

ACT

Help save a child's life



Information for school nurses, teachers and parents about Adrenoleukodystrophy (ALD)

What is ALD?

ALD is a rare genetic disorder that mostly affects young boys and men. Onset usually occurs between 4-10 years and can include many different behavioural symptoms.

How can you help?

As a teacher, parent or school nurse, you could be the first to see the early signs of ALD. If you do see signs of ALD ensure the child sees their doctor quickly.

ACT when you see the early signs of ALD:

Absences from school for frequent infection

Change in personality or skills

Tan that doesn't go away



What causes ALD?

ALD is caused by a faulty enzyme which cannot break down Very Long Chain Fatty Acids (VLCFAs) so they accumulate in the brain, adrenal glands and throughout the body. This causes the destruction of the nerve cells affecting speech, listening, comprehension and eventually all the faculties.

Made famous by the movie *Lorenzo's Oil*, ALD affects 1:17,000 newborn children.

More about the symptoms of ALD?

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Absences from school:

- Boys can have trouble fighting infections
- Frequent and prolonged absences for illness
- Frequent hospitalisations

C

Change in personality or skills:

- Change in behaviour
- Change in how a boy walks or runs
- Change in vision
- Poorly articulated speech
- Decline in handwriting and school work
- Poor memory

T

Tan skin:

- Tan skin with no tan line
- Tan doesn't fade
- Tan gums and cuticles

Why is recognising the early signs of ALD important?

Very early diagnosis will save lives as a bone marrow transplant can help to halt the progression of ALD.

How is ALD diagnosed?

ALD is diagnosed via a blood test which measures Very Long Chain Fatty Acids. The Leukodystrophy Resource and Research Organisation (LRRO) is working to have mandatory ALD screening of newborn children in Australia.

Are there different forms of ALD?

Boys with ALD can present in three ways:

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

What treatment is available?

Cerebral ALD is treated with bone marrow transplant.

Addison's Disease is treated with steroids taken as a liquid or a pill.

For more information contact:

Leukodystrophy Resource and Research Organisation Inc. (LRRO)

Phone: 61-7-3283 7224 or 0419 683 195
www.leukodystrophyresourceresearch.org

Useful links:

www.ninds.nih.gov/disorders/adrenoleukodystrophy/adrenoleukodystrophy.htm

www.kennedykrieger.org/patient-care/diagnoses-disorders/leukodystrophy/adrenoleukodystrophy-ald

This resource was developed in conjunction with ALDConnect to meet the needs of Australian families.
www.aldconnect.org/

