LEUKODYSTROPHY .org.au AUSTRALIA

Family Advocate

In March 2010, Leukodystrophy Australia employed a Family Advocate, as a result of a grant from the Paul Newman's Own Foundation. Further grants from the St George Foundation and Lord Mayor's Charitable Trust, together with other donations, have enabled us to continue the role beyond the initial 12-month period.

Our Family Advocates are part of a team of people at Leukodystrophy Australia who are committed to supporting people affected by leukodystrophy. Others in this team include a volunteer Management Committee and volunteer Peer Support Leaders, together with Leukodystrophy Australia members who volunteer their time.

The Family Advocates are qualified social workers with extensive experience. They are available to talk to individuals, families and others right across Australia. As well as contact via phone or email, the Family Advocate aims to visit each state.

What does the Family Advocate do?

This role has three main parts:

Direct family support

The Family Advocate has direct contact with people who are diagnosed with a leukodystrophy, their family members, and/or friends. You might want to talk to the Family Advocate about things like:

- What it's like when you or someone you care about is affected by leukodystrophy
- Finding information about your particular type of leukodystrophy
- What services are available
- How to access services (including assistance if you are having difficulties accessing a service to which you are entitled)
- Where to find the right support or assistance for anything else that is troubling you.

The Family Advocate can also talk to your doctor, other workers, or anyone else that you give her permission to speak to. (For more details, see our full Privacy & Confidentiality Policy www.leuko.org.au)

The Family Advocate does not replace your own local support network. It is important that you have a doctor, case manager and/or other workers who can meet with you regularly and who are familiar with your situation and local service system.

Professional liaison

An important part of the Family Advocate's role is to be in contact with professionals from a wide range of disciplines around Australia, including doctors, nurses, therapists, social workers and teachers. In this way, Leukodystrophy Australia contributes to local service systems' effectiveness in responding to the needs of individual families and family members. Individual information is only shared according to the principles of our Privacy & Confidentiality Policy.

Community Education

The Family Advocate gives talks to professionals and community groups, to raise awareness about leukodystrophy. She also provides information directly to medical and other staff to ensure that they are informed about the needs of people with leukodystrophies.

A note about advocacy

Advocacy can be divided into two areas: individual advocacy, and systemic advocacy.

Individual advocacy means helping your voice to be heard. This can involve the Family Advocate attending meetings or appointments with you, or speaking to other people on your behalf (with your permission). The Family Advocate can also write support letters to help you access services and other supports.

Systemic advocacy means promoting the interests of people with leukodystrophy generally. For example, the Family Advocate writes submissions, links in with other advocacy groups working to improve the services available to people with disabilities or health conditions, and meets with decision-makers to inform them of the needs of people affected by leukodystrophy.

How can I contact the Family Advocate?

You can contact the Family Advocates on: 1800 141400 or 0418 790 059 or advocate@leuko.org.au

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