



May 2, 2023

Dear members of the Canadian Movement Disorders Group,

Re: Brain donation program supported by CurePSP

As I mentioned at a CMDG meeting a few months ago, our Rossy PSP Centre in Toronto is establishing a brain donation program supported by CurePSP in a similar fashion to one that exists in the United States, whereby brains are collected from across the country and sent to be evaluated by Dr. Dennis Dickson at the Mayo Clinic. Dr. Gabor Kovacs will be conducting the neuropathological studies here in Toronto. We are interested in collecting brains of patients with PSP, MSA, CBS and other related atypical parkinsonisms (including possible variants of PSP such as nonfluent variant primary progressive aphasia, behavioural variant FTD, pure freezing of gait, etc.).

We are in the process of working out the details and trying to establish an infrastructure that will successfully support this program. To begin with, the plan would be that a pathology site affiliated with interested Movement Disorders and Behavioural Neurology programs would arrange to have a neuropathology assistant remove the brain, process it in a standardized fashion if possible (e.g. bisecting the brain, freezing half and placing the other half in formalin; we would provide all the details outlining the handling of the brains) and then ship the brain to Toronto. Dr. Kovacs would then conduct the neuropathology studies and provide a formal report back to the clinicians caring for the patient as well as the family. In addition to covering the costs of the formal neuropathology evaluation, CurePSP will provide funding to cover the costs of removal of the brain, processing and shipping as well as at least a proportion of the cost of transferring the remains to the hospital and then back to the funeral home. The cost of transferring the body to the pathology site will obviously vary depending on distance; for practical reasons, to begin with this program will likely work best for brain donations from patients sited close to the hospital centres. In the future, it might be possible to have brains removed by experienced dieners who go to the funeral home, as is currently done in remote areas of the United States for this program.

To start with, we would like to develop a listing of all of the members of the CMDG (and any of your Behavioural Neurology colleagues seeing these patients) who would be interested in participating in this program. With your help, we would then need to establish contact with the pathology department at the hospital where the brains would be removed so that we can set up the necessary arrangements to support the details of the program as summarized above.

If you are interested in participating we would greatly appreciate if you could let us know and also provide us the contact information of the pathology department that would be involved in removing the brain and shipping it to Toronto. Obviously, this would need you to connect with them and confirm their interest and availability. Please email me at: anthony.lang@uhnresearch.ca

Anthony E. Lang, OC, MD, FRCPC, FAAN, FCAHS, FRSC

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Looking forward to hearing back from you. Thanks in advance for your support of this very important new Canadian collaborative development.

Kind regards

Tony Lang

A handwritten signature in black ink, appearing to read 'A.E. Lang', written in a cursive style.

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