



21 March 2020

WHERE TO NOW?

We have talked before about putting the CF Community in the driver's seat of CF Research. The truth is that it's easier said than done. We know that our community has vital insights and information. They also have the right to choose a path.

However, the staggering complexity of cystic fibrosis (CF) as a condition is and always has been a roadblock to our cause.

Researchers can spend a lifetime studying a short gene sequence or a small set of mutations. Others may work for years to hone the craft of CF care, and best practices in their field will always be changing and updating under their feet.

Children are born in Australia and around the world whose life expectancies may fluctuate from year to year - quality of life is continuously changing, CF goals are continuously changing.

That is our starting point, constant change. The task is to figure out where we're headed as a community, to set a course for dry land. I've already mentioned that it won't be easy.

Cystic Fibrosis Australia (CFA) has prepared a course of three in-depth Survey rounds. Feedback on the first Survey will help calibrate questions in the second round which will inform the third which will be a 'cross community' Think Tank. The Surveys will aim to form an outline of your personal priorities for CF Research over the next five years.

The survey data will be put before our Priority Setting Think Tank made up of Researchers, Clinicians, parents, partners, carers and individuals with CF. The exhaustive talks and negotiations which follow will produce a roadmap, a treasure map, for what we are trying to achieve.

In a time of global uncertainty it is more important than ever to align our goals and strive for a common vision. At CFA we do everything we can to promote education and best practices around the tangled topic of cystic fibrosis, but this month we are asking you will full pride and confidence "Where to now?"

For further information or to apply for our Priority Setting Committee please contact nickim@cfa.org.au.

Kind regards

A handwritten signature in black ink, appearing to read "Nettie Burke".

Nettie Burke
CEO
Cystic Fibrosis Australia