



Being diagnosed with a rare disease that little is known about would be scary for anyone. The ALect2 Alliance was formed to provide updated information on this disease, and to provide a point of contact for patients and family members to discuss their experiences.

We hope to be a part of helping the community of researchers and patients come together to work toward finding a cure for this disease. Find out more information about this disease and our organization by visiting:

<http://www.lect2.org>

Where Can I Learn More?

For more information on LECT2 Amyloidosis, how you can contribute to better understanding it, or to learn more about clinical trials, please visit and register at the following web-sites:

- ALect2 Alliance:
<http://www.lect2.org>
- Amyloidosis Support Groups:
<http://www.amyloidosisupport.org/>
1-866-404-7539
- The Amyloidosis Foundation:
<http://www.amyloidosis.org/index.html>
1-877-AMYLOID
- Mayo Clinic - Amyloidosis Page
<http://mayocl.in/1zqX2cv>
- Boston University Amyloidosis Center:
<http://www.bu.edu/amyloid/>



<http://www.lect2.org>
info@lect2.org



LECT2 AMYLOIDOSIS (ALECT2)

WHAT IS IT?

HOW IS IT DIAGNOSED?

CAN IT BE TREATED?

What is Amyloidosis?

Amyloidosis occurs when proteins form improperly, causing them to deposit abnormally in otherwise normal tissue. Once the abnormal protein is trapped in the tissue, it commonly leads to organ failure. The kidney is the most commonly affected organ.

What is LECT2 Amyloidosis?

There are different types of amyloidosis and different proteins cause each one. Some are genetically linked and some are not. LECT2 amyloidosis (ALect2) makes up 5% of amyloidosis cases and has not yet been found to have a clear genetic link. However, patients with ALect2 tend to be older (over 50 years of age), and in the United States, are often from Mexican descent. Other groups have also been found to have higher incidence rates, such as First Nations Peoples in Canada, Punjabis, Sudanese, and some Native American groups. For people in these populations with slowly progressive chronic kidney disease, LECT2 amyloidosis should be suspected.



What are the Risk Factors?

The only risk factor currently identified is the correlation between LECT2 Amyloidosis and elderly patients from Mexican descent who have chronic kidney disease.

How is it Diagnosed?

The only way to diagnose LECT2 Amyloidosis at this time is by kidney biopsy. This is an invasive procedure, and should only be considered in patients with clinical evidence of kidney disease who might benefit from knowing its cause.

Once the kidney biopsy is performed, a series of tests will be done on the sample to determine what is causing the kidney disease. If amyloidosis is found, additional tests will be performed on the kidney biopsy to determine the type of amyloidosis present.

What are the Symptoms?

Kidney failure and its associated symptoms are typically present due to LECT2 protein deposits in the kidneys. Symptoms can include appetite loss, fatigue, headaches, itching and dry skin, nausea, and swelling of the legs.

Is There a Genetic Link?

There is no clear genetic cause at this time, but this type of amyloidosis has been found in siblings in the past. Additional research is needed to determine if there is a genetic link.

Can it be Treated?

There are no treatment options at this time, beyond treatment of the symptoms. It is important to note that cancer-focused treatments like chemotherapy do not help LECT2 Amyloidosis, and should be avoided.

However, research can help provide treatments in the future. For more information on, or to inquire about upcoming clinical trials for potential new therapies, please visit:



<http://www.lect2.org>

