



EXPRESSION OF INTEREST – COMMITTEE MEMBERS

Leukodystrophy Australia

Leukodystrophy Australia is the national peak organisation representing people impacted by leukodystrophy. We collaborate with local, national and international stakeholders to advance the care of our members, improve quality of life and ultimately seek a cure for leukodystrophy.

Number of Paid Staff: 2

Number of Volunteers: 3-7

Community Segment: Health, Disability, Wellbeing

Current Committee Size: 3-5

Committee Meetings (frequency): Monthly - Bi-monthly as required

Committee Meetings Held: 7pm

State where Committee Meetings Held: Teleconference or Zoom from any state

Other Meetings/Events: AGM, other occasional events where possible i.e. Family Gathering

Location: National

Payment: Nil - honorary role

Committee Positions:

Leukodystrophy Australia (LA) Board positions vacant – President, Vice President, Treasurer, Secretary, Public Officer, General Committee. People with skills to share: Governance, Finance, Medical, Scientific, IT, Social Media, Networks, an interest in rare disease.

We are seeking experienced and committed qualified persons with an interest in maintaining an effective, professional and accountable Committee to oversee operations in our Mission to support and empower individuals and families living with the rare disease, Leukodystrophy, to live their best possible life.

As a specialist not-for-profit LA is the peak support organisation in Australia, providing information and support across all stakeholders, in a non-discriminatory and equitable basis to some of the most disadvantaged and isolated men, women and children across Australia.

We advocate for clients and educate stakeholders, operating holistically to empower and assist individuals and families and the common issues they face.

LA embraces innovation in responding to emerging issues in the health landscape. We are seeking enthusiastic individuals who align with our Vision, Mission and Values.

Vision

Empower people affected by leukodystrophy, through knowledge and support, to lead their best lives.

Mission

We strive to support people throughout their leukodystrophy journey and beyond. We foster member connections, provide service linkages, financial support, education, advocacy and promote current trends in treatment and research.

Values

Leukodystrophy Australia are committed to the following values:

Respect:

We respect and recognise our members' abilities, qualities, achievements and lived experiences.

We strive to ensure equitable access for all people with a focus on priority populations (Aboriginal and Torres Strait Islander peoples, people living in regional, rural and remote areas, people from Culturally and Linguistically Diverse backgrounds and people experiencing socio-economic disadvantage).

We demonstrate a commitment to providing respectful, safe and inclusive support for people of all abilities, gender identities and ages.

Self-determination:

We support and advocate for the rights and choices of members in their health and wellbeing decisions.

We work collaboratively with health professionals and other service providers to assist members to reach their full potential.

We promote and contribute to multidisciplinary research that seeks to improve treatment, quality of life and find a cure for leukodystrophy.

Accountability:

We have rigid and transparent practices and processes that value the contributions of people affected by leukodystrophy, members, volunteers, donors, and beneficiaries ensuring accountability, financial integrity and high-level service delivery.

Professionalism:

Our employees, committee members and volunteers demonstrate professionalism in undertaking our organisational activities.

Our service delivery is guided by the principles of social justice, accountability, transparency, trust, equality and equity.

Evidence informed:

We incorporate our members' experiences and feedback, current research and ongoing professional development to inform our program and support services planning and delivery.

As we strategically look at ongoing succession planning, we would like to appoint Committee Members with significant financial and governance experience, other talented and varied skills, as we sustain our organisation into the future.

Please contact us for further information, including role descriptions and our committee vacancies. We encourage all candidates to apply. Our goal is to make everyone feel involved, respected and connected. Your applications will be assessed for suitability by the committee.

Please include in your expression of interest:

A cover letter outlining your interest in the position and relevant skills

A Curriculum Vitae (limited to 2/3 pages) outlining:

- your contact details - phone and email
- your experience including relevant employment and volunteering, honorary positions held and qualifications
- your reason for wishing to join LA

Do you have further questions?

For a confidential discussion about the position, please contact:

0418 755 994 or 1800 141 400 or email info@leuko.org.au

We look forward to hearing from you.