

Cystic Fibrosis WA (Inc)

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DRAFT Minutes of the Annual General Meeting

Held at

The Niche 11 Aberdare Road Nedlands WA 6009

Wednesday 15th June 2022

Commencing 6:05pm

Present

Stephen Bastow, Lisa Bayakly, Amanda Bearcroft, Caz Boyd, Charlotte Bradley, Michelle Buck, Matthew Casey, Rachael Clifton, Sharon Dewar, Deidre Gorrie, Gillian Hoyland, Anthony Kicic, Mitch Messer, Damien O'Reilly, Peter Pratten, Ric Reyerson, Haylee Riddell, Anna Rodger, Sally Rose, Feliciano Sanchez, Rowena Smith, Vanya Tierney-Sanchez, Paula Wallace, Samantha Wallace, Chelsea Weaver

Apologies

Apologies were received from:

Nigel Barker, Fiona Byrne, John Byrne, Rob Endebrock-Brown, Wendy Endebrock-Brown, Lynette Gillam, Veronika Metcalf, John Rothwell, Ruth Thomas, Mel Tibbitts

Welcome

CFWA CEO Lisa Bayakly (LB) welcomed those present to the Annual General Meeting. LB then called upon CFWA President Caz Boyd (CB) to introduce the guest speaker Jo Armstrong, CEO of Cystic Fibrosis Australia, who spoke via a pre-recorded video presentation.

Guest Speaker (pre-recorded)

Due to unforeseen circumstances, JA was unable to attend the AGM and presented a short, pre-recorded video, introducing herself as incoming CEO of CFA and setting out her goals for CFA and the Federation.

JO thanked those present for the opportunity to speak our AGM and began with her background, having worked more than ten years in the not-for-profit sector. JA noted CFA's recent AGM last May and noted that Mitch Messer was voted as incoming President.

JA reflected on the first few months of her tenure at CFA noting the high level of community and CF engagement and thanked everyone for their support. In those short few months, JA has restructured CFA to now include a dedicated fundraiser which will greatly assist with not only CFAs revenue streams, but also national fundraising collaboration.

She then spoke about her focus on business and community relationships, and in particular, with government following the recent national election. JA felt this was a priority given the recent announcement of Trikafta's listing on the PBS for those aged 12 and over.

Going forward, JA noted CFA is about to launch a new strategic plan with the aim of extending life expectancy to a target 55 years of age in four-year's time whilst also improving quality of life. This will include a revision of the standards of care for those with cystic fibrosis which has proven inconsistent across the CF clinics around the country.

JA confirmed CFA's commitment to CF research through the ACFRT citing to date, the Trust has committed over \$6m in research funding.

JA concluded with the announcement that the CF medical conference in August will now be opened for a lay audience to attend (listen in, but not participate) and encouraged the community to register.

Vote of thanks

DO extended a vote of thanks and then opened the floor to questions.

L Bayakly queried whether CFA felt advocacy would be diluted with the recent listing of Trikafta on the PBS.

In JA's absence – and as President of CFA – Mitch Messer responded that this very issue on the CFA board agenda given that there are a number of those with cystic fibrosis who either currently do not have access to Trikafta or Trikafta is not for them. Additionally, CFA is pursuing the expansion of outpatient services at CF clinics as patients will still retain CF symptoms affecting their lives irrespective of any small molecule modulator they may be taking.

MM added the ACFRT is undergoing a review over the course of the next five years focusing on areas of research involving the community, researchers, and clinicians.

DO then thanked MM, the audience for their questions, and particularly outgoing President Caz Boyd for her years of dedication to the board and the CF cause.

LB thanked DO and officially opened the AGM and declared quorum.

Confirmation of Minutes of AGM held 23rd June 2021

The minutes of the previous meeting had been tabled. It was moved that the minutes be accepted as a true and correct record.

Moved Caz Boyd

Seconded Damien O'Reilly

For: all

Against: 0

Abstentions: 0

Approved and carried

Business Arising

There was no business arising from the minutes of the AGM held on Wednesday 23rd June 2021.

Joint President's and CEO's Report

CB welcomed everyone present to the 2021 Annual General Meeting.

CB highlighted key events throughout 2021, notably how COVID-19 continued to impact on fundraising – through adaptation of existing campaigns and the introduction of new initiatives, and the successful re-negotiation of the contract with the Department of Health for a three-year term.

This contract is vital as it provides funding for core services to those with cystic fibrosis such as home visits, counselling, practical and financial support, and CF education in schools. As a result of the successful tender of the contract, some process improvements were made to ensure CFWA can continue all services to people with CF.

Despite COVID challenges remaining in 2021 - including four lockdowns - CFWA continued to run all its normal community events such as the Parents' Retreat and Post-transplant Dinner (with COVID-safe protocols), though many of these took place in the latter half of the year.

The second half of the year was also busy with fundraising. After fundraisers were impacted earlier in the year, major events like the John Gillard Family CF Golf Classic and the Albany Christmas lights proceeded with great success. New initiatives were introduced such as our first ever Bridge Climb and a Matched Giving Day - both exceeding expectations.

