BREAKING BARRIERS FOR CYSTIC FIBROSIS

TODAY'S DEDICATION

DAY 1: FRIDAY 1st SEPTEMBER 2023

Ben

As Ben was born on the 1st of September, it is very fitting that Layne would want to share our Cystic Fibrosis story. Ben is only 11 years old and already he knows what he wants to be when he grows up – a professional AFL player, or failing that, a sports scientist.

He also loves rugby, running, tennis, and bike riding – sports that are good for keeping his lungs healthy.

Ben and his family have never hidden his cystic fibrosis and they are big supporters of Cystic Fibrosis Australia (CFA).

Mum, Jo is happy to share the story of her son's diagnosis and how the family learned to cope.

"One of the reasons I'm so open about Ben having cystic fibrosis (CF) is that if you try and hide it, it becomes more of an interest to people. We've always been very open at school and with friends and family that he has what he has.

At first it was a big deal at school with kids asking, 'why are you taking pills?' But after finding out they don't make a fuss or make him feel like he's different. Ben asks why he needs to have to take tablets with each meal, and he's old enough now for me to explain that they are important for him to digest food properly and put weight on.

I will always remember the day Ben was diagnosed. I was at home when she received a call from the Obstetric Surgeon. Ben was 4 weeks old and had issues with weight gain and also digestive issues after every time I fed him. He had never been able to sleep well, I would be out driving him at 3am and he would not even sleep with the motion of the car. I knew something was not right.

As soon as my Obstetrician started talking, I knew the call was about me and that it was bad news. It was the results from Ben's heel prick test – he had come up as an alert for CF. We were given the phone number of the Royal Children's Hospital Cystic Fibrosis Department in Melbourne (as we lived in Melbourne at the time). As

it was around 5pm on a Friday, we could not book in for an appointment, until Monday morning. After that I couldn't think of anything else. I distinctly remember the Obstetrician saying to me, "don't worry you will cope well" due to the fact that I am a perioperative nurse, working within the operating room. I don't know if that makes it worse for my son, as I am a germophobe, who is always on the kids with their hand sanitisation!

Once we had our intensive cystic fibrosis parent education, we were able to get Ben the enzyme replacement medication he needed, and his digestion improved, as did his sleeping. It was such a blessing.

After Ben's diagnosis was confirmed with a blood test it was full on from there – doctors, nurses, physios, and spirometry scientists. Both my husband and I also had genetic testing (blood test), in which it was confirmed that we both carried the same cystic fibrosis gene (DF508). We did not know of anyone in either family that had cystic fibrosis. However, that is the same story for the majority of cystic fibrosis families in Australia. Most of us do not know we are carriers of the CF gene until we have a child with cystic fibrosis.

Pretty soon, cystic fibrosis had become normal to us. I guess you just learn to accept it. I've read that there are three stages of cystic fibrosis. 1. You want to wrap your child in cotton wool. 2. You become a bit more relaxed as they get older. 3. You end up doing a bit of both – and I think that's where we are now.

We are fortunate that Ben has got to 11 and only had three hospital admissions. We have Ben's treatment routine sorted. It's 20 minutes of hypertonic saline with a nebuliser and PEP (physio) in the morning and then 30 minutes of PEP, hypertonic saline, and Pulmozyme in the evenings.

It's good to know there's help available from Cystic Fibrosis Australia. We have been able to move from Melbourne, Victoria to the Sunshine Coast, Queensland in 2019, and always have a wonderful Cystic Fibrosis team to back us up.

But there's still the uncertainty about the future – you just don't know what's around the corner. We've met some lovely people along the way and maybe it makes you appreciate life more and to live for the moment.

When Ben was born, we were told it was lucky that he's born in this generation because of all the new medicines being developed overseas. He has now commenced Trikafta, which is a new medication that has proven to increase lung function and improve weight gain in people with CF. A lung transplant is not a cure,

and I don’t want my son to have a lung transplant unless he needs one – but I don’t want him to get to that point.

My hopes for Ben are the same as they are for my daughter, Annika– who does not have CF. I want both of my children to live long, happy, and healthy lives, and to have a family of their own one day.