

Beat CF - Together

Life with cystic fibrosis (CF) can be hard on families and individuals. This year we are have had to come to grips with large scale problems like pandemics and air pollution, problems that pose a disproportionate threat to the CF community.

At the same time we are reminded of the brave fighting spirit that persists in our community and in CF warriors like Bradley Dryburgh and Mitch Messer who have taken on life's challenges and won inspiring victories.

Next year we will convene our 14th Australasian CF Conference and take on the challenge of pushing Trikafta through the PBAC assessment process on the way to getting this essential medicine funded by our government.

But not everything in life is Big Picture. If you or your child are living with CF and want to make a difference in the CF world, there is important research going on right now Australia-wide. 'BEAT CF' is a research program aimed at studying exacerbations in CF and understanding the best ways to treat or manage them.

Exacerbations, as many of you will know, are periods in which the regular symptoms of CF in a person's life worsen or in which new symptoms develop. The advent of new or more drastic symptoms can be stressful, confusing and needless to say, dangerous. Pulmonary Exacerbations can be especially sudden and serious. These are the critical moments when clinical care needs to be focussed, well-informed and perfectly timed.

We cannot attain to those needed levels of clinical care without hard data and evidence, and that means widespread participation in trials. 'BEAT CF' means individuals stepping up to fight this thing together. All Australian children, teens and adults with CF are invited to participate in the study, unless you have had a lung transplant.

To learn more about this vital program or to register your interest, visit the BEAT CF website at https://www.beatcf.org.au/

Kind regards

mttelshe

Nettie Burke, CEO Cystic Fibrosis Australia 0404 034 294 <u>nettieb@cfa.org.au</u>