

## Letter to Politicians from Community

On your horizon is a day at the ballot box and on our horizon is a key date in March – the day the Pharmaceutical Benefits Advisory Committee (PBAC) meets to consider two cystic fibrosis (CF) drugs that are vital to so many people in the CF community ...

- KALYDECO for children 12 to 24 months with a gating mutation
- SYMDEKO for people 12+ F508del homozygote or one copy of F508del and one residual function mutation.

In fact, more than 1,300 people with CF will be affected by the PBAC decision plus of course their partners, parents, siblings and children.

For any rational person, it would be unconscionable for any of these drugs to be rejected for reimbursement by the PBAC but as we all have experienced the sensible and most reasonable outcomes are not always delivered.

It goes without saying we appreciate the sheer weight of issues facing you between now and the election. But equally, the focus of any issues is your constituents – including the CF community in your electorate. Please don't confuse "small numbers" with "insignificance".

And yes, we do deal in "small numbers" with CF but no, they are far from "insignificant". To look into the eyes of a child or young adult suffering the debilitating effects of CF is to gain a glimpse on what real suffering is and every day these drugs are denied shortens lives.

At this point of time I only ask for you to support our endeavour by letting the leaders of your party know that the issue of drug access is important to you and your constituents.

We sincerely wish you well in the run-up to the election. But in doing so we urge you to keep in mind those in your constituency who need your help and support to achieve their life goals.

We need reimbursement for these drugs approved by the PBAC and if you would like to discuss the merits of these life extending drugs I would be happy to tell you our CF story.

In anticipation, thank you for your support.

Please remember a key tenet of our national anthem ... With courage let us all combine to Advance Australia Fair.

During the run up to the Federal Election please embrace what our community, your electorate and the entire Australian community wants and needs ... access to the best healthcare to ensure people can live a full and valuable life.

Kind Regards

Community Member  
Person with CF  
Parent of a person with CF  
Sibling of a person with CF