Throughout 2021, CFWA continued to invest in CF research with the awarding of our 13th PhD Top Up Scholarship to Andrew Vaitekenas, and research grants to Julie Depiazzi and Crystal Bourke from PCH, as well as Dr Luke Garratt from TKI for his work on neutrophils. All these were made possible with funds raised through the Golf Classic event.

Last, but not least, 2021 involved a major advocacy push for Trikafta access, which came to fruition in 2022 for those eligible aged 12 years and over. CB acknowledge CFA, and particularly the former CEO Nettie Burke, who has since retired, for their relentless focus on advocating for all the CF community.

CB thanked the board who provided counsel and advice during the Department of Health contract review and CFWA's COVID response. CB then took the opportunity to introduce new board members Amanda Bearcroft and Rowena Smith who joined in 2021.

On behalf of the board, CB also thanked the staff of CFWA for their dedication and loyalty' the hospital, health and research teams CFWA collaborated with; and the hundreds of organisations and volunteers who support the organisation throughout the year.

LB thanked CB for her contribution as a board member and for her support at CFWA events.

LB noted key achievements in 2021, particularly CFWA's ability to maintain services and events despite the impacts of COVID and the four lockdowns. On a services level, over 4,000 occasions of service were provided under the Department of Health contract; 7 community events were held; over 1300 individuals were educated; and on a fundraising level over 17,000 roses were sold and the Golf Classic reached its second-best result. New initiatives were introduced with great success including the Matagarup Bridge Climb and the Matched Giving Day.

CFWA continued to invest in research including PhD Top Up scholarships, a small project (floppy airway outcomes), and a major project investigating the effects of neutrophils.

LB introduced new team members in 2021 including the appointment of a new services manager, CFWA's physiotherapist Sam Wallace, following Kathryn Pekin's resignation. Also new in 2021 were the introduction of virtual Zoom catch ups for CF clients and families; myABCF book for CF children under the age of seven to understand how their body works and the important of CF treatments; and the adult wellbeing support program funded by HBF and CommBank.

LB noted there is now a stronger shift to adult support services including advocacy, particularly since Trikafta has been listed on the PBS.

In closing, LB thanked the board, the staff, the members and stakeholders for their continued support in 2021.

LB then called upon Sally Rose (SR) to present the Treasurer's Report.

Presentation 2021 Audited Accounts and Treasurer's Report

Sally Rose (SR) presented the audited accounts and Treasurer's Report for 2021.

2021 delivered a surplus of \$227k on a turnover of \$2.6M, of which \$127k was attributed to COVID-related Commonwealth government support through JobKeeper in the first quarter of the year, and \$64k was attributed to the fair value gain on the Entrust investment portfolio - though these gains are not realised.

In what was yet another challenging year due to COVID, it was worth noting that CFWA benefited from innovative revenue sourcing - such as the Matched Giving Day - and a highly successful Golf Classic with over \$163,000 raised. Additionally, CFWA secured a new contract with the Department of Health for a three-year term, however with funding reduced, SR noted the association was expecting to utilise some of its reserves in order to continue service delivery as it adjusts to the new terms of the contract.

Other key highlights of 2021 included \$170k in grants obtained; operating results were positive and well above prior year (\$255k compared to \$120k); and fundraising income was well above prior year at \$824k (compared to \$684k in 2020), with net results on budget.

Of particular importance to the association was the level of cash generated in the year and overall access to funds in order to allow the association to deliver services to its members. By curtailing some spending to allow for future contingencies, given the significant Department of Health contract review previously mentioned, CFWA increased reserves by just over \$200,000,

Consequently, SR was pleased to report the finances of the association continued to be managed in a manner which supports the objectives of CFWA.

The financial statements for the year ending 31 December 2021 were audited by Mr James Komninos of RSM Australia and approved by the board of CFWA. Signed copies are available for inspection by members and will be lodged with the ACNC following the AGM.

SR noted RSM recently resigned as auditor due to staffing constraints in their business. SR acknowledged their past service and thanked their team.

In closing, SR acknowledged the efforts of the CFWA team.

Appointment of Auditors

SR proposed that Hall Chadwick be appointed as the auditors for Cystic Fibrosis WA in 2022.

Moved Sally Rose
Seconded Damien O'Reilly
For: all
Against: 0
Abstentions: 0
Approved and carried

Proposed changes to CFWA Constitution

The proposed changes to the CFWA Constitution had been tabled with no questions from the audience. It was moved that the proposed changes be adopted at this Annual General Meeting.

Moved Sally Rose

Seconded Damien O'Reilly

For: all

Against: 0

Abstentions: 0

Approved and carried

Elections or Declaration for the Board of CWFA

In accordance with the constitution, nominations had been called for to fill four two-year vacancies on the board.

Nominations closed at 7m on Tuesday 14th June 2022. At that time, nominations had been received from the following to fill the three of the two-year vacancies:

- Caz Boyd
- Rowena Smith
- Damien O'Reilly

There being no surfeit of nominations over vacancies there was no need for an election and those people nominated were declared duly elected.

General Business

There was no general business.

Questions from the Floor

LB called for questions from the floor, of which there were none.

Close of Meeting

LB thanked everyone for attending and supporting the organisation.

There being no further business, the meeting closed at 6.50pm.

Signed as a True and Correct Record

Name _____ Date _____