



19 September 2023

### **Breaking News - Layne's Challenge Reaches Halfway Milestone!**

We've hit a significant milestone on Layne's incredible journey! He's officially crossed the halfway point in his 36 Half Ironman Challenge, and we couldn't be prouder of his determination and grit.

But here's the scoop: Layne still has a way to go to reach his fundraising goal of \$100,000! Right now, there's approximately \$78,000 left to raise over the next 18 days, and we know that with your help, we can make it happen. Your support means the world to Layne and everyone in the CF community.

[Donate Now](#)

### **KALYDECO INPUT**

In other news, the PBAC consumer comments close tomorrow the 20th of September, so if you haven't had a chance to share your thoughts, please do so now!

The submission for Kalydeco includes an extension of treatment access to CF patients aged 4 to 12 months and are shown to be responsive to Ivacaftor potentiation. The list of responsive mutations includes rare mutations as well as R117H and RF mutations (irrespective of the presence of an F allele).

As part of your submission, please consider commenting on access to Trikafta, and urging Australia to align this with other countries which already have access granted to a wider range of rare gene mutations.

Your insights are invaluable in advancing CF care and treatment.

[Provide your Input Now](#)

### **Third Sector Awards**

We also want to share that Cystic Fibrosis Australia was honored to be a finalist for the Third Sector Excellence Awards and would like to thank everyone who voted for us. Whilst we did not take home the win, it was a privilege to be nominated and we are incredibly grateful for the supportive community we have around us. Our heartfelt congratulations to Warrior Women for their well-deserved victory!

Stay tuned for more updates and let's keep the momentum going for Layne and the CF community!

Yours sincerely

Jo Armstrong

**CEO**

**Cystic Fibrosis Australia**