

Australian Leukodystrophy Support Inc was established in 1992 by Sr Julie Thomas (OAM) to provide support to sufferers of Leukodystrophy, their families, and their friends.

Activities of the ALDS also include raising awareness of the disease, disseminating information and raising funds for research.

The ways in which the ALDS does this include:

- **ALDS website**
- **Quarterly Newsletter**
- **ALDS Information Kit for Families**
- **Social gatherings**
- **Fundraising activities**
- **Guest speaker at the AGM**
- **ALDS Conference**
- **Promotional DVD**

The ALDS is a voluntary, non-profit organization, which is dependent upon membership subscriptions and the generosity of those who make donations.



Sharing ideas at a Social Gathering in SA

## What is Leukodystrophy?

Leukodystrophy is an inherited progressive, degenerative disease of the nervous system. It is estimated to affect 1:5,000 people worldwide.

Individuals afflicted by Leukodystrophy have a genetic mutation causing an enzyme deficiency. This affects the nervous system as the protective covering (myelin sheath) around the nerve cells of the brain, spinal cord or peripheral nerves, is slowly destroyed.

Investigations such as magnetic resonance imaging (MRI), blood tests and gene analysis are used to confirm a diagnosis of Leukodystrophy.

The range of Leukodystrophies currently identified include:

- **Adrenoleukodystrophy (ALD)**
- **Adrenomyeloneuropathy (AMN)**
- **Metachromatic Leukodystrophy (MLD)**
- **Vanishing White Matter Disorder or CACH**
- **Canavans**
- **Alexander Disease**
- **Pelizaeus-Merzbacher**
- **Krabbe Disease**
- **Neonatal ALD**
- **Zellwegers**
- **Refsum Disease**
- **Aicardi-Goutieres**
- **Cerebrotendinous Xanthomatosis (CTX)**
- **Multiple Sulphatase Deficiency**
- **CADASIL**
- **And the Undiagnosed Leukodystrophies**

The ways in which the defective gene causing Leukodystrophy is passed on through families varies. For example, in X-linked ALD, the mother carries the abnormal gene; while other Leukodystrophies require both parents to have passed on the abnormal gene.

## Signs and Symptoms

The gradual onset of signs and symptoms can occur at any age, from infancy, childhood, to adult life. They include:

- Loss of hearing
- Loss of vision
- Changes in movement, balance, gait
- Speech and swallowing difficulties
- Behaviour problems
- Memory problems
- Adrenal insufficiency (ALD)



Josh entered the Australian Transplant Games in October 2008, participating in athletics.

## Therapies used for Leukodystrophy

There is currently no cure for any of the Leukodystrophies. In certain cases Bone Marrow Transplantation, or a modified diet, may be treatment options but the long-term benefits are not clear.

There are a range of therapies used to assist in living with the disease: physiotherapy, occupational therapy, speech pathology.

Research has made advances into earlier diagnosis and treatments, which gives hope to sufferers and their families and can be useful for genetic counselling.



**Australian Leukodystrophy Support Group Inc.**  
**Membership: \$25 per year**

Please find enclosed my membership subscription/  
donation for \$ .....

Name: .....

Address: .....

..... Post Code.....

Telephone: .....

Cheque - Please make payable to ALDS Inc.

Credit card -  Bankcard  
 Mastercard / Visa

Cardholder's Name .....

Card Number .....

Expiry date .....

Signature .....

Payment      Membership      \$      .00

                  Donation         \$      .00

Total enclosed:                     \$      .00

*Donations of \$2.00 or over are tax deductible.*

I am a:

- Parent
- Affected individual
- Relative
- Friend
- Teacher
- Doctor
- Other health worker

Send to:

ALDS Inc  
10 Mitchell St  
Mentone Vic 3194



## Mission Statement

To provide assistance and information  
to those affected by Leukodystrophy  
and to support research into  
Leukodystrophy

### Contacting the ALDS:

Email            mail@alds.org.au

Phone            03-9584 7070

Fax                03-9583 4379

Website          www.alds.org.au



### DISCLAIMER

The Australian Leukodystrophy Support Group Incorporated  
(ARBN 091 020 021) is proud to be a source of information about  
Leukodystrophies.

This information draws upon a wide range of professional views,  
published experience and expert opinions, which views and conclusions  
remain those of the relevant authors.

The Australian Leukodystrophy Support Group Inc. does not represent  
or warrant the accuracy or effectiveness of the information which is  
provided and it does not represent therapeutic recommendations or  
prescriptions. For specific information and advice,  
you must consult your doctor.

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LEUKODYSTROPHY  
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