

On behalf of the Board of Cystic Fibrosis Community Care (CFCC), I am pleased to present the Chair's Report for FY22.

FY22 was a year of progress, achievement, and change for CFCC, although not without material impact from the lingering shadow of the COVID-19 pandemic. It certainly had its lows, but also some significant highs.

We were absolutely delighted by the progress made in March 2022 when it was announced that Trikafta would be listed on the PBS for individuals 12 years and over who carried at least one F508del gene change. This was a huge step forward after years of lobbying and campaigning by CFCC, other CF organisations, and many members of our community.

In addition, we quickly re-joined the campaign to make Trikafta for 6-11 years old also available on the PBS, and we were equally delighted when Pharmaceutical Benefits Advisory Committee (PBAC), recommended Trikafta for children aged 6-11 years old who have at least one F508del mutation in the CFTR gene. With the recent news of PBS listing taking place on 1 May 2023, this is another critical step forward for our community.

While it is exciting to hear this news, we know that there are many in our community who have not yet gained access or cannot be helped by Trikafta. Whether you are post-transplant, have a rare gene, or are someone for whom Trikafta has come too late, please know that we are not stopping until every person with CF has a bright future ahead.

The pandemic and the subsequent cost of living crisis have also created new challenges for many members of our community, both socially and economically. We are increasingly aware of the need to support not just physical health but also mental health, and the additional pressures that can now arise in seeking to achieve a fulfilled life.

Achievements across New South Wales and Victoria in 2022:

- Our information line responded to over **1900** enquiries from people affected by CF.
- We supported **550** members by advocating for their individual hospital care.
- We provided social work care and support to **1062** members.
- We carried out **117** hospital visits and supported **797** members in outpatient clinics.
- We provided **998** grants and subsidies, totalling **\$185,675**.
- We provided emergency funding support to **163** members, totalling **\$32,583**.

Change was most notably marked by the leadership transition from Karin Knoester to Andre Carvalho in May 2022. We celebrated Karin's achievements last year, and we have worked closely with Andre for the rest of the year to prioritise areas for improvement and growth. As part of this process, we welcomed three new staff members to the team to form our new Leadership Team; Clare Finucane, Head of Fundraising & Marketing, Stephanie Quattromani, Head of Programs and Services and David Camilleri, Head of Shared Services.

We believe that everyone in the CF community has the opportunity to flourish and lead a fulfilling and enriching life and the team delivered a number of reforms and improvements across the organisation in the second part of 2022, to help us better deliver this vision.


Looking forward to the next 12 months, we are set up for a year of transformation. The past six decades have seen remarkable improvements in health outcomes for people with cystic fibrosis. However, although life expectancy for people with cystic fibrosis has increased substantially, the condition continues to limit survival and quality of life and results in a large burden of care for people with cystic fibrosis and their families.

We need to ensure we recognise these changes and deliver a new strategy that will meet the changing needs of all members of our community. We look forward to engaging in important conversations with people with CF, their families, our partners, and our dedicated supporters.

I would like to thank all our wonderful donors and supporters for their dedication and determination to support the work of CFCC. In these challenging times, your ongoing support is needed more than ever, and we couldn't do what we do without you.

I would also like to thank the CFCC staff and volunteers' team, and my fellow Board members for all that you do to support our community. Your skills, experience, empathy, and caring nature ensures we can deliver critical support and care to our community across New South Wales and Victoria.

Best wishes for 2023.



Katherine Kaspar, Non-Executive Director & Chair

27 April 2023