



press clip

A rose for home and rose for cystic fibrosis

BY JEMILLAH DAWSON

TWO Bunbury mothers are calling on the federal government to put the drug Trikafta on the pharmaceutical benefit scheme in the lead up to 65 Roses Day on May 28.

Cystic Fibrosis is a rare recessive genetic disease for which there is currently no cure.

May is Cystic Fibrosis awareness month and people living with the disease and their families were hoping to celebrate access to the latest of promising drug treatments, Trikafta through the PBS.

Bunbury mum Taryn Barrett said Trikafta was effective for 90 per cent of people that have cystic fibrosis where as the current drug on the PBS, Orkambi only works for 50 per cent.

Patients that using Trikafta in Australia are currently paying more than \$272,000 per year for the drug.

Bunbury mum Beck Walker's two year old boy Josh has a form of cystic fibrosis which cannot be treated with Orkambi.

The two mums are friends, but haven't been able to see each other with their sons because of the risk of cross infection

"Cystic Fibrosis can be such an isolating condition between the CF families due

to cross infection limitations and in general CF and all the daily medication, treatments and limitations is often underestimated due to CF being such an invisible disease," Ms Walker said.

"I never imagined giving my two year-old over 20 doses of medication daily and I know for sure that I never imagined having to rely on the government and a drug company to negotiate costs as to whether my son and 2000 other Australians

could access a life changing medicine."

On May 28, West Australians are called on to help make a difference to those living with cystic fibrosis with 65 Roses Day.

"Sixty-five Roses day not only helps raise vital funds and provides education about CF it also shows the CF community how much love and support there is for our CF warriors and their families," Ms Walker said.

Places such as the Health Hub at Eaton Fair will be selling for the cause but people can also buy a virtual rose as well.

Cystic Fibrosis WA Chief Executive Officer Lisa Bayakly said the foundation had to think quickly on how to fundraise last year when the pandemic hit.

"This year we can't wait to get back on the streets selling

roses from Broome to Albany, spanning over 2,500kms," she said.

"We hope people will buy both on 65 Roses Day, - maybe a beautiful fresh rose for home and a digital rose for a colleague or friend."

For more information visit <https://www.cfwa.org.au/65roses/>



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Connor Barrett and Josh Williams both have cystic fibrosis and cannot play with each other because of the risk of cross infection.