

1 May 2020

### **We Belong to a Symphony, Not a One Man Band**

In 2020 the Australian Cystic Fibrosis Research Trust (ACFRT) and Cystic Fibrosis Australia (CFA) will be rolling out our Research and Advocacy Priority Setting program to roadmap the next five years of cystic fibrosis (CF) research funding and advocacy.

The ACFRT and CFA are committed to expert consultation and informed decision making, but we recognise no greater authorities than those Australians living with CF and their care teams.

In the last few years we attained a succession of victories at the national level, securing funds for KALYDECO, ORKAMBI and SYMDEKO. We are seeing increased life years for people with CF and huge dividends in symptom relief. As with everything we do, we are committed to visibility and equality of access for Australians with CF.

It is a time of great optimism for our ongoing quest, but we must consistently concentrate our resources and energy on the most practical and tangible goals. CFA is a respected voice in the health sector but we do not go in for unilateral plans. **We belong to a Symphony, not a One Man Band.**

The National Research and Advocacy Priority Setting initiative is consumer focussed by definition, but we always seek to blend quantitative and qualitative sources. To that end we will be working with professional medical and allied health adjudicators and researchers to ensure our research is robust and well analysed.

Research and Advocacy Priority Setting will take place in multiple stages over 12 months.

1. The first stage is our Initial Survey [click here](#).
2. We are committed to feedback and so the second survey will go into more depth in areas that the CF community has flagged as high priorities.
3. Stage three will be a face-to-face Think Tank where voices from across the entire Australian CF community - medical, research and lay will come together to finalise priorities.
4. Finally, findings from the Think Tank will be distributed for consultation and from that feedback we will set our Research and Advocacy Priorities for the next five years.

Setting priorities for CF research and advocacy is essential to maximise the impact of the ACFRT and CFA's investments. It is also a way to address diverging principles or values between different stakeholders and disciplines in a fair and legitimate manner.

CFA will ensure there is equitable involvement of stakeholders and appropriate representation of different areas of expertise. We hope to achieve a balance for all participants.

Please take the survey as broad stakeholder involvement is beneficial for the outcomes of a research and advocacy priority setting exercise for several reasons:

1. Minimise the chances of research and advocacy options being overlooked as different groups of stakeholders tend to prioritise differently
2. Fosters ownership of the established priorities among those involved, in turn increasing the chances of implementation of the priorities

3. Allows priorities to correspond with the needs of those who will implement and those who will benefit from the research priorities, increasing the credibility of the exercise and the potential impact on health and health equity
4. Prevents unnecessary duplication of prioritisation efforts and wasting of resources.

**Transparency increases the credibility and the acceptability of the final result.**

If you would like to be part of the Research Priority Setting process, please email [nickim@cfa.org.au](mailto:nickim@cfa.org.au).  
If you would like to learn more about the Research and Advocacy Priority Setting program please visit our website page <https://www.cysticfibrosis.org.au/research/research-advocacy>.

Kind regards

A handwritten signature in black ink that reads "Nettie Burke". The signature is written in a cursive, flowing style.

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