

7 September 2021

## LAY OF THE LAND

Medical research, as with every aspect of the CF cause, should be consumer driven and informed by the needs of end users. Even the most advanced medicine is pointless if it does not serve a real need in the Lay population.

In the world of CF, our problems often boil down to a single word, a single common obstacle that prevents us getting moving forward. Complexity. There is plenty of bravery, enthusiasm and intelligence in our Community. However, the complexity of CF as a disease and the different ways it manifests for different individuals, makes it hard to coordinate and strike at root causes.

Over the last few years there has been a campaign to combat the CF 'complexity problem' through CF education and consumer consultation. This is an ongoing process, but we are already seeing results with ambitious projects like the Priority Setting initiative, the 'CF Donut' and all the amazing research funded by the Australian Cystic Fibrosis Research Trust.

Right now we need your help to make sure that current research is informed and on-target. We have a number of research projects reaching out for your knowledge and perspective on CF.

Help us to help them.

Pick one or all of these online surveys and devote five minutes of your time. That's all we ask.

The data will of course be both anonymous and secure and it will go a long way to helping our Medical community get the Lay of the land.

### **1. Gerard Kaiko – Colon Cancer and Cystic Fibrosis**

Help us break down the health risks associated with cystic fibrosis in order to better understand its connection with Colon Cancer.

<https://www.surveymonkey.com/r/CXNG2GC>

### **2. Anastasia Ward – Pilot Study on Genetic Polymorphisms**

We are conducting a pilot study on the effect of genetic polymorphisms on the pathophysiology and disease progression of cystic fibrosis. Please complete this short survey to assist our project.

[https://scuau.qualtrics.com/jfe/form/SV\\_bjQn3DcHr8IURBc](https://scuau.qualtrics.com/jfe/form/SV_bjQn3DcHr8IURBc)

### **3. For Benefit Medicines – Airway Clearance**

CFA is conducting research on behalf of For Benefit Medicines (FBM) to better understand how people with CF use airway clearance. FBM is a registered charity that supports CFA with the profits from the sale of their CF medication.

<https://www.surveymonkey.com/r/6VF5JWC>

Kind regards

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

Nettie Burke

CEO

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