23 August 2023

YOUR VOICE MATTERS:

PARTICIPATE IN THE NOVEMBER 2023 PBAC CONSULTATION

Consultation is now open for the November 2023 PBAC (Pharmaceutical Benefits Advisory Committee) meeting. This is a critical opportunity for our community to advocate for change and improved access to life-changing treatments.

The request for Kalydeco (Ivacaftor) extension has been listed on the agenda.

This extension aims to provide treatment access to cystic fibrosis (CF) patients aged 4 to 12 months, as well as to those who have shown responsiveness to Ivacaftor potentiation. This inclusive approach covers a range of responsive mutations, including R117H, and RF mutations, regardless of the presence of an F allele.

The impact of this extension is immense – approximately 85 patients will gain access to a CFTR modulator for the first time. This goes beyond mere numbers; it's about transforming lives. While some individuals may already have access to other modulators, this extension becomes a lifeline for those who might not respond well to existing treatments and offers early access to transformative care.

Now, it's your turn to make a difference. Consumer Comments are being welcomed by the PBAC, and your unique insights and experiences hold the power to shape policy and access for people living with cystic fibrosis.

Here's how you can contribute effectively:
→ Share Your Story: Detail your lived experiences, daily challenges, symptoms, and feelings. Help decision-makers understand the reality of living with CF.
→ Highlight the Need: Emphasize the difficulties of CF and why improved access to treatment matters to you and your community.

Your input holds the potential to create a lasting impact. Make your voice heard by submitting your comments through the Office of Health Technology Assessment hub at: https://ohta-consultations.health.gov.au/ohta/pbac-nov-2023/

As part of your submission, we encourage you to also comment on access to Trikafta, advocating for alignment with countries that already offer access to a wider range of rare gene mutations.

Consumer Comments close on September 20, 2023. Let's come together and drive change for a brighter future for everyone affected by CF.

Submit your comments