BREAKING BARRIERS FOR CYSTIC FIBROSIS

TODAY'S DEDICATION

DAY 17: SUNDAY 17th SEPTEMBER 2023

William

William is turning 8 this Sunday and he has cystic fibrosis.

William was diagnosed a month after his birth. I will never forget the phone call from the paediatrician.

His heel prick test showed that he had cystic fibrosis. He was born healthy.

My husband and I were just so shocked because we had no prior history of CF within our families. We thought it just couldn't possibly be true.

When we showed up at the clinic for the first time in Brisbane, we asked if they had made a mistake. No, he has two double Delta 508 genes the most common cystic fibrosis one. They told us there was no cure and the best-case scenario was he lived until he was in his 30's. We were so scared for our beautiful baby boy.

Being first-time parents, we were way in over our heads. We had really no idea what it all meant but we sure do now. He has had 6 or 7 hospitalisations now for different reasons.

When we heard about Trikafta we were so keen to get him on it. What an amazing chance this could change his life totally.

Little did we know it would be the start of our next battle in the process of being able to start this drug, as we also found out Will has early-stage liver disease.

CF just loves throwing grenades at you.

Trying to focus on the positives and remember nothing is guaranteed. You don't get to choose the cards you are dealt but you can play the heck out of them.

I think what Layne is doing is amazing to raise money and awareness for the CF community.

Thank you, Layne, for working hard to raise awareness and change the lives of people living with cystic fibrosis.


Sweet
SOUTH BANK
BRISBANE
Jelly Belly


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