



## EXPRESSION OF INTEREST – COMMITTEE MEMBERS

### **Leukodystrophy Australia**

Leukodystrophy Australia is the national peak organisation representing all people impacted by Leukodystrophy. We share in the same vision to source a cure for Leukodystrophy worldwide. We collaborate internally and externally with all stakeholders to advance the care of our members.

**Number of Paid Staff:** 2

**Number of Volunteers:** 3-7

**Community Segment:** Health, Disability, Wellbeing

**Current Committee Size:** 3

**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

### **About these vacancies:**

Leukodystrophy Australia (LA) Board positions vacant – President, Vice President, Treasurer, Secretary, Public Officer, General Committee. People with skills to share: Governance, Finance, Medical, 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**

Those living with leukodystrophy, through knowledge and support, lead their best lives.

### **Mission**

We assist in empowering people throughout their Leukodystrophy journey and beyond. We offer support, foster member connections, provide service linkages, education, and advocacy, and promote current trends in treatments and research.

## Values

Leukodystrophy Australia are committed to the following values:

- Respecting and recognising our members' abilities, qualities, achievements and their lived experiences.
- The rights and choices of members to have a say in their health and wellbeing.
- Collaboration with health professionals and other service providers to assist members in reaching their full potential.
- Rigid processes by which members, donors, beneficiaries and their financial contributions assist in sustaining service delivery.
- Current multidisciplinary research in the hope for improved outcomes for members and finding a cure for Leukodystrophy.
- Professionalism in all activities and a team environment.
- Service delivery informed by the principles of social justice, accountability, transparency, equality and equity.

LA is at the early stages of a new strategic sustainability journey. With a re-brand in 2015, plans for growth of services to meet our clients' needs and increasing client demand due to advancement in genomics, we see an increase in numbers diagnosed. Securing alternative sources of funding, and expanding our Family Advocate Program are areas of focus for the year ahead.

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

Please contact us for further information, including Role Descriptions. 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](mailto:info@leuko.org.au)

Please note: screening and interviews may take place prior to the advertised close date. As such, please submit your EOI as soon as possible.

Please send your Expression of Interest to [info@leuko.org.au](mailto:info@leuko.org.au) with the subject line **"Expression of Interest: LA Committee."**

Applications are acknowledged by email and treated in confidence. We look forward to hearing from you.