



24 February 2022

SHOUT AND KEEP SHOUTING LOUDER

It is incredible that only a week has gone by when I was last writing to you and anticipating 10,000 signatures on our petition to the government to list Trikafta on the PBS with urgency. Now, it is only one week later and currently we have more than 30,000 signatures! By the time you get this, it will be far more. This is truly a mammoth effort by you all, thank you!

I am amazed and inspired by you and how you have made your voice heard. We need to shout and keep shouting louder. We are being heard. Indeed, the media have been quick to pick up on our cause.

Lizzie is based in Tasmania and has been campaigning for Trikafta. This week I was pleased that her story was published both on 7 News and local radio. Similarly, CFA Ambassador Jess Ragusa, who recently shared her remarkable story on Consumer Connect, has also had her story published by Channel 7 and The Daily Mail as well as featuring on the Late Show on Channel 7, (make sure you follow us on social media where we are posting these articles and videos). It is very brave to share such intimate details of being so unwell and what life is like living with CF.

If you don't know Jess, she has an amazing story. She and her family have managed to self-fund Trikafta, for a time, at enormous expense. The health improvements Jess experienced on Trikafta exceeded any other therapy she had previously tried. Jess experienced a 24% increase in lung function, and this had benefits in every area of her life. However, the monthly payments on Trikafta are over \$21,000. Jess and her family have done more than enough. It is time for the Federal Government and Vertex to step up and ensure her access, along with every other Australian living with CF.

Thank you to all of you who have been sharing your journey and experience of CF. Someone in my network said to me this week, "this week has been the first time I have heard the words cystic fibrosis in the mainstream media in a very long time." This is a credit to you all.

This week I have been interviewed by Chris Kenny, live on the Kenny Report for Sky News. You can see the segment here [Cystic Fibrosis - Trikafta Advocacy Plan](#)

As I look to the coming week, I have some important meetings with various stakeholders, including government decision makers. I remain hopeful that soon, I may have some good news for you.

As I reflect at the end of this week, I think about the Red Rose in our logo. It is a powerful symbol, but the true emblems of this cause are the many and varied faces of our community. The slickest ad and the most poignant slogan pales in comparison to the impact and staying power of real-life CF experiences. Thank you to everyone who has taken the time to share their story or amplify CF voices.

Best Regards,
Jo Armstrong, CEO Cystic Fibrosis Australia