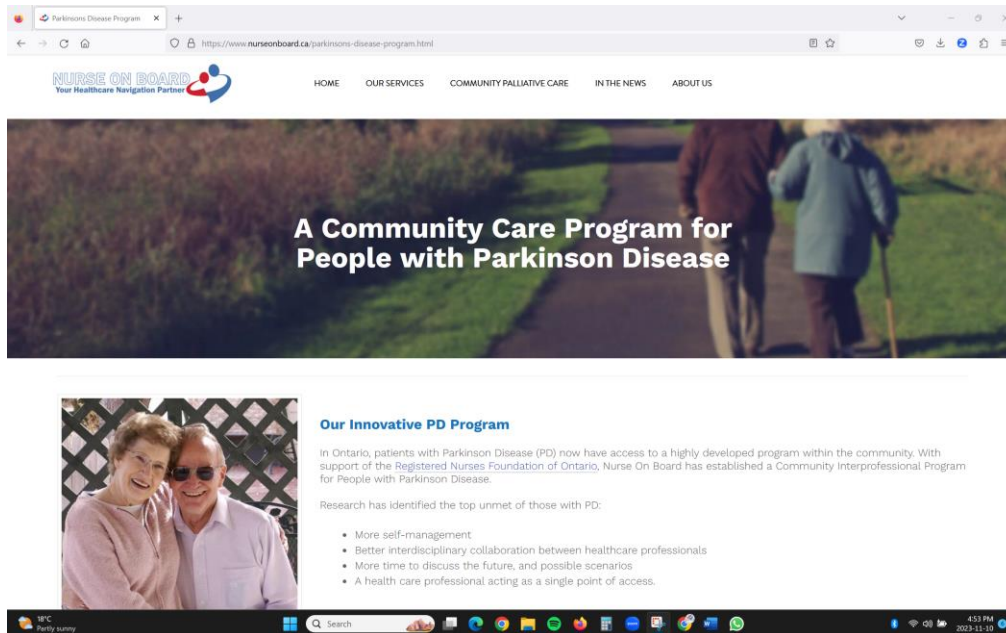
I would like to take this opportunity to thank the RNFOO for their outstanding work and tremendous support of nurses. I'm committed to expanding the CIPPwP for the benefit of PwP and for the growth of my unique nursing business. I would be pleased to speak with you should you require any additional information.

Kindest regards,




Susan Hagar RN BCPA (Board Certified Patient Advocate)
Founder and CEO, Nurse On Board Inc.
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(website and Facebook ad on following page)



Do you know someone struggling with Parkinson's Disease (PD)?

Let them know there are Registered Nurses who provide expert guidance to address their unmet needs



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