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Date: MM/DD/YYYY

Dear Family of Mr./Ms. Patient,

Thank you for your inquiry about the Brain Tissue Donation Program of the Ann Romney Center for Neurologic Diseases at Brigham and Women's Hospital. Providing the tissue of a neurodegenerative disease patient to our research program allows us to meet two important goals.

The first is that the brain can be carefully examined to confirm the diagnosis of neurodegenerative disease and to validate the diagnosis of neurodegenerative disease for your family. Since the tissue takes some time to prepare for examination, the histopathology report with the final diagnosis can take 6-8 weeks to be completed. Please contact Dr. Khurana to provide you with the results and the report once it is available.

The second is that the tissue can be used in research efforts now underway to understand the mechanisms of brain cell degeneration and ultimately to find a treatment and prevention for this devastating disease.

To enroll your family member in our program, simply fill in the attached forms, and provide a signed health care proxy form for the patient and any additional information noted. Then email, mail or fax these items as directed on the form back to me. I will then prepare documents for your records and that can be given to your family member's caregivers, and others that may be involved in the event so they understand your wishes and will know what to do when the time comes. Once you confirm that all parties have received this information, the enrollment is complete. When he/she appears to be in decline, please be in touch. It's best to let us know as soon as that process becomes evident, so we can alert the pathologist here to anticipate arrival at BWH (even if it's a few days ahead) and help things go smoothly.

He/she can be transported by the funeral home to BWH at any time, day or night, and the autopsy will be performed as soon as is practicable by the neuropathologists, generally within 24 hours. Since your family member was a patient at BWH, the autopsy will be performed free of charge. The costs for transport would typically be incurred by the family to and from the Brigham, but please let us know if you require assistance in this matter. As noted above, and upon request, we will send you the autopsy report confirming his/her diagnosis which will likely take about 6-8 weeks to be completed accompanied with a letter explaining the results.

Thank you again for your willingness to support our research in this very important way. I look forward to receiving the enrollment forms. Let me know if there are other questions or concerns, and I can answer. My cell phone number is 617-872-2912. You can also reach our tissue collection coordinator, Ms. Olivia Laun, at 412-326-5736.

Sincerely,

Vikram Khurana, MD PhD