28 January 2020

UNTAPPED POTENTIAL

2019 was a big year for the CF community in Australia. We had hoped for a very long time to get CFTR modulators on the PBS and we made multiple huge leaps forward. Getting Orkambi for infants 2-5 was an especially hard-fought battle and it's so gratifying to see the results.

But give us an inch and we'll take a mile. That's how it is when we are fighting for your CF community to have a better future.

We want Australia to go further. We want the latest CF drugs of tomorrow today.

There is untapped research capital on our doorstep. Clinical trials require well-run facilities and a broad range of trial participants. The trials themselves are extremely expensive and pharmaceutical companies prefer to field their trials in areas with a good track record and Australia has an outstanding international reputation in CF clinical trials.

Many Australians with CF are already participating in drug trials but not for the full range of medicine applicable to their condition. We need trials in Australian clinics because there is no sense in waiting until potentially lifesaving medicines are more widely available.

Late-phase trial drugs are a crucial beacon of hope to so many, particularly for those with advanced symptoms and rare mutations. To get those drugs we need to attract the big names in pharma.

A formal clinical trials network that aids distribution, governance and recruitment will bring Australians with CF into a common pipeline under a rigorous database. We can offer detailed and coherent trial matching to both patients and drug patent-holders.

Watch this space in 2020 because CFA will be creating and overseeing a clinical trials network in association with our clinical investigator partners, the ACFDR, TSANZ and the state and territory CF bodies.

This is the initiative we need to make Australia a global focus point for cutting-edge CF medicine.

Kind regards

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