

Cystic Fibrosis WA (Inc)

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Minutes of 2025 Research Spotlight and Annual General Meeting

Held via Teams videoconferencing and at The Niche 11 Aberdare Road Nedlands WA 6009 on Thursday 19th June 2025, commencing 6:00pm

Present

Marija Andacic, Lisa Bayakly, Kate Bingemann, Caz Boyd, Michelle Buck, Laura Cardy, Matthew Casey, Steffan Crausaz, Wendy Endebrock-Brown, Kara Gard, Luke Garratt, Anthony Kicic, Ingrid Laing, Lawrence Liew, Mitch Messer, Kak Ming Ling, Siobhain Mulrennan, Renee Ng, Damien O'Reilly, Jackie Parker, Stella Ray, Ric Reyerson, Anna Rodger, Colin Savory, Linda Smith, Rowena Smith, Craig Spangler, Sarah Thomas, Paula Wallace, Sam Wallace, Zoe Wolski

Formal Apologies

Fiona Byrne, John Byrne, Alan Clyne, Rob Endebrock-Brown, Julie Foott, Carly Mara, Chris Mara, Amanda Nobbs, Rosalind Pignatiello, Holly Ralph, Sally Rose, Adrienne Thomas, Andrew Weddell

President's Welcome

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

DO made special acknowledgements:

- Thanked the CFWA team for their dedication and efforts
- Thanked CFWA's many supporters
- Introduced three new co-opted board members, being Kate Bingemann, Laura Cardy, and Craig Spangler

Research spotlight – Guest Speaker

DO introduced the guest speaker Dr Luke Garratt (LG), Research Fellow at the Kids Research Institute

LG spoke of the ever-changing landscape in CF research and the timeline of developments from the introduction of Pulmozyme, enzymes, lung transplants, to the discovery of the CF gene. Modern technology is now empowering more rapid research insights, often at a lower 'unit cost'.

LG introduced a new research project regarding marking biological ageing in those with cystic fibrosis using multi-omics. LG's aim is to determine whether it is possible to identify age-related disease risks in the CF community through singling out signatures in blood which change over the human lifespan and precede certain diseases.

LG's project will commence this July following ethics approval, with broad recruitment of research participants.

Vote of thanks and questions

LB extended a vote of thanks and then opened the floor to questions. Discussion included eligible cohorts (i.e. age groups, transplant recipients, those currently taking modulator therapies) and the nature of testing required (being one blood test).

Annual General Meeting

LB officially opened the AGM, declared quorum, and noted several apologies and one proxy were received.

CFWA Updates and achievements

LB highlighted key 2024 achievements, as follows.

- Launch of new Strategic Plan, with continued focus on empowering and supporting individuals, families and communities; and evolving services based on changing community need.
- High instances of practical support including home and community support sessions; professional consultations; and online peer support sessions; and financial subsidies across metro and regional areas; and individuals and families.
- Continued focus on education, awareness & advocacy; and research. LB acknowledged the remarkable progress in care and treatments for CF but our efforts continue as there is still no cure, not everyone has an effective treatment; and there are complex and changing needs to address.
 - Research: We secured a \$1m co-contribution from the Future Health Research and Innovation Fund (FHRI), to support a record \$2m grant program in 2025. This is in collaboration with Conquer CF.
 - Advocacy helped ensure access to Trikafta and Kalyedco was extended in 2024 to younger children. Recently it was announced that Trikafta would be extended to people with responsive rare genes (another 271 mutations), providing the first effective treatment of the underlying cause for these individuals. CFWA's current focus is aimed at better access to CF-related diabetes support; and a new or redeveloped adult CF outpatient clinic
 - Education: We re-branded our respiratory education program to Lungsmart, reflecting its broader respiratory focus. The team travelled to 7 regions for CF outreach and 16 locations for respiratory education reaching over 2000 people.

LB thanked the CFWA team for their efforts and collaboration with stakeholders; and all fundraisers & supporters such as runners, rose sellers, tin collectors and more, noting record numbers across many campaigns, including over 25,000 roses.

LS highlighted key aspects of CFWA's financial performance:

- CFWA achieved a positive overall financial result in 2024, with a net surplus of over \$300,000 and our equity position remains strong. This surplus will partly fund our research commitment; and new resources for community (CF Futures).
- In 2024, we made excellent progress on several funding strategies to better prepare us for the future challenges and risks facing the not-for-profit sector.
 - We continued to diversify funding sources.
 - The Health Dept WA renewed our core funding contract for 5 years; covering about 45% of our income needs.
 - We engaged more with corporations, foundations and major donors.
 - We uplifted grant activity to focus on strategic areas.
 - We secured the FHRI research co-funding support.

Linda acknowledged and thanked CFWA's fundraisers, donors, volunteers and valued partners and supporters.

The 2024 Annual Report and financial statements are available on CFWA's website.

AGM Formalities

Confirmation of Minutes of AGM held 19 June 2024

LB tabled the following resolution: The minutes of the 2024 AGM are a true and correct record.

Moved Damien O'Reilly, Seconded Marija Andacic; Approved and carried

(For: all, Against: 0, Abstentions: 0)

Appointment of Auditors

LB tabled the following resolution: This AGM appoints Hall Chadwick as financial auditors for the 2025 financial year. Moved Linda Smith, Seconded Marija Andacic; Approved and carried

(For: all, Against: 0, Abstentions: 0)

Business Arising

There was no business arising from the 2024 AGM and no new general business.

Elections of Board members

Nominations to fill up to three two-year Board vacancies closed 20 June 2025. With three nominations and no surfeit, these individuals were duly elected: Linda Smith, Sally Rose, and Ingrid Laing.

Presidents close

DO thanked everyone for attending and supporting CFWA. With no further questions or business, the meeting closed at 7.00pm.

Signed as a True and Correct Record



Lisa Bayakly, CEO, Dated 30/6/2025