

4th July 2024

## **CYSTIC FIBROSIS FEDERATION OF AUSTRALIA**

To the Australian CF community,

The Cystic Fibrosis Federation of Australia is a national group of community organisations working together, side-by-side with the CF community, to pursue better care and treatments for all Australians with CF. Since CF Australia was formed in 1983 by the state and territory CF associations in existence at that time, by working together the CF Federation has delivered services to thousands of people with CF across Australia, and meaningful progress in the fight against Cystic Fibrosis.

In recent times, the advocacy of CF Federation members has been instrumental in securing access for Australians with CF to better clinical treatment and new therapies, including Trikafta, which are transforming a growing number of lives. Together we have contributed over \$7 million to CF-specific research through the Australian Cystic Fibrosis Research Trust, administered by Cystic Fibrosis Australia, and over the past 40 years the average life expectancy of Australians with CF has increased by around 30 years.

With everything that has been achieved, we were disappointed that Cystic Fibrosis Community Care (formerly CF NSW and CF Victoria) has chosen to leave the CF Federation. While we wish them well, we want to assure every member of the CF community in Australia that this will not disrupt our work to improve the lives of those living with Cystic Fibrosis. Collectively we will continue to fund research, advocacy, community outreach, and direct support to individuals and families around the country, including in New South Wales and Victoria.

**Unity is our greatest strength.** Our unified vision and collaborative efforts enable us to provide enhanced support and resources to you, make major progress in research and facilitate better access to new treatments.

Cystic Fibrosis Australia (CFA) remains your dedicated National Peak Body, supported by all member state and territory organisations. We reaffirm our commitment to working together as one united group. We will continue to support each other, share knowledge, resources and, importantly, stand in solidarity with those living with cystic fibrosis and their families as we strive for the best outcomes for all.

CFA is the driver of key national programs focussed on improving quality health care outcomes including the National Standards of Care, the Peer Review clinical improvement program and the Australian Cystic Fibrosis Data Registry. Further, Cystic Fibrosis Australia will continue to administer the Australian Cystic Fibrosis Research Trust.

I encourage you all to remain engaged and connected with your CF Federation. Let us continue to inspire one another. Your voice, your ideas, and your passion are vital to our collective success.

United we will continue to achieve great outcomes and improve the lives of many,  
always *Embracing Tomorrow*.

With sincere appreciation,

Jo Armstrong  
CEO  
Cystic Fibrosis Australia