

28 April 2019



## RUBBER, MEET ROAD

There has been a lot of talk lately about the need for CFTR Modulators and the call for measures in health equity that can bring the best practices, medicine and resources for CF treatment to a wider array of people.

This is not empty rhetoric. When we write to the Government or Pharmaceutical companies and insist that there is more to be done for CF in Australia, we are speaking from a position of hard data.

In the coming months we will be fighting for Compassionate Access to Trikafta. You will be hearing us at our loudest and most vociferous. But today I want to take the time to acknowledge the bedrock of CF related research in Australia, the Australian Cystic Fibrosis Data Registry (ACFDR).

CF is a personal disease, its effects and symptoms vary widely. This problem is so pervasive in the treatment of CF that CF researchers have even pioneered organoid technology to test drug molecules in a way that predicts the responses of individual patients. When it comes to CF, everything must be tailor fitted. In Australia, we depend on the ACFDR to store and distil the overwhelming amount of crucial medical data that it takes to service this community.

The data itself is precious. Not only must privacy be strictly guarded, but metadata analysis can offer crucial medical insights to fuel new research and give feedback on medicines currently circulating in the market. Even more significant is the impact of the Registry on attracting overseas trials. By maintaining top of the line medical data we can make Australia competitive in the international struggle for securing cutting edge drug trials. This means that our people get the drugs as early as possible and can have a shot at tomorrow's CF medicine today.

The ACFDR is managed by Monash Registries Unit and funded by CFA. We are joint data custodians. Monash University's facilities, staff and expertise are indispensable. We want to thank Monash University and also acknowledge the sterling work of Professor Scott Bell and the Steering Committee.

The latest report from the ACFDR is out now and is a treasure trove of knowledge about the state of this disease in Australia – CF boffins both professional and amateur are encouraged to take a look.

For CFA, the Australian Cystic Fibrosis Data Registry is where the rubber meets the road, and you can bet that, with Trikafta still on hold this year, all roads will be leading to Canberra.

**[ACFDR 2019 ANNUAL REPORT CLICK HERE](#)**