

Family Gathering: Western Australia

BACKGROUND

Leukodystrophy Australia is a national peak organization, which has been in operation for 29 years. It exists to provide information, support and advocacy to individuals and families affected by leukodystrophy, to raise awareness of this group of conditions, and to encourage leukodystrophy-related research. It supports families across Australia, including those in regional, rural and remote locations, by providing crisis support, service linkages, education, advocacy, and ongoing support. Leukodystrophy Australia also recognises that opportunities to build connections with other families, who are similarly affected, has significant potential to enhance well-being and quality of life. Peer support, family gatherings and events are core to these aims.

AIMS

- To deliver a Family Gathering to Leukodystrophy Australia families and members in Western Australia (4000 kilometres from our current base) and across the second largest country sub-division in the world.
- To provide education and support to Western Australian families affected by leukodystrophy.
- To support reconnection and facilitate new relationships between this population.
- To understand the potential for future support, linkages and events.

EVENT

Despite being required to cancel our scheduled 2020 event due to a Covid-19 lockdown, and restrictive Australian state border controls in 2021, we were able to hold a successful - although modified - Family Gathering on October 30th, 2021. The event was held in Perth at St Catherine's on Park, in the suburb of Nedlands. It hosted 21 Western Australian participants for a full day of activities.



The day commenced with virtual messages from the Leukodystrophy Australia Committee and Family Advocates (who were initially planning to attend, but were unable to due to border closures). Speakers from two local organisations (Carers WA and People With disabilities Western Australia [PWdWA]) presented on topics including caring support, local services, disability and self-advocacy, and good discussion ensued. The event also included an exploratory musical experience by a group of local artists, facilitated through the *Safe in Sound* program. This program creates music that explores sound to stimulate the listener, hence encouraging participation and much enjoyment for the audience as they witness the star of the show, a Leukodystrophy Australia family member, alongside the SIS musicians.



Importantly, families were provided with welcome bags including information about our organisation, important resources and self-care items. Families were offered the opportunity to connect and support each other through sharing experiences, successes and losses prior to the commencement of the day's planned agenda, over the lunch time period, and while enjoying the fresh air in the garden courtyard and grassed area. Furthermore, a variety of creative activities were offered in the afternoon, including a photo booth with fun props, card games, colouring and learning the Japanese art of gold repairing (Kintsugi).

ONGOING CONNECTIONS

Plans are being made, through our on-ground representative, to develop these existing linkages across time, engage in networking with services and programs within the area, and to participate in training opportunities. This will assist with the planning and development of future activities and peer support, ensuring service provision is community informed and led.

