

Leukodystrophy Australia

Leukodystrophy Australia is a not-for-profit charitable organisation that exists to support families with one or more members who have been diagnosed with a leukodystrophy, and to raise awareness of this group of conditions. It is a national organisation run by a volunteer Committee of Management and supported operationally by paid staff comprising an Office Manager/Company Secretary and a Family Advocate (both part-time). Volunteers assist with counselling, sourcing and writing grant applications, compiling the newsletter and maintaining the website www.leuko.org.au. Peer support is provided by individuals who volunteer their time to support other affected families, on a one-to-one basis.

The group supports approximately 200 families, who may be at any stage of their journey with leukodystrophy, from awaiting confirmation of diagnosis, through dealing with the health and socio-emotional impact of the condition, to bereavement and beyond. Leukodystrophy Australia was established 20 years ago by a Brigidine nun, Sister Julie Thomas, who was herself diagnosed with a form of leukodystrophy and found there was no support group in Australia. Leukodystrophy Australia has since grown into an incorporated association providing services to families throughout Australia. As Leukodystrophy Australia's public profile and awareness of leukodystrophies increase, particularly amongst the medical fraternity, our Australia-wide membership remains on an upward curve. Leukodystrophy Australia does not currently receive Government funding. Instead the organisation relies on the generosity of donors, subscribers, fundraisers and philanthropic organisations to maintain the level of support that we know families affected by this group of conditions need and deserve.

In addition to advocacy, which is a strong focus of the support we offer our members, Leukodystrophy Australia also provides many other practical supports where possible:

- Counselling
- Direct financial assistance at times of crisis
- Funding for specialised equipment and support services
- Information and resources
- Strengthening local formal and informal support systems
- Companionship through social functions and links with similarly affected families
- Quarterly newsletter
- Website
- E-News

Privacy & Confidentiality

At Leukodystrophy Australia we treat any information you give us with the utmost respect and confidentiality. It is securely stored. Our full Privacy Policy is available on our website www.leuko.org.au.

When you contact Leukodystrophy Australia, we are able to talk to you without knowing your name or any personal details. We will make every effort to provide the information and support you need, and if you prefer to remain anonymous we will certainly respect that wish. However, in many cases we can support you more effectively if you are willing to provide some personal information about your circumstances.

What information might you be asked to provide?

There are three different levels of information that we may ask you to provide:

Contact details. Simple contact details assist us to tell you about services that are local to you (Leukodystrophy Australia supports families from all over Australia), and to enable us to send you printed or emailed information.

If you choose to become a member of Leukodystrophy Australia we do need some basic information:

This may include such details as the name of the particular leukodystrophy that has been diagnosed (if known), the birth date of the sufferer, and general information about other family members. You are also welcome to provide additional information as relevant, to help us to meet your needs.

More comprehensive personal information, including other services that you receive, your particular issues and support networks, and more detailed health-related information.

Confidentiality and consent to share information

Similarly, Leukodystrophy Australia personnel will only share your information to other people, including workers in other organisations, if you have given written consent for this to occur or, if this is not possible, with verbal consent that is documented at the next available opportunity.

Our Family Advocate is required by her professional Code of Ethics to keep professional notes of her contact with individuals and families. Our intention is that you experience openness, trust and respect in all your dealings with Leukodystrophy Australia, and you are entitled to ask for information about what has been documented. You are also entitled to see the contact notes, although the documents themselves remain the property of Leukodystrophy Australia. You can only access information that relates to yourself or your dependent children.

The 3 most common reasons for Leukodystrophy Australia to ask your permission to share information are:

To assist families affected by a leukodystrophy to meet and offer mutual support, and

To enable the Family Advocate to adequately support you and advocate on your behalf, for example by making referrals to other services or to receive information from them that concerns you.

To assist in grant writing, although it can be de-identified and permission will be requested beforehand.



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