

30 December 2021

### WHAT CAN WE SAY ABOUT 2020?

**What a Year!** Cystic Fibrosis Australia (CFA) had a blueprint of new initiatives in place as we launched into 2020, but the COVID-19 International Pandemic meant that we had to manoeuvre and manipulate our plans to assist and provide value and support to the cystic fibrosis (CF) community.

We are after all here to meet your needs and ensure health equity for all people with CF.

In a nutshell our three pillars remain intact and remained very active.

- **Advocacy** and political engagement was done by Zoom, mail, email and phone. Predominantly we focused on COVID-19 related issues, however we made sure that all were aware of the need for high cost highly effective modulators.
- **Clinical improvement** assets including the Australian Cystic Fibrosis Data registry (ACFDR), Peer Review and Australasian Cystic Fibrosis Conference were all adapted to survive and thrive in pandemic times. The creation of a Clinical Trial Alliance has begun and will be completed in 2021.
- **Research** through the ACFRT supported 10 grants totalling over \$300,000.

In 2020 CFA actively looked for innovative supports for the CF community and here is a list of activities that we hope made some small positive difference to you all.

1. 21 Consumer Connect Sessions were held to shed light on the Coronavirus and share worldwide outcomes for the CF community. They can all be viewed here:  
<https://www.cysticfibrosis.org.au/consumerconnect>
2. 76 Communiques and they can all be found here:  
<https://www.cysticfibrosis.org.au/advocacy/communiques>
3. Woolworths and Coles Priority Access Shopping was established for the CF community early on in the pandemic.
4. CFA held six Pharma meetings to confirm drug supplies during the pandemic.
5. CFA convened international CF organisation regular Zoom meetings.
6. We supported the further development of the Perx App and it continues to bring support and value to our constituents.
7. The Australian Cystic Fibrosis Data Registry (ACFDR) was developed to accommodate COVID-19 data and allow Australia to participate in an international initiative.
8. CFA wrote to every Member of Parliament (151) and Senator (76) four times in 2020 to ensure we were not forgotten and our cause remained top of mind.
9. Phase One and Two of the Research and Advocacy Priority Setting program and Research Road Map development completed.
10. CFA was invited to join the National Medicines Policy Review Working Group.
11. Our Policy Asks focused on the codification of consumer in all policy development from the beginning and the mandatory inclusion of PREMs and PROMs in all Government programs. Government initiative in both these areas are underway.
12. CFA COVID-19 Website was established for community information.  
<https://www.cysticfibrosis.org.au/about-cf/covid-19>

13. CF and transplant COVID-19 ID cards <https://www.cysticfibrosis.org.au/getmedia/1e693efe-fcce-478b-84e1-664b632b3baa/CF-MedCard-S.pdf.aspx>

Advocacy was challenging and not focused solely on drug access. CFA campaigned for:

- Acceptable Care Pathway and Coronavirus treatment equity for people with CF
- Rights, protections and fair work practices for CF workers
- Priority resuscitation
- Priority testing for CF community
- Preventative Health Strategy for CF comorbidities
- HTA process improvements (TGA and PBAC processes)
- Medical Research Future Fund priorities
- NDIS access for people with CF
- Codification of consumer in all policy development
- PREMs (Patient Reported Experience Measures) and PROMs (Patient Reported Outcome Measures)
- Trikafta.

I hope you all had a very happy Christmas and let's hope that 2021 is full of good news, in particular the approval of Trikafta. Don't forget these key dates and links.

- 10 February 2021 PBAC portal closes
- CFA Trikafta portal for all facts and messages:  
<https://www.cysticfibrosis.org.au/advocacy/trikafta-advocacy-plan>
- 10-12 March 2021 PBAC Meeting
- PBAC Consumer Comments Portal:  
[https://www1.health.gov.au/internet/main/publishing.nsf/Content/PBAC\\_online\\_submission\\_form](https://www1.health.gov.au/internet/main/publishing.nsf/Content/PBAC_online_submission_form)

CFA is planning to take some time off in January 2021 to recharge our batteries. However, if you have an urgent issue please call or email me anytime.

Stay safe and most importantly stay positive. If we can make it through 2020 nothing can stop us now!

Kind regards



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