

2 November 2023

## UPDATE FROM CFA

A lot has been happening over the last few weeks and here are some of the key updates.

- **GENETIC CARRIER SCREENING ADDED TO PBS**

It is great news that genetic carrier screening for Cystic Fibrosis (CF), Spinal Muscular Atrophy and Fragile X has been added to the Medicare Benefits Scheme (MBS). This means that someone who is pregnant or planning to fall pregnant will have the cost of their carrier screening covered through Medicare. This is great progress because previously the cost would be anywhere from \$350 to \$2200 to undergo the same testing.

One in 25 people carry the CF gene and we hope that this will encourage more people from all over Australia will access the testing. We have been working hard at Cystic Fibrosis Australia (CFA) to support this change and hope that in the future other genetic conditions to be included.

- **CONSIDERATION FOR IVACAFTOR EXPANSION WITH PBAC**

The PBAC has been reviewing the request to expand Ivacaftor on the PBS for 4 – 12 months of age. We hope that more therapies will be made available to more people quickly and without long delays. We will keep you updated on the progress.

- **CEO ICE BATH CHALLENGE**

You may recall in my last update, that Jo made a pledge to get into an ice bath when Layne reached his fundraising target of \$100,000 for CFA. He hasn't hit the target yet so if you want to provide support here is the link [Breaking Barriers for CF – Cystic Fibrosis Australia](#)

You may recall Layne completed 36 half-iron men in 36 consecutive days. This is a huge feat! Each day Layne dedicated to someone in our community because our cause is so close to his heart. Layne is determined to support CFA to get better outcomes for everyone with CF, so please get behind him and help him reach his fundraising goal.

- **T-SHIRT DESIGN COMPETITION**

If you or one of your loved ones are 17 years old or younger, you are eligible to enter this competition. The goal is to create a t-shirt design that raises awareness or brings hope to people living with CF. There are some great prizes to be won including a holiday on North Stradbroke Island for the first prize. Here is the link for more information [Let's Cure CF \(launchpad6.com\)](#)

- **EARLY BIRD TICKETS AVAILABLE FOR THE 2024 AUSTRALASIAN CF CONFERENCE**

Finally, don't forget that the early bird tickets are currently on sale for our upcoming conference. 2024 is not far away and we are excited to gather in the river city of Brisbane. Our committees are working hard on the conference program, and it will be an enjoyable and informative time together. To get your tickets please click on this link [CFA 2024 Conference \(eventsair.com\)](#)

See you in Brisbane!