

15th February 2024

EXCITING UPDATES FROM CYSTIC FIBROSIS AUSTRALIA

Dear Community Members

I hope this email finds you all in good health and spirits. We're thrilled to share some exciting updates with you from the past week:

- We're excited to announce the official launch of the 2022 Australian Cystic Fibrosis Data Registry (ACFDR).
- This marks a significant milestone in our ongoing efforts to collect and analyze crucial data that will drive research and enhance patient care.
- The data within the ACFDR is sourced directly from our community, and we extend our heartfelt thanks to each of you for your contributions.



New Vertex Modulator

Recent news revealed the positive completion of Phase 3 Clinical Trials for a new Vertex Modulator. While this is promising, Cystic Fibrosis Australia is actively engaged in discussions to understand its implications for Australians living with cystic fibrosis (CF).

Stay tuned for further updates as we navigate this development.

[Read more HERE](#)

TGA Approval

We're pleased to share that the Therapeutic Goods Administration (TGA) has approved the expanded use of Trikafta to include children aged 2-5 years with CF.

Whilst Cystic Fibrosis Australia welcomes this significant milestone, our attention remains focused on the forthcoming Pharmaceutical Benefits Advisory Committee (PBAC) meeting in March, where discussions will determine whether this expansion will be included on the Pharmaceutical Benefits Scheme (PBS).

We anticipate news of this outcome on April 26th and pledge to keep our community informed every step of the way.

*Thank you to everyone who submitted their comments for this upcoming meeting.

Upcoming Events and Updates:

Parliamentary Roundtable

On February 28th, Co-Chairs of the Friends of Cystic Fibrosis Parliamentary Group, Dr. Mike Freeland MP, Mrs. Bridget Archer, and Dr. Monique Ryan along with Cystic Fibrosis Australia, will host a Parliamentary Roundtable in Canberra, bringing together stakeholders to discuss critical issues facing individuals with CF.

This event presents a unique opportunity for advocacy, with attendees including Clinicians, MPs, Patients, Federation Members, and more.

Stay tuned for updates from this event, which will be shared with our community as soon as possible.

Conference Update

Abstract submissions for our upcoming conference are now open! This is an excellent chance to contribute your insights and research to the community. Submit your abstracts by March 5th for consideration.

Tickets are selling fast, so be sure to secure yours today!

[2024 Conference Website](#)

As we move forward, rest assured that we're hitting the ground running and committed to amplifying the voices of our community.

Together, we can drive positive change for those affected by CF.

Warm Regards,

Jo Armstrong
CEO
Cystic Fibrosis Australia