

## How do I get involved?

*Please visit:*

<http://www.aldconnect.org>

- ❖ Become an ALD Connect member!
- ❖ Make a financial contribution.
- ❖ Read and watch our material on line.
- ❖ Join our informational sessions, webinars, and annual meeting to learn more about ALD.
- ❖ Contact your local representative to support newborn screening for ALD.
- ❖ Always feel free to contact us with questions!

[Admin@aldconnect.org](mailto:Admin@aldconnect.org)

[info@aldconnect.org](mailto:info@aldconnect.org)

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## What can I do to help?

**ACT** when you see the signs of ALD  
(**A**bsences, **C**hange in personality or skills &  
**T**an that doesn't go away)

- If you see these signs talk to your pediatrician about checking for ACTH
- Go to [www.aldconnect.org](http://www.aldconnect.org) to learn more
- Contact your local representative to support newborn screening for ALD

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ALD connect seeks to address treatment needs and empower patients, caregivers and their affinity groups to move beyond conventional research participation, advocacy, and fundraising efforts to improve care for and ultimately eradicate this debilitating single-gene disorder.

<http://www.aldconnect.org>

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**Working together for a future  
without**

**Adrenoleukodystrophy.**

**ACT**

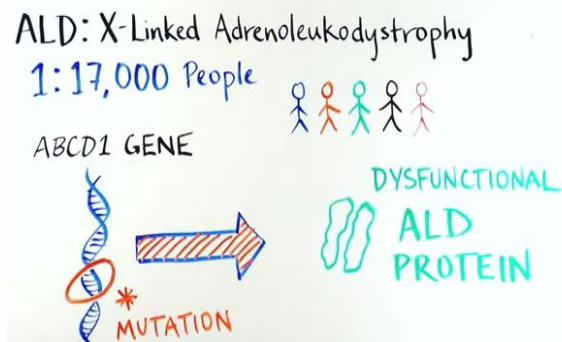
**Help Save a Life!**

**Information for School  
Nurses, Teachers, & Parents**

## What is ALD?

Adrenoleukodystrophy (ALD) is a genetic disorder, made famous by the movie "Lorenzo's Oil."

It is an x-linked disorder that affects 1:17,000 individuals. The condition has a pan-ethnic distribution and affects men more severely than women. Symptoms result from mutations in a single gene (ABCD1), which codes for a peroxisomal protein whose dysfunction leads to the accumulation of fatty acids in blood, myelin, and adrenal tissue.



## Are there different forms of ALD?

Yes. Boys with ALD can present in three ways.

1. No Symptoms
2. Adrenal Insufficiency or Addison's Disease
3. Cerebral ALD (Brain)

Later in life, men can have a 4<sup>th</sup> kind of ALD called Adrenomyeloneuropathy (AMN).

## How can you help?

As a teacher, parent, school nurse, or student you could be the first to see the early signs of ALD. If you see these signs **ACT** and talk to your primary care provider (PCP).

### **ACT when you see early signs of ALD!**

**Absences** from school for frequent infection

**Change** in personality or skills

**Tan** that doesn't go away

- Ask your pediatrician for an ACTH level to check adrenal function.
- Ask if very long chain fatty acid testing is right for your son.

## Why are the early signs of ALD important?

With early diagnosis there are very good treatments for boys with ALD. If boys are not diagnosed early, the treatments available may no longer work. ALD kills boys every year. **YOU can make the difference for a child's life!**

## What are the symptoms of ALD?

### Absences from school:

- Boys can have trouble fighting even small infections.
- Frequent and prolonged absences for illness
- Frequent hospitalizations

### Change in Personality or Skills

- Change in behavior
- Change in how a boy walks or runs
- Change in vision
- Decline in handwriting and school work

### Tan Skin

- Tan skin with no tan line
- Does not fade
- Tan gums and cuticles can also be seen

## How is ALD diagnosed?

Today ALD is diagnosed with a blood test measure of very long chain fatty acids.

New York State has newborn testing. Other states are working to have testing approved as well.

## Treatment

- **Cerebral disease** can be treated with bone marrow transplantation
- **Addison's Disease** is treated with steroids taken as a liquid or a pill.