LIGHT CHAIN (AL) AMYLOIDOSIS OVERVIEW

Amyloidosis Research Consortium

WHAT IS LIGHT CHAIN (AL) AMYLOIDOSIS?

AL amyloidosis is caused when your body makes too much of a certain protein, called light chains. The light chain proteins fold in the wrong shape. These misfolded proteins stick in tissues and organs and can cause organ failure. Finding out the type of amyloid fibril (using a test called mass spectrometry) is needed for the right diagnosis and treatment. Early diagnosis and treatment are key to preventing organ failure and preserving organ function.

POSSIBLE SYMPTOMS

- Swelling in legs or feet
- Lightheadedness or dizziness with positional changes
- Shortness of breath
- Poor exercise tolerance
- Bruising around the eyes
- Neuropathy (numbness/tingling in hands or feet)
- Enlarged tongue
- Foamy urine

SOME CLINICAL SIGNS

- Protein in the urine
- Worsening heart failure
- Carpal tunnel syndrome
- Orthostatic hypotension (e.g. low blood pressure with standing)
- Elevated cardiac markers

WHAT ARE SOME TESTS MY DOCTOR WILL ORDER?

- Complete blood count
- Comprehensive metabolic panel
- Serum Protein Electrophoresis (SPEP)
- Serum Free Light Chains
- Serum Immunofixation Electrophoresis (SIFE)
- Serum immunoglobulins
- Cardiac biomarkers (troponin, NTproBNP)
- Urine studies (24 hour urine immunofixation electrophoresis, protein electrophoresis, and total protein)
- Lactate dehydrogenase
- Coagulation studies
- Serum immunoglobulins

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WHAT ADDITIONAL TESTS WOULD BE CONSIDERED?

- Echocardiogram
- EKG (Electrocardiogram)
- Cardiac MRI
- PET scan or CT scans
- Bone marrow biopsy
- Fat pad biopsy
- Organ tissue biopsy
- Mass spectrometry to confirm amyloid typing

WHO SHOULD I SEE FOR DIAGNOSIS AND TREATMENT?

Your primary care doctor should send you to a hematologist that specializes in AL amyloidosis. Depending on which organs are involved, patients may also see specialists to help keep those organs working well. For example, patients who have heart problems should see a cardiologist to watch their heart function and manage their medications.

IS AL AMYLOIDOSIS TREATABLE?

Yes, AL amyloidosis is treatable. Quickly getting on treatment is important to prevent organ damage. Treatment focuses on the plasma (blood) cell or lymphatic system (immune system). In the case of plasma cell disorders, the goal of treatment is to remove the plasma cell clone and stop more build-up of protein fibrils. AL amyloidosis treatments come from therapies used for multiple myeloma, using anti-plasma cell therapies to destroy clones making amyloid fibrils.

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Ask ARC Your Questions:
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