

24 December 2020

THE NIGHT BEFORE CHRISTMAS

This time last year I sent out a Communique entitled '2020 Vision' about all the things we were looking forward to in the new year. With Christmas only one sleep away, it seems strange to say that I feel extremely grateful for this year because of how much we learned and the strength we showed in adversity.

There is no way to talk about 2020 without talking about COVID-19. Our hearts go out to all those affected by the pandemic, but I think it will be useful to discuss a few ways in which it relates specifically to the cause of fighting cystic fibrosis (CF).

For one thing we have seen our community rally together in a big way – our largest ever Consumer Connect meetups were held during the Quarantine period and we were able to keep everyone informed about the emerging data on CF/COVID interactions only because our community was so pro-active and level headed. It truly felt like a collective effort and I am in awe of the way this threat was handled in the CF community.

With crowd sizes limited all year we had to get creative, and we really racked our brains at CFA to come up with fundraising streams that could replace traditional sources like our Mother's Day markets and coin collections. We managed to greatly increase our online footprint this year by bringing the markets online and by making sure that our social media community was really engaged with fundraisers that were going on in local communities.

The most dramatic example of a local CF hero this year was Bradley Dryburgh and his #42forCF marathon, we are still amazed by his efforts and we know he captured the imagination of many young Australians living with CF.

With that said, some important projects did need to be placed on hold, and we hope that 2021 will provide a clear runway for exciting events like the CF Kokoda Trail that was originally planned for September.

What is certain is that 2021 is a very important year for our cause in Australia. The 14th Australasian Cystic Fibrosis Conference is going ahead in a digital format and we are incredibly proud of our guest line up. What's more, 2021 will see the culmination of our fight for Trikafta, with the PBAC sitting to decide whether they will recommend this life saving drug for government funding.

Take a long and well-earned rest this Christmas, and CFA will do the same because next year will be a doozy. My team and I are looking forward to it already.

We will be keeping up the pressure on our politicians and big pharma. We know that you are counting on us, and although we may not always have '2020 Vision' for unexpected crises, we are looking at a bright future in the New Year.

Merry Christmas and Happy Holidays.

A handwritten signature in black ink, appearing to read "Nettie Burke". The signature is fluid and cursive, with the first name "Nettie" being more prominent than the last name "Burke".

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