



MEDIA RELEASE

23 August 2019

EMBARGOED UNTIL 5.15pm AEST

Every Child Deserves a Head Start

This afternoon the Pharmaceutical Benefits Advisory Committee (PBAC) recommended ORKAMBI for reimbursement for infants 2-5 years old with two copies of the F508del cystic fibrosis (CF) gene mutation.

<http://www.pbs.gov.au/info/industry/listing/elements/pbac-meetings/pbac-outcomes>

If the government honours this recommendation and finds the funds to quickly make this drug available, it will lift the enormous burden of 400+ parents of CF children Australia-wide who fall into this crucial age range. We say crucial because the benefits of ORKAMBI are only fully realised through early and consistent exposure to the drug.

CF infants in Australia can now benefit from a world class medical treatment in their formative years, with ORKAMBI alone providing 23 years of additional life expectancy. ORKAMBI also improves quality of life and makes everything from basic digestion to regular attendance at school possible for these kids.

“The flow on effects of this ‘head start’ treatment include deferring lung damage and transplants; better management of CF Related Diabetes (CFRD) and pancreatic insufficiency; plus easing the mental health burden of cystic fibrosis on individuals and families.” Nettie Burke, CEO of Cystic Fibrosis Australia (CFA) said today.

“This is the ‘head start’ our young CF community needed. Coping with a demanding chronic disease like CF is a full time job for the whole family and ORKAMBI reduces this burden dramatically for many” she said.

ORKAMBI has literally changed and extended lives for our CF population over the age of six years already but it is not the answer for everyone. The CF community is still waiting for access to SYMDEKO, a super effective CFTR modulator drug that was recommended by the PBAC in March this year and price negotiations have stalled. This is a cruel and unacceptable delay and CFA implores the Government and Vertex to return to the table and negotiate in good faith.

“It is reckless to confuse what a life is worth with what a life costs” Nettie Burke added.

CFA expects all financial stakeholders to come together on a viable commercial agreement for SYMDEKO and we hope they never lose sight of the basic truism that no dollar amount can ever be placed on a young life.

The active and passionate Cystic Fibrosis Community wrestles with this terrible disease every day and still they take the time to advocate for better drugs and treatments and fundraise for CF research. Our CF Community is cohesive and supportive and nothing gets in their way. They deserve access to the best treatments immediately.

“In the decades to come, this Community and the country as a whole will be stronger and richer on account of the lives that the PBAC's ORKAMBI decision saves today” Nettie Burke said.

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- For further comment on the PBAC announcement and the drug ORKAMBI, contact our CEO Nettie Burke (0404 034 294) nettieb@cfa.org.au
- To get in touch with CF Community members for personal comment on the benefits of ORKAMBI, contact Nicki Mileham nickim@cfa.org.au.