

## Leukodystrophy Australia Strategic Plan 2019-2021

<b>Vision</b>	Those living with leukodystrophy, through knowledge and support, lead their best lives.			
<b>Mission</b>	We assist in empowering people throughout their Leukodystrophy journey and beyond. We offer support, foster member connections, provide service linkages, education, advocacy and promote current trends in treatments and research.			
<b>Strategic Objectives</b>	To be uniquely positioned as a proactive national peak body for LD.	To represent a collective voice of people impacted by LD.	To provide updated education and information and improve awareness / understanding of LD.	To provide valued support services to meet members' needs and foster their self-determination around their LD.
<b>Actions</b>	<p>1) Maintain an effective, professional and accountable Committee to oversee operations.</p> <p>2) To deliver effective service provision annually. <b>KPI provide 200 phone counselling / support / information, to members and their families, 50 face to face, 4 group events (identify service provision LA can monitor and provide a result)</b></p> <p>3) To grow financial revenue for continual service delivery via donations, fund raising, grants and bequests.</p> <p>4) To provide membership for members and others impacted by LD.</p> <p>5) Improve our public profile by engaging in strategic PR activities.</p> <p>6) Provide a culturally sensitive organisation where all people feel welcome.</p>	<p>1) Deliver a professional and effective advocacy program.</p> <p>2) To provide regular opportunities for members to collaborate and assist with policy changes and research.</p> <p>3) Render, network and maintain strong relationships with genetic services and other professionals with an interest in LD.</p> <p>4) Engage with government agencies, non-government organisations, corporate and the community. <b>KPI Develop tools in partnership with key stakeholders, or hold 10 meetings with 5 key stakeholders eg genetic organisations etc.</b></p> <p>5) Engage families impacted by LD to be involved with all policy related to LD and rare diseases.</p> <p>6) Engage with International LD service providers to keep up to date with latest developments.</p>	<p>1) Deliver education and information on LD via multiple channels. Improve the reach to cover more rural and remote communities. <b>KPI Website upgrade to deliver one stop shop for information and resources.</b></p> <p>2) Design, implement and evaluate tools to deliver across the medical, allied health providers, NDIS, disability and community sectors. <b>KPI Education and community engagement with 5 per state based major hospitals, 20 x neurological and related health professionals nationally, 1 x Massimo's Mission Leukodystrophy Clinic RCH, 10 x networking i.e. conferences (in-house and/or other organisations).</b></p> <p>3) Engage with educational institutions to provide academics and students with an insight into how LA operates.</p> <p>4) Engage families to deliver education on their personal lived experiences.</p> <p>5) Seek opportunities to improve profile of LA to raise community awareness.</p> <p>6) Provide current information based on evidence-based practice on diagnosis, treatments and supportive care to maintain an optimal quality of life.</p>	<p>1) New LD members / carers are supported and made to feel welcome.</p> <p>2) Offer support and referral to those who are bereaved.</p> <p>3) To foster knowledge sharing opportunities in order to develop new informational resources for all stakeholders.</p> <p>4) Link families so they may form and strengthen appropriate relationships and provide peer support.</p> <p>5) Provide families with financial assistance to meet required needs. <b>KPI provide financial support to 20 families annually</b></p> <p>6) Provide appropriate social events for our members such as family gatherings, charitable events and sporting events.</p>
<b>Outcomes</b>	<p>1) Improved public policy for those living with LD.</p> <p>2) We are provided with feedback via members and other stakeholders.</p> <p>3) LA will continue to meet their obligations.</p> <p>4) LA continues as a going concern. Engagement of all stakeholders.</p> <p>5) PR strategies will raise the consciousness of LD to a wider audience.</p> <p>6) Engagement of all people.</p>	<p>1) We deliver a national advocacy program to our members and others.</p> <p>2) Members and others are well informed and policy and research continues to be fostered.</p> <p>3) We are an active and effective partner with relevant stakeholders.</p> <p>4) Relationships maintained with strategic partners. Maintain / encourage staff productivity and innovation with supportive, diverse, nurturing and open environment.</p> <p>5) Representation of LD families nationally.</p> <p>6) Current information from a broad International base available for the benefit of members.</p>	<p>1) Appropriate information on LD is provided via multiple channels.</p> <p>2) Effective delivery of LA information resources.</p> <p>3) Provide relevant LA information to academics and offer student placements.</p> <p>4) Community consciousness is raised in relation to those impacted by LD.</p> <p>5) Increased funding and support broadly across the community.</p> <p>6) Options around improved health and wellbeing.</p>	<p>1) Engage with and welcome new members as soon as possible.</p> <p>2) Support through bereavement nurtures healing.</p> <p>3) Members' lived experiences are acknowledged and utilised.</p> <p>4) Positive feedback about Family Gatherings and peer support.</p> <p>5) Families provided with appropriate equipment, respite and other resources.</p> <p>6) Socialisation and fundraising for the benefit of members.</p>