

ANNUAL REPORT 2021-2022

The Australian Pituitary Foundation (APF) has had a busy year throughout 2021-2022, with the Board appointing our inaugural General Manager, who is charged with actioning the vision and strategy of the APF, as set by the Board in May 2022. The Board also recognised the importance of re-connecting and bringing the community together after the last few years of the COVID-19 pandemic and held a series of successful Pituitary Awareness Month events.

We are grateful to our two new Board members, Geoff Musgrove and Robert Price, who have made a significant contribution to the success of the APF over the last 12 months, especially in relation to our ongoing compliance with finance, risk and governance requirements. The APF Board would also like to acknowledge the contribution of Kimberly Statham for her contribution and the professional expertise that she provided over the last couple of years as a Director of the APF Board and Chair of the Finance Risk and Governance Subcommittee. Kimberly stepped down from her position as Director in July 2022 and we wish her all of the best.

We also extend this gratitude to all Board members for their unwavering dedication to the APF community and for the significant contribution made by each individual Board member, and to the Board as a whole. This is the first year that we have held the positions of Co-Chairs of the APF Board and it has been a successful transition from the wonderful work of Yi Yuen Wang as Chair of the APF Board. Yi Yuen continues to be a dedicated and invaluable Board member and we are proud of the work that he had done and continues to contribute to the APF.

We also wish to acknowledge and thank the APF Medical Advisory Committee (MAC) for their dedication and support, with many members of the MAC having a long-standing association with the APF. The contribution and expertise of the MAC is very greatly appreciated and valued by the Board and the APF community and we are very grateful.

Activities

At the start the year, we wanted to make sure that the APF was structured in an effective way to ensure we were able to better support pituitary patients and their families, and also ensure we remained transparent in our activities and compliant as a registered charity. As part of this the APF established a number of sub-committees including:

- Finance, Risk and Governance – Chaired by Robert Price
- Fundraising and Comms – Chaired by Kimberly Downes
- Patient Support – Chaired by Malini Raj

- Pharmaceutical Advisory – Chaired by Lisa Sullivan
- Medical Advisory Committee – Chaired by Yi Yuen Wang

These sub-committees are also partially run and supported by patient volunteers so we thank these volunteers for their contribution.

The APF hosted a Meditation and Mental Health Awareness Webinar on the 9th October 2021. We felt it was important to acknowledge the potential mental health impact on patients and carers when managing a chronic medical condition, and acknowledge that this is an area in which patients may require support. The presenter ran a meditation session and there was a demonstration of the Allevi8 app.

In honour of Cushing's Awareness Day, the APF hosted a Cushing's Awareness Webinar on Saturday 9th April 2022. As part of this Webinar, we had speakers representing a cross section of patients and specialists, with the information being presented in a way that was easy to understand. This Webinar has also been shared on the APF YouTube Channel.

The APF had our inaugural General Manager, Marla Cawthorne, commence at the start of May 2022. This also coincided with our Board strategy day which was held on the 14th May 2022, with the focus being on better outcomes for pituitary patients. There were a number of key areas identified, including better education on pituitary conditions for health professionals (such as GPs), greater patient and family support and increasing awareness.

In terms of advocacy, at the March 2022 Pharmaceutical Benefits Advisory Committee (PBAC), a position recommendation was provided for the listing of long acting (once-a-week) Growth Hormone (GH) treatments on the PBS. We thank the patients and their families/carers who provided valuable input into the PBAC consultation as this was integral to the outcome, which will help improve the quality of life for adults and children with GH deficiency.

In June 2022, the APF also re-established the quarterly newsletter, The Pituitary Connection. We wanted a way to regularly stay in touch and keep our community connected and a newsletter is a great way to share information, events and other relevant topics with our APF family. The first issue was sent out in June 2022 and has continued each quarter since then.

Prior to the end of 2021/2022, it was recommended to the Board that we refresh the APF website with relevant and up to date information that was easy to access and understand. It was also identified that the APF IT services and security and member database were also in need of an update. These activities have now been completed and will be reported in the 2022/2023 annual report.

The APF also hosted a series of support groups via Zoom in August 2022, and in-person events for Pituitary Awareness Month in October 2022 – these will be reported in the 2022/2023 annual report.

Membership and Community

We continue to see growth in membership, donors and friends of the Foundation, with over 500 members of our community. There were some minor issues experienced with the new automated membership renewal reminders and process, however we have done further work in 2022 to ensure these issues do not continue and a new membership database has been implemented to assist with these improvements.

APF as at 30th June 2022

- Community – 533
 - Membership – 71
 - Friends – 430
 - Donors – 32

- Volunteers
 - Directors – 6
 - Medical Advisory Committee – 5
 - Patient Support Subcommittee – 3
 - Fundraising and Comms Subcommittee – 2

Finances

The APF continues to remain in a good fiscal position (P&L attached) based on the steady sponsorships, grants and donations in the prior 12 months and low operating costs. In light of this, the APF Board were able to appoint Marla Cawthorne into the role of General Manager in May 2022, with a 12-month contract. The APF were also able to fund a research grant to the Garvan Institute of Medical Research in support of the pituitary tumour bank, this is with thanks to the generosity of Mr PS Lee for his kind contributions to the research fund in prior years.

Events/Activities that have occurred during the period 1st July 2021 to 30th June 2022

- APF subcommittees established and holding regular meetings.
- Mental Health Awareness Webinar – 9th October 2021
 - 1 Speaker – Cathy Brown (Allevi8) - meditation mentor and clinical hypnotherapist.
- Cushing’s Awareness Webinar – 9th April 2022
 - 5 Speakers – Dr Yi Yuen Wang, Dr Cecilia Gzell, Dr Dilan Seneviratne, A/Prof. James Lee and Jack Forrest (patient speaker).
- Submissions provided to the March 2022 PBAC meeting for long acting (once a week) growth hormone treatments.
- Funding grant provided to the Garvan Institute of Medical Research in support of the pituitary tumour bank, thank you to the generosity of Mr PS Lee for his kind contributions to the research fund over the years.
- Board Strategy Day held in May 2022, with clear strategy and associated actions agreed by all.
- The Pituitary Connection Quarterly Newsletter – re-established and distributed via email in June 2022.