

2022



Chair Report



Sheridan Campbell

Fabry Australia

The Fabry Australia Committee of volunteers, continued to fulfil its goal of, 'Uniting and Supporting the Australian Fabry Community', in the 2021-2022 year. Fabry Australia provided ongoing support to patients, carers, and health professionals, as well as fostering working relationships with industry and other patient advocacy groups.

Advocacy and Activities.

Guidelines Review Project and Life Saving Drug Program Review.

The Fabry Australia Medical Advisory Committee published a White Paper titled, 'Preventing the consequences: An evidence-driven proposal for a change in the treatment paradigm for Fabry disease to ensure timely and equitable access to treatment after confirmatory diagnoses'. The purpose of this paper was to examine the evidence and advocate for review and change, of the eligibility guidelines for treatment, within the Life Savings Drug Program (LSDP). The guidelines for treatment have not been reviewed for 15 years. Fabry Australia presented this White Paper to the LSDP and will shortly publish an article for peer review, based on the findings of the research. Thanks to the Medical Advisory Committee and medical writer, Hazel Palmer, for their extraordinary efforts on this project, which we hope will instigate change, regarding access to treatment.

The Life Savings Drug Program review is ongoing, with both the Fabry Program and the review of the medicine 'Migalastat' occurring concurrently. Fabry Australia lobbied for improved access to Migalastat (an oral Fabry medication) and for improvements to the program overall. Fabry Australia welcomed both reviews and we hope for a favourable outcome.

Webinar and Events.

In September 2021, we hosted a webinar, with speaker Virginia Wiggins, of the NDIA. She presented and generously offered her time, to answer attendees' questions about the NDIS.

Fabry Australia hosted a WA patient meeting in Perth, in December. Unfortunately, face-to-face gatherings remain challenging, and we need to continue to find innovative ways to meet. Despite the small attendance, those who did attend, appreciated the opportunity to meet.

International Rare Disease Day was again a highlight of the calendar, with the 'Be Rare, Be You' temporary tattoos, once more spreading the message of the need for support, in the rare disease community. We look to expand our 'Be Rare, Be you' merchandise range, so keep an eye out for this, later in the year.

In April we celebrated Fabry Awareness month. We participated in the 'Cool down for Fabry' social media campaign and collaborated with Optometry Australia, to raise the awareness of Fabry disease amongst optometrists, who often detect early signs of Fabry in the eye.

Member support.

The 'E news' is published quarterly, containing important 'news' items to our membership, we also communicate regularly via Face book and Instagram. We host a closed face book page, for members to share information. We continue to respond to numerous email and phone enquiries.

This year we updated and reprinted the 'Understanding Fabry' fact booklet and continued to distribute OMIM cards to members, as requested.

With close to 500 members, we've recently upgraded our data base program, to assist in management and administration of our member data base. Integrations have improved efficiency and our website is currently in the process of being revamped, making it more user friendly and accessible.

A project which is nearing completion is the adaption of the 'Faber the Dragon' book into an animation. This will be a useful resource for our younger patients, and we look forward to sharing the final edit with you in the coming months.

We have been planning a virtual conference for October this year and also look forward to the opportunity to meet in Qld in March, for the long-awaited wellness retreat – hopefully, third time lucky.

Representation.

Fabry Australia participated in various forums throughout the year. In December, Sheridan took part in a 'Fabry Women' round table, hosted by the Japanese Fabry Association. This was an opportunity for dialogue between Australia, Japan, Taiwan, and South Korea.

Fabry Australia attended the Fabry International Network (FIN) virtual expert meeting, as well participating in FIN meetings via zoom. Fabry Australia virtually attended the WORLD lysosomal storage disorders conference and the Rare Voices Australia virtual summit. We continue to work with other advocacy groups including Rare Voices Australia, Genetic Alliance Australia, Genetic Services Network Victoria, and the National Patient Organization Network.

We continue to work collaboratively with industry groups, who have an interest in Fabry disease. We advocate for access to currently available treatments and encourage participation in clinical trials.

Acknowledgements.

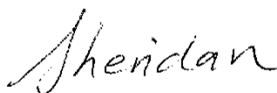
I'd like to thank the Fabry Australia committee of volunteers, for gifting the Fabry community with their knowledge, energy, and time. Thank you to Di Wallyn, Linda Schmetzer, Anne Hunter, Tanya Tindall, Mark DeWolf, and Gavin Schmetzer.

Thanks to our Fabry Australia Medical Advisory Committee, consisting of Dr Kathy Nicholls, Dr Charles Denaro, Dr Michel Tchan, Dr Carolyn Ellaway, Dr Mark Thomas and Dr Drago Bratkovic. Their advice and expertise is invaluable.

Thanks also to industry groups, Amicus Therapeutics, Sanofi Genzyme and Takeda, for their ongoing support of Fabry Australia and our activities.

Thank you to our various contractors who assist with book-keeping, accounting, research, IT support, printing, and publishing. A special thanks to Sam Spence, who assists us so wonderfully with our social media pages and administrative support, when needed.

Lastly, thanks to our members, for their ongoing association and support of Fabry Australia. It's truly appreciated, and by working together we can achieve wonderful outcomes for the Australian Fabry community.



Sheridan Campbell
Chair Fabry Australia Committee

