

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 3rd June 2020
Commencing 7:30pm

Present

Nigel Barker, Stephen Bastow, Amanda Bearcroft, Caz Boyd, Charlotte Burr, Fiona Byrne, John Byrne, Matthew Casey, Maggie Cunnington, Sharon Dewar, Sally Edwards, Julie Foott, Craig Hosking, Rachael Hosking, Angelo Karelis, Anthony Kicic, Ingrid Laing, Simon Martin, Marcia Messer, Mitch Messer, Veronika Metcalf, Renee Ng, Damien O'Reilly, Kenny Paterson, Kathryn Pekin, Ric Reyerson, Haylee Riddell, Anna Rodger, John Rothwell, Feliciano Sanchez, Gae See, Ken See, Marc Stocklmayer, Marnie Thomson, Vanya Tierney-Sanchez, Paula Wallace, Samantha Wallace

Apologies

Apologies were received from:
Colin Savory

Welcome

CFWA CEO Nigel Barker (NMB) welcomed those present to the Annual General Meeting. NMB then called upon CFWA President Caz Boyd (CB) to introduce the guest speaker, Assoc Prof Anthony Kicic (KC), Head of Airway Epithelial Research, Telethon Kids Institute (TKI).

Guest Speaker

KC thanked those present and spoke about pathogens and the airways – how they are at *war* with each other – and strategies to prevent infection occurring.

The primary *villain* for those with CF – using KC's analogy – is *Pseudomonas aeruginosa*, with the prevalence of this pathogen increasing with age. Similarly, the primary *resistance* for those with CF is the airway which forms a physical and immune barrier. Current *P. aeruginosa* treatments include antibiotics and hospitalisation with four to eight-week treatment periods not uncommon. However, with there being no new classes of antibiotics in recent years, pathogenic resistance is diminishing; it is estimated there will be up to ten million deaths annually due to anti-microbial resistance (AMR).

KC spoke of a new treatment available: bacteriophages, or introduced viruses that infect bacteria. In the case of CF, interest is directed to those phages which attack *P. aeruginosa*.

The first known use of phage therapy was used to treat dysentery in 1919 by a company which has grown to become L'Oréal. However, antibiotics took over in Western medicine in the 1930s. TKI currently has more than 120 phages in their research laboratories.

P. aeruginosa forms protective biofilms; phages are able to penetrate these biofilms and kill the bacteria in particular areas (those areas less dense). KC's current research is focussed on how to break down the biofilms and resultant outcomes when mixing with a course of antibiotics.

KC finished with noting CF adults are already asking for phage therapy as part of their treatment regime, however, there is no official use for compassionate grounds in Australia. TKI has approached the Dept of Health (WA) resulting in a positive response, however, compassionate use is currently *only* offered at Westmead (NSW).

Vote of thanks

FS proposed a vote of thanks which was warmly acknowledged with a token gift to be presented post-AGM. NMB then opened the floor to questions.

NMB then thanked the audience for their questions.

C Boyd queried the use of phage therapy post-transplant; will it work on sinus infections?

KC responded that phage therapy will work irrespective of where the bacteria lies in the body.

J Foott queried how the phage enters the body?

KC responded that there are a number of ways of introducing a phage to the body, however, the most effective is inhalation via nebulization straight into the lung.

NMB thanked KC and officially opened the AGM. NMB then called for apologies.

Confirmation of Minutes of AGM held 17th April 2019

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 Feliciano Sanchez

Approved

Business Arising

There was no business arising from the minutes of the AGM held on Wednesday 17th April 2019.

Joint President's and CEO's Report

CB welcomed everyone present to the 2020 Annual General Meeting.

CB highlighted key events throughout 2019 including Perth hosting the 13th Australasian CF Conference which witnessed an unprecedented 20% growth in attendees across both medical and lay delegates. Additionally, the benefits of new therapies such as Kalydeco® (listed in 2014), Orkambi® (listed in 2018), and Symdeko® (listed in March 2019) started to be felt and with Tricafort® and Elexacaftor® in the pipeline. Only last week (end of May 2020) did Monash University's Registry Science Unit announce the (median) survival of people with CF in Australia is now 47.4 years.

The CFWA team has been proactive in developing new programs and services to meet these needs and will be participating in the development of a new Model of CF Care in 2020.

In 2019, the services team focussed on the implementation of its mental health strategy thanks to funding from Lotterywest and Telethon. This included the employment of a new social worker; subsidies to enable carers to attend the Australasian CF Conference; a new mental health gap subsidy; and fitness subsidies particularly increasing engagement with the growing number of adults living with CF.

A dedicated communications team was established responsible for all print and electronic media across both service provision, fundraising and administration which has already shown results with huge increases in online traffic and well-maintained up-to-date information resources particularly during the COVID-19 emergency.

