

# Stay Ahead of the Game: Why Annual MRIs are Essential for Men with Adrenomyeloneuropathy



Detection of brain lesions at an earlier stage allows for more effective treatments compared to those detected at a more advanced stage.

## ADDRESSING PATIENT COMMENTS

We've asked international adrenoleukodystrophy (ALD) experts to respond to statements we often hear from men with AMN in regards to getting annual MRIs.

### WHY GET AN MRI NOW

**"I'll get an MRI if I develop symptoms."**

Then it might be too late. Brain lesions can appear before neurologic symptoms develop. It is important to identify brain lesions as soon as possible.

**"Why should I go looking for something?"**

To remove uncertainty. Knowledge is power. You can plan for your future.

**"I have lived a good life."**

Even if there is no direct benefit, you can feel proud that you are contributing to research that might help others.

## TREATMENT AND NEXT STEPS

**"My doctor said there are no treatments for cerebral ALD."**

Contact an ALD expert who can review current treatment options with you.

**"I'd rather not know if I have cerebral ALD since there's nothing that can be done."**

Men with cerebral ALD might be eligible for a bone marrow transplant or a clinical trial with an investigational drug that might improve your symptoms or slow progression of disease.

**"The odds are against me if I have a bone marrow transplant."**

Early detection of cerebral ALD improves your chance of a favorable transplant outcome. There are also other potential treatment options, in addition to transplant.

**"I got an MRI, but I don't know what the results mean."**

Many ALD experts will review MRI images if you send the discs to their center.





## ADDITIONAL RESOURCES

### WEBINAR

#### Cerebral ALD in Adults

Our experts discuss standards of care for men with AMN, transplant for cerebral ALD in adults, and current clinical trials.



[Watch Now](#)

### STANDARDS OF CARE

#### International Recommendations for the Diagnosis and Management of Patients With Adrenoleukodystrophy

Researchers used a consensus-based approach among 28 international ALD experts to develop best-practice recommendations for diagnosis, clinical surveillance, and treatment of patients with ALD.



[Read On](#)

### CLINICAL TRIAL

#### A Clinical Study to Assess the Efficacy and Safety of Leriglitazone in Adult Male Subjects with Cerebral Adrenoleukodystrophy

The purpose of this study is to evaluate if the study drug, leriglitazone, is able to increase survival and slow disease progression for those with cALD when compared to placebo.



[Learn More](#)

### COMMUNITY CALL

#### ALD Connect Hosts a Monthly Community Call for Men with AMN

Consider joining a Community Call to meet other men in the community and give or receive support.



[Register Here](#)

## QUESTIONS OR COMMENTS?

Email us at [info@aldconnect.org](mailto:info@aldconnect.org)

## ADDRESSING PATIENT COMMENTS

*Continued*

### COMMON MRI CONCERNS

#### **"My doctor doesn't recommend annual MRIs."**

The published international consensus guidelines state, "All boys and men with ALD should be screened for cerebral ALD, including in the absence of neurologic or cognitive symptoms."

#### **"I can't afford to pay for an MRI."**

You may be eligible for a clinical trial that would provide travel to be evaluated by an ALD physician and have an MRI at no cost.

#### **"I'd rather not be exposed to radiation."**

No ionizing radiation is produced during an MRI, unlike X-rays. MRIs are safe.

#### **"I'm claustrophobic."**

Ask your physician if they are willing to prescribe medication to help with anxiety prior to the scan.



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