



2 June 2022

## **ADVANCING OUTCOMES**

I have now been serving our community for almost 6 months and I have been completely bowled over by how incredible our community is.

I have been humbled to hear of your journey's and so many of you have courageously shared your stories with me. Some full of joy, and some full of sadness, and many a mixture of both joy and sadness. One thing is for sure, life with cystic fibrosis (CF) is not easy.

As we have been journeying together over these last few months, we have had the incredible news of the PBS listing of Trikafta! Finally, we got the outcome much needed for our community. But there is still a long way to go.

**I am currently advocating for the age group 6-11 years to have access to Trikafta, and this is currently with the TGA.**

I am also continually seeking ways to secure better outcomes for what some people have called the "forgotten 10%". This is the group of people who do not respond to the modulator therapy. No one is forgotten by Cystic Fibrosis Australia. This group is very much a remembered 10% of people where alternative therapies are required.

Advocacy is one part of my role. On top of this there are many other important projects that further the outcomes for people with CF.

Since 1989 we have funded more than 300 research projects at a value of more than \$6 million and counting.

We continually seek and are promoting clinical trials which are vital in developing new treatments. We are committed to driving national clinical improvement, which is ultimately measured by the extension of life expectancy. We do this through our management of the national data registry, peer review process and standards of care.

**We are working hard to advance the outcomes for you and your loved ones.**

You may have seen us recently launch our 2022 Tax Appeal, where we will be sharing stories over the coming weeks from people within our community and the journeys they are on.

**Thank you to everyone who has donated and supported us in this appeal so far.**

We know that life with CF can be tough, but as those CF Warriors whom we have spoken to say, 'you are stronger than you think'. This is what we hope people take from our appeal, that the CF Community are tough and will continue to fight, not just for themselves and those currently living with CF, but for the children yet to be born with CF.

At Cystic Fibrosis Australia, we work tirelessly to advocate and ensure our voices are being heard. Our focus is on long-term outcomes, including research into better treatment and hopefully one day finding a cure. While all this critical work is taking place, I hold close at hand another critical task. I must ensure that we are financially sustainable into the future. This means, I need to raise money so that this important work,

will continue into the future. Cystic Fibrosis Australia does not receive government funding and therefore to carry out our essential work we rely on the generosity of the community to help us.

**Please can you consider making an investment into the ongoing work of Cystic Fibrosis Australia?**

Your support will enable better outcomes for people with CF through our advocacy, data registry, standards of care and research work, as well as many other important areas, that advance the outcomes for thousands of people in Australia.

It is quick and easy to donate today via this link [Support Cystic Fibrosis Australia](#). Together, with your investment, we can make a very tangible impact so that people with CF can have better quality of life and longer lives.

Please do not underestimate the impact of your contribution. I have seen how as a community we are able to unite and get great outcomes. I hope we can continue to do this as we move into the next chapter as we keep striving for the best outcomes that you and your loved ones deserve.

Thank you and warm regards

Jo Armstrong  
CEO  
Cystic Fibrosis Australia



PS. Please help by supporting us today.