

ALSPAware

A genetic counseling and testing program for Adult-Onset Leukoencephalopathy with Axonal Spheroids and Pigmented Glia (ALSP)

InformedDNA®, with support from Vigil Neuroscience, Inc., is providing no-cost genetic counseling and testing to individuals who are suspected of having Adult-Onset Leukoencephalopathy with Axonal Spheroids and Pigmented Glia (ALSP).

ALSP is a neurologic condition caused by a change (also called a mutation or variant) in the *CSF1R* gene. The symptoms of ALSP can be very similar to many other psychiatric and neurologic conditions such as Alzheimer's disease or multiple sclerosis. Because of this, it can be difficult to make an accurate diagnosis based on clinical symptoms alone.

Genetic testing is available to individuals suspected of having ALSP by an *ALSPAware* participating physician. This testing includes 24 genes (including *CSF1R*) known to cause symptoms similar to ALSP.



Who is eligible for this program?

- ✓ Adults (18 years or older), AND
- ✓ Living in the United States, AND
- ✓ Are referred by an *ALSPAware* participating physician



What is genetic counseling?

Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the following:

- Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence.
- Education about inheritance, testing, management, prevention, resources and research.
- Counseling to promote informed choices and adaptation to the risk or condition.



What to expect in a genetic counseling appointment with InformedDNA®

The genetic counselors at InformedDNA® working on this program are highly trained in hereditary neurological conditions. As part of this program individuals will receive initial and post-test genetic counseling over the phone.

At the initial appointment, the genetic counselor will:

- ✓ Collect medical history and a 3-4 generation family history where available;
- ✓ Discuss the genetics of ALSP;
- ✓ Review the benefits and limitations of genetic testing;

If you decide to proceed with genetic testing, then the genetic counselor will coordinate the test order and sample collection kit to be sent to you (cheek swab)

- ✓ Results will be available in approximately three weeks from when the lab receives the sample back from you

At the post-test appointment, the genetic counselor will:

- ✓ Review the genetic test result and implications for personal health and risks to family members
- ✓ Provide a written summary of the discussion and a copy of the genetic test result to the individual

All appointments occur over the phone. Family members or friends may participate in the call, regardless of location. Appointments are available during usual business hours as well as evenings and weekends.

How to find more information about ALSP

Vigil Neuroscience Resources

vigilneuro.com/patients-and-caregivers

ALSPInfo.com

Patient Advocacy Organizations and Resources

Sisters' Hope Foundation
(sistershopefoundation.org)


United Leukodystrophy Foundation
(ulf.org)

Hunter's Hope Foundation
(huntershope.org)

**To schedule an appointment, call 888-418-9309
or visit InformedDNA.com/ALSPAware**



InformedDNA is the largest independent provider of genetic counseling services, offering a nationwide staff of board-certified geneticists and genetic counselors. A pioneer in increasing access to genetics expertise, InformedDNA uses proprietary telephone and Internet service delivery systems, allowing patients the convenience of participating in genetic counseling sessions from the location of their choice. For more information, visit www.InformedDNA.com.

This testing program is sponsored by  **vigil**
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No personal identifying information of individuals participating in this genetic counseling and testing program will be shared with Vigil Neuroscience, Inc.