

28 May 2022



OUTCOMES FOR ALL

During the month of May, we have been driving the awareness of cystic fibrosis (CF). May is a time of reflection, education, and action! We need the best outcomes for Australian's living with CF today.

There has been recent success with the listing of Trikafta on the PBS for people ages 12+ with at least one Delta F508 mutation, and hopefully there will soon be progress for those aged 6-11 years old regarding Trikafta too. I will never forget the very much remembered 10% of people where alternative therapies are required. There is still so much on the national agenda to do, and what I am sure of is that there is no shortage of important projects that further the other outcomes we need for people with CF. These include getting the best outcomes in areas such as mental health, fertility, and aging to name but a few.

Through the Australian Cystic Fibrosis Data Registry, we are able to analyse data to identify trends and effects of treatments to help drive outcomes for improved quality of life. This is an ongoing project for us and helps provide the information to continually improve outcomes for our community.

Each week I get feedback from our community about how there are inconsistencies in the care that people receive around the country. We are working hard to overcome these discrepancies because all people should have consistent levels of care. We are going through every detail, for all stages of life, to set standards that you can expect.

Our research work is critical in ensuring that the cutting-edge research is funded to get the best outcomes for people living with CF. We are committed to funding research into the treatment and cure of CF, improving quality of life outcomes for people with CF and we ensure that research projects are based on scientific merit. We have a rigorous process to ensure the right research gets funded and the outcomes benefit our community.

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 cystic fibrosis.

At Cystic Fibrosis Australia (CFA), 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. CFA 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 CFA?

Your support will enable better outcomes for people with cystic fibrosis 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.

Warm regards

Jo

PS. Please do not delay in supporting us today.



Donate Now

Make your tax deductible donation by June 30 to help **transform lives** for people living with Cystic Fibrosis.

TAX DEDUCTIBLE

CYSTIC FIBROSIS Australia