

BREAKING BARRIERS FOR CYSTIC FIBROSIS

TODAY'S DEDICATION

DAY 34: WEDNESDAY 4th OCTOBER 2023



CLARE

Our daughter, Clare, was born 15 October 2021 and at less than 2 days old was rushed to emergency surgery for an obstructed bowel. She spent the next 4 weeks in NICU recovering while we learned of her CF diagnosis and started to understand how to care for her.

She began physio treatments (percussions) when she was just 3 weeks old, and we still give her physio daily. We took her home for two weeks and then back to the hospital for stoma reversal surgery at 6 weeks old.

At 6 months old, Clare spent her first Easter in hospital, due to an infection that required IV antibiotics to treat.

Despite our rocky start, we are balancing the management it takes to care for a child with CF well. We have made adjustments to our lives and financial sacrifices to ensure Clare is cared for as best we can for now, and we are very hopeful Trikafta will be available soon (currently only on PBS for age 6+ in Australia).

We are optimistic that Clare is going to have access to life-changing drugs in the near future, so much research and progress has taken place, but not enough access just yet – so close.

Clare turns 2 in a couple of weeks, and we are grateful for the cheeky, strong-willed toddler she has become. We learned early on not to underestimate her, she's stronger than she looks. She tries to deadlift things 4 times her size.

