

25 May 2020

ALL ABOARD

Cystic Fibrosis Australia's (CFA) National Priority Setting is well underway and we are excited to see how it will take shape. The stakes are high, because this Priority Setting program will set the framework for Research spending and Advocacy for the next five years.

This is more than just a "help me to help you" survey, it is an in-depth multi-stage discussion of where we are in the struggle against cystic fibrosis (CF) and where the money and energy needs to go. Our first survey does not pull its punches, we know that we have to get deep into the technical detail of this disease in order to make this discussion meaningful.

It was always going to be a difficult endeavour. People living with CF are no stranger to Sophie's Choice scenarios – early this year the air pollution on the East Coast of Australia was so bad that people were having to choose between inhaling bushfire smoke or going without aerobic exercise. Making hard decisions is a honed skillset in our community, but that doesn't make it any easier to have to prioritise pancreatic research over transplant improvements when we all want funding for both.

The current feedback suggests that our community is enthusiastically engaged with this Priority Setting program and we are well over halfway to our response target and the Survey has only been live for a few weeks.

Naturally we want as many of you as possible to have your say. Let me re-iterate that anyone completing the questionnaire who finds it unclear or impenetrable is welcome to contact me via nettieb@cfa.org.au so that we can talk through the details. Our aim is to lead a high level discussion that leaves no one out.

Click through the link to put your stamp on Cystic Fibrosis Australia's work for the coming years:

<https://www.surveymonkey.com/r/F38Q8K2>

Kind regards



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