

Cystic Fibrosis WA (Inc)

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Minutes of the Annual General Meeting

Held via Zoom videoconferencing and at The Niche 11 Aberdare Road Nedlands WA 6009 for the Panel. Wednesday 19th June 2024, commencing 6:00pm

Present

Marija Andacic, Lisa Bayakly, Amanda Bearcroft, Caz Boyd, Charlotte Burr, Matthew Casey, Rachael Clifton, Steffan Crausaz, Victoria Glassey, Jessica Hollinshead, Gillian Hoyland, Anthony Kicic, Ingrid Laing, Sophie Longton, Mitch Messer, Nadia Mitsopoulos, Damien O'Reilly, Cesare Papa, Gavin Pearce, Ric Reyerson, Anna Rodger, Feliciano Sanchez, Colin Savory, Linda Smith, Rowena Smith, Adrienne Thomas, Sarah Thomas, Mel Tibbitts, Vanya Tierney-Sanchez

Formal Apologies

Nigel Barker, Michelle Buck, Wendy Endebrock-Brown, Tracey Kane, Bob Laing, Sue Morey, Jennie Nilsson, Sally Rose, John Rothwell, Sam Wallace

Welcome

CFWA President Damien O'Reilly (DO) welcomed attendees and delivered an acknowledgement of country.

Special Acknowledgements

DO made two special acknowledgements:

- Retired Patron John Rothwell who served as patron of CFWA for 14 years.
- Retiring board member Caz Boyd (CB) who served as a CFWA Director (including two terms as Board President) for 14 years.

Both made invaluable contributions to the organisation during their respective tenures and DO paid tribute and thanked them both. DO then invited CB to say a few words. CB reflected on her connection with CFWA over many years. She thanked the board and CFWA team for their support during her Board tenure and pledged her continued support for the organisation.

Panel Discussion

DO introduced the guest speaker panel comprising facilitator CFWA Occupational Therapist Mel Tibbitts (MT), ABC Radio Mornings host Nadia Mitsopoulos (NM), and 2024 Western Australia of the Year (Community Award) Mitch Messer (MM).

MT opened the panel discussion by sharing information about her role and focus at CFWA and CFWA's CF Connect peer connection forums. Each of the panel members then spoke about the meaning of community and connection to them, relevance professionally and personally, and how they build connection.

Some highlights included:

- the importance of a supportive peer community throughout life stages;
- the importance of community voice and engagement and its impact on advocacy and treatment outcomes for the CF community;
- community participation in radio enabling diversity in perspectives;
- the impact of constructive communication in helping to drive change;
- being open to perspectives and connecting with the person first; and
- listening and taking time to gain deeper insight from interactions.

Vote of thanks and questions

MT extended a vote of thanks and then opened the floor to questions with some follow-on questions and discussion about the experience on radio and dealing with different stakeholders including politicians.

Formalities

LB officially opened the AGM, declared quorum, and noted several apologies were received which are recorded in the minutes. LB added her thanks to the panel, highlighting how important community connections are for CFWA, in supporting individuals, families and carers, and working with our stakeholders.

CEO's & Treasurer's Overview

Before overviewing results, LB gave upfront thanks to the CFWA team for their client focus and ongoing efforts to better support community.

LB highlighted key aspects of CFWA's financial performance:

- 2023 was a positive year for CFWA financially.
- CFWA's financial performance and reserves are well managed to make sure the association can continue to meet client needs.
- Our largest portion of income is from the Dept of Health WA (HDWA) at 40%.
- As the HDWA income is a fixed amount per annum (indexed), CFWA has increased fundraising and grants to meet growing demand and costs.
- Fundraising is prone to ups and downs but CFWA's 2023 result was excellent, being \$1m in income, which was above budget and back to pre-COVID levels.
- After balancing operating income and expenditure, CFWA had a positive move in its invested reserves leading to a net \$100k profit.
- LB noted above budget income funded increased service demand and costs; some essential IT upgrades; and further research.

LB thanked every single volunteer, ambassador, community fundraiser and donor, and referred people to CFWA's annual report for more stories and photos.

LB highlighted key aspects of CFWA's operational achievements:

- Demand for services and supports was strong in 2023.
- CFWA supported 140 clients with airway clearance, exercise support or respite. Despite plenty of change through COVID, client feedback tells us these services are very relevant to treatment routines and quality of life.
- We supported more people experiencing financial pressure, with 25% increased payments.
- We increased our focus on wellbeing and peer support including the remote peer connection sessions for children that MT runs.
- We undertook a major consultation/review of changing community needs and identified priority areas such as planning for the future (finance, employment) and adapting to changes in self-care and support networks. In 2024, CFWA will focus on new resources and supports in these areas, working in close collaboration with health professionals.
- We provided CF and respiratory education across WA, including with TKI, to raise awareness that chronic wet cough should be assessed. We provided resources, education sessions and HP training, similar to CF programs.
- CFWA's advocacy contributed to the expansion of Trikafta™ access to eligible 6-11-year-olds, expanded access to other treatments; and increased staffing at the adult CF clinic to cater for increased patients and needs.
- CFWA contributed \$205k toward CF research through grants.
- The CFWA John Gillard Family Golf Classic marked a milestone \$1 million raised for CF research.

CFWA's new Strategic Plan for 2024-2027

LB noted CFWA has finalised its new *Strategic Plan 2024 - 2027* following significant consultation with community and stakeholders. Strategic objectives are build off progress in recent years. Key points noted included:

- Our vision looks a little different. This was previously *Lives unaffected by CF*, however, the new vision is more meaningful to all our clients. It recognises that the experience of each person with CF is different and provides for our work in other respiratory areas.
- Our team's purpose and vision is "To improve the lives of people and communities impacted by cystic fibrosis, respiratory conditions, and rare disease"; to help enable "thriving individuals, families and communities"
- A key focus will be adapting our resources and supports to cater for people aging with CF and changing needs and evolving our advocacy and research to focus on these. These areas are aimed at enabling all people with CF to benefit from enhanced treatments, care and support.
- We will continue to focus on raising awareness and education on respiratory health and rare disease. We have found a lot of synergies in the chronic wet cough work with regional communities. It has led to new staff, ideas and funding; all of benefit to the CF community too.
- The plan also reflects that we are part of a network of people supporting the CF and broader community – we will continue to focus on relationships and collaboration; and feedback will be a key way we measure our success.

The Strategic Plan and 2023 Annual Report can be found on the CFWA website.

Resolutions LB tabled the following resolutions:

Confirmation of Minutes of AGM held 14 June 2023

The minutes of the 2023 AGM are a true and correct record. Moved Damien O'Reilly, Seconded Sally Rose; Approved and carried
(For: all, Against: 0, Abstentions: 0)

Appointment of Auditors

This AGM appoints Hall Chadwick as financial auditors for the 2024 financial year. Moved Damien O'Reilly, Seconded Sally Rose; Approved and carried
(For: all, Against: 0, Abstentions: 1)

Business Arising

There was no business arising from the 2023 AGM and no new general business.

Elections of Board members

Nominations to fill up to four two-year Board vacancies closed 17 June 2024. With 4 nominations and no surfeit, these individuals were duly elected: Damien O'Reilly, Rowena Smith, Steffan Crausaz, Marija Andacic.

Questions and close

With no further questions or business, the meeting closed at 7.20pm. LB thanked everyone for attending and supporting CFWA.

Signed as a True and Correct Record



Lisa Bayakly, CEO, Dated 15/7/2024