To Whom It May Concern:

This letter is to inform you that Adult-onset leukoencephalopathy with axonal spheroids or ALSP (a medical condition that can cause executive dysfunction, memory decline, personality changes, motor impairments, and seizures) has been identified in your family. A family member was also found to have a genetic cause of this condition. Specifically, a pathogenic or disease causing genetic change in the CSF1R gene was identified.

Genes are the blueprint for our bodies and control not only the way a body is made, but also how it works. One gene of each pair comes from the mother's egg and the other from the father's sperm. DNA is the building block of each gene and is made up of four chemical bases represented by the letters C, T, G and A. The DNA is like the letters of the alphabet which when put together creates our body's instruction manual. A variant in the DNA of a gene is like a typo in an instruction manual.

The type of variant that causes disease is called "pathogenic." A gene variant is usually inherited from one of the parents and may have been in the family for many generations.

Because this is a genetic condition, there is a possibility that you have a variant in CSF1R, one copy of the gene which causes Adult-onset leukoencephalopathy with axonal spheroids. Knowing your genetic status could impact your medical management and/or family planning. There are research studies ongoing for this condition, including clinical drug trials that you may qualify for if you also have this genetic variant. There are pros and cons of genetic testing so it is important that each individual consider his or her options carefully. Because this is an important decision, it is helpful to discuss this decision with a genetic counselor who can go through the pros and cons of testing and help each individual come to an informed decision for themselves. Talking to the genetic counselor does NOT mean you have to have genetic testing.

Labs that offer testing for the genetic variant identified in your family include: **(Insert Lab)**

Only include patient information if they are comfortable

Please note that any lab completing testing will require specific information about the genetic variant found in your family member. The specific information for the variant identified in your family is:

Testing ID Accession Number:
Gene:
Variant Information:
Identified at (Insert Lab)
My DOB:

To find out more about testing options or to speak to a genetic counselor, **please feel free to contact (Insert GC or Physician Name) at (Insert Institution).** All initial

contacts will be confidential. You may also be interested in contacting a Genetic Counselor in your area: search https://www.nsgc.org/page/find-a-genetic-counselor (a find a genetic counselor tool on the National Society of Genetic Counselors website). You are also strongly encouraged to notify your primary physician that there is a pathogenic variant in your family.

Please feel free to reach out to us with any questions.

Best Regards,

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Licensed, Certified Genetic Counselor