

12 May 2022



## MAY IS OUR MONTH

You are probably aware that we are officially in the Cystic Fibrosis Awareness month now that we are in May! I have been reflecting on 65 Roses and how back in 1965, 4-year-old, little Ricky Weiss misheard “cystic fibrosis” as thought it was “65 roses”. It is incredible that in the innocence of his youth he had made an awful disease be represented so beautifully. In fact, this is the reason why our logo is a rose! Now, almost 60 years later we are still taking time this month to reflect and bring awareness to cystic fibrosis. What a legacy Ricky has!

Over the last few months there has been increased awareness of cystic fibrosis especially as our community has been relentlessly campaigning for Trikafta. I have had much positive feedback from many of you about how great it has been that our cause has frequently made it into the national media.

My hope is that the awareness of cystic fibrosis continues. Most importantly, I hope that we continue to get the best outcomes for our community and while this starts with awareness there is still so much more that we need to do to so that people with CF can have a full life.

Cystic Fibrosis Australia is your national peak body and mouthpiece, in driving advocacy but did you know we are also involved in many other critical projects?

### **Did you know that Cystic Fibrosis Australia runs the national data registry for people living with CF?**

The data registry analyses data to identify trends and effects of treatments to help drive outcomes for improved quality of life. This is an ongoing piece of work for us, with the help of Monash University, and helps provide the information to continually improve outcomes for people with CF.

Another area that Cystic Fibrosis Australia is driving for better outcomes is through our standards of care that are currently being revised and updated. 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 ensure there are clear and consistent standards across our country.

### **Did you know that we have funded more than \$6,000,000 to cystic fibrosis research?**

Cystic Fibrosis Australia also manages the operations of the Australian Cystic Fibrosis Research Trust. 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, so that the outcomes provide a tangible benefit for people with CF.

The work of Cystic Fibrosis Australia is only possible because of the investment of people like you. We do not get any government funding. This month we reflect on 65 Roses and the legacy of 65 Roses, we too can create a legacy by our actions today. Please partner with us and help create a legacy that has life changing outcomes for people living with cystic fibrosis.

It is quick and easy to donate today via this [Support Cystic Fibrosis Australia \(grassrootz.com\)](https://grassrootz.com)

Your partnership with us will ensure the best national outcomes for people living with CF. Thank you for being on this journey with us and your generous support.

Thank you.

Warm regards,

Jo

Ps. Please do not delay in supporting us today.