CFWA continued to invest heavily in research, thanks in large part to the generosity of the late Stan Perron, the Golf Classic committee, sponsors and supporters. These funds supported AREST CF at Telethon Kids Institute as well as two new PhD Top Up Scholarships for 2020.

In closing, CB thanked the board, the staff, the CEO NMB, and the audience. CB then called upon NMB.

NMB thanked CB, CFWA's patron, John Rothwell, and the audience.

In 2019, CFWA delivered a profit of \$165,502 on a turnover of \$2,446,858. A proportion of this was unrealised (as a result of accounting treatment to the investment portfolio), however, landed well ahead of budget having delivered in excess of its contracted outcomes to meet the needs of people whose lives are affected by CF.

NMB offered special thanks to the dedicated home care workers who delivered over 4,300 occasions of service to people in their homes and to the admin team who ensured all grants were properly acquitted and all administrative tasks were completed on time and on budget.

Fundraising saw significant growth in 2019 with a near 30% increase in revenues for 65 Roses month, 16.5% increase in Golf Classic revenues, and over 21% increase in collection tins revenues.

On the research front, one of the outcomes of the Little Lungs Big Futures Research strategy has been the OPTIC project which is bringing phage therapy to the masses sooner rather than later with compassionate use available later in 2020. Applications for funding to support this amounting to \$1.5m over 5 years were delayed because of the COVID-19 emergency.

In 2019, CFWA appointed a new social worker; provided transition and support packs; adult activity subsidies; greater online resources; mental health gap funding; family support through Food Bank and Good 360; regional support through Telethon; and provided 52 InnospireGo nebulisers.

Furthermore, CFWA attracted 428 new donors, received over 2,400 donations and sold a record 16,500 roses during 65 Roses Day. 65 Roses Day and May month fundraisers raised over \$97,000 combined, an increase of 29.8% on 2018. Appeals raised over \$89,000; combined community fundraisers raised over \$83,000; the HBF Run for a Reason raised over \$35,000; and CFWA's collection tins, located in over 120 locations, raised over \$12,000, an increase of 21.7% on 2018.

In closing, NMB thanked the board, the staff, volunteers, the Department of Health WA, Lotterywest, Telethon, the late Stan Perron, CFWA's sponsors and supporters.

NMB then called upon Simon Martin (SM) to present the Treasurer's Report.

Presentation 2019 Audited Accounts and Treasurer's Report

Simon Martin (SM) presented the audited accounts and Treasurer's Report for 2019.

2019 delivered a profit of \$165,502 on a turnover of \$2,446,858. However, \$109,468 of the profit was due to an unrealised increase in the value of CFWA's investment portfolio as per new accounting standards. This also included a \$250,000 donation from the Stan Perron Charitable Foundation, 100% of which was forwarded to the Little Lungs Big Futures researchers at the Telethon Kids Institute.

Operating expenditure was 1% lower than 2018 at \$2,281,356.

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. Overall, cash holdings improved to \$805,476 compared to \$803,826 at the end of 2018. The cash holdings and funds held as investments of \$1,075,862 are up from \$831,670 at the end of 2018, which means the association remains in a strong financial position.

Consequently, SM 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 ended 31 December 2019 were audited by Mr James Komninos of RSM Australia Pty Ltd with a copy of the signed accounts available for inspection by members on the ACNC website.

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

Appointment of Auditors

The financial statements for the year ending 31 December 2019 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 later this week.

SM proposed that RSM Australia again be appointed as the auditors for Cystic Fibrosis WA in 2019.

Moved Simon Martin

Seconded Caz Boyd

Approved

Elections or Declaration for the Board of CWFA

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

Nominations closed at 7.30am on Tuesday 2nd June 2020. At that time, nominations had been received from the following to fill the two of the two-year vacancies:

- Caz Boyd
- Simon Martin
- Damien O'Reilly
- Amanda Bearcroft

There being an excess of nominations over vacancies there was an election. Invited members present three of the four candidates and voted in favour of:

- Caz Boyd
- Simon Martin
- Damien O'Reilly

These were declared duly elected.

General Business

There was no general business.

Questions from the Floor

NMB called for questions from the floor.

A Karelis queried the outcome of the current 2020 virtual rose campaign in lieu of real rose sales due to COVID-19.

NMB advised the campaign exceeded expectations and netted to date ~\$44,000. NMB then thanked the team at Deloitte for their assistance with the campaign through their Impact Day.

V Metcalf queried how the COVID-19 situation will impact CFWA's investments.

SM responded, noting the board and CFWA team were (and currently are) monitoring through monthly reporting, however, despite the financial impact, CFWA remains in a strong financial position.

I Laing commended the board and CFWA for their financial management of the organization during the COVID-19 emergency, citing many NFPs will unlikely survive when the pandemic is over.

Close of Meeting

NMB thanked everyone for attending and supporting the organisation.

There being no further business, the meeting closed at 8:35pm.

Signed as a True and Correct Record

Name _____ Date _____