BREAKING BARRIERS FOR CYSTIC FIBROSIS

TODAY'S DEDICATION

DAY 26: TUESDAY 26th SEPTEMBER 2023

RORY

Rory was born in September 2022. At 10 days old we got the call to say he had CF and they were able to confirm his genetics to be homozygous DF508, the most common genetic variation. We were obviously incredibly shocked when we found out; we quickly embarked on an intense learning journey of what his and our future would look like.

We learnt that things were positive and he has a strong future ahead. He is very lucky to be born in the generation where modulators are available; he will hopefully be on Orkambi soon and Trikafta in a couple of years' time. While he needs daily treatment to keep him healthy and has had a winter full of antibiotics (and parents filled with anxiety), he has had a strong first year.

He's a chubby, healthy, and incredibly happy little boy. We aren't sure what his CF journey will look like just yet but we are grateful to be living in Brisbane with access to the amazing medical team at the Queensland Children's Hospital in an era where there are fantastic advancements in CF treatment.