

2011

Cystic
Fibrosis
a fight we
must win

Sarah's diary

27
Monday

Made arrangements for the tropical fish to be collected this weekend, have to say goodbye, bit sad but Rhys comes first. Hopefully my friend's children will really enjoy them. Sent some pics of Rhys to a modelling agency online today. He is so beautiful and I hope they think so too. I will have an answer in 24 hours, fingers crossed.

Changed feed to higher amount.

Creon goes up.



29
Wednesday

Started blog.

Cried about starting blog.

Organised day today – meds are now going to plan. Started more feeds Rhys not taken anymore milk than normal yet but I'm glad he now has the option.

We have baby clinic at CH next week so I have taken a urine and stool sample today to send off and we will have the results when we get there. I hope they don't get lost in the post, wouldn't want to be the one to find them!

Finally got the strength to fill in the DLA forms today.

Organised day today
- meds are now going
to plan.



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Thursday

Rhys woke at 5.15 for a feed, now he has a different milk amount. I think it will take a few days to get back to a 4-hour routine. Completely disorganised the day and felt like all I was doing was giving medication all day. Could not stop thinking about CF today. CF nurse came to weigh Rhys, 8oz on. Well done my boy. Filled in the rest of the DLA forms with CF nurse.

Me, Dan and Rhys had a cuddle on the bed, it made me really happy, the only problem is that when I'm happy it doesn't take long for me to remember the CF, I start crying again but Dan seemed to understand.

The more time I spend with Rhys, the more I love him. I wish I could take the CF away from him, he does not deserve this.

When I'm happy it doesn't take long for me to remember the CF.

1

Friday

Today was a great day, I may go as far as to say the best day yet!

Took CF nurses' advice and got medication out of the way first thing in the morning. Rhys woke and fed at 5.15 so did physio at 6 which meant we could enjoy the rest of the day. We had our first trip to Babies 'R' Us together to buy some new toys. It was nice to go out and do normal family things.

We also went to the local shops for a walk around. To everyone else he is just a normal baby. I'm not ashamed of his condition but its nice to have the option of who to tell and who not to tell because if you look at him he looks so healthy.

We played with Rhys' new toys, he is in a good mood today, a few coughs which have been noted but nothing to worry about.

Early physio session at 6, feed at 9 and bed by 10.30.

I have now realised that with a good routine, it does not seem so bad. Is this just being a new mum or is this trying to deal with CF? Only time will tell, I pray tonight for more days like today.

PS. No tears today :-)

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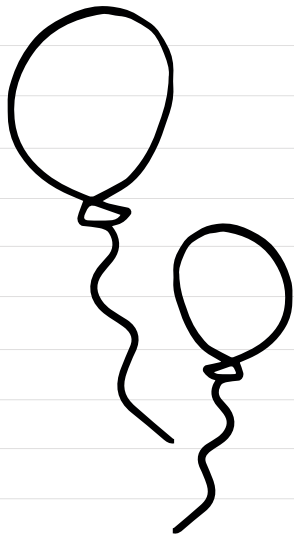
Saturday

Today we had to say goodbye to our tropical fish. Sad day but they are going to a good home. I had to take Rhys out for the day as messing around with the tank water in the house can prove to be dangerous for him.

We went to a friend's house for a small get together for her birthday. We have known each other 17 years and she has known about the CF from the beginning. I had presumed she would have told the other people at the party at some point.

I got chatting to Serena, an old school friend, we only seem to see each other at these get togethers. After an hour or so I asked if she knew about Rhys's CF, she did but did not want to say anything, I told her that I would rather be open about it, after that she wanted to know everything.

It was nice that everyone was treating Rhys like a normal child, after all he is.



Had a little fall out with Dan today over going away for Sam's hen weekend. I am worried that Rhys's physio and medication and night feeds may be too much for him, am I being over protective?

Rhys is now becoming a little demanding, wants attention all the time, this reminds me that no matter what happens he's still a baby and he will still want normal things.

For the first time today I did Rhys's physio because its one of our daily things, not because he has CF, this is now becoming the norm.

Cried once today, this was because Rhys had been crying for a while and I didn't know why, turned out to be a wet nappy, I cried because I felt guilty for not knowing.

No crying because of CF, this has been the case for a few days now. Is this a turning point? Maybe, maybe not, we will just have to wait and see.

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Sunday

5
Tuesday

It seems like things are getting a bit easier. Now that Rhys is more responsive to things it makes me realise there's more to him than just CF. I told Dan that I thought it was getting easier, he said that he had a bad day with it yesterday, I know what the bad days feel like and I just want to take the feeling away from him.

Picked up Rhys's medication from the chemist, only a little set back with this order. Maybe third time lucky, I will get the correct prescription and chemist will know how to issue it all.

Oh no I have just realised that I have not done Rhys's second physio. It's 11.30pm and Rhys is asleep, do I just leave it, just once?? ...No, so I get Rhys up, luckily he sleeps through the whole session. That's the first time I have forgotten.

We have baby clinic at the CH tomorrow, I hope it all goes well, especially as Rhys is still on his amoxicillin. Filled in the rest of the DLA forms, wasn't too bad, did not like having to put the worst case down but I suppose we have to be realistic.



6
Wednesday

Baby clinic day

We went to baby clinic today. You can't help but wonder if you are sitting next to another child with CF, how would you know? Do you strike up a conversation with the parent to find out? What if it's a yes, do you move seats? We sat and spoke to nobody!

Dietician was pleased with his weight. Consultant went through changing the doses of medication in accordance to his weight.

We had the results back from last weeks cough swab test, they had found a germ which is quite common in children but normally it just comes and goes.

But for Rhys it's yet another different antibiotic and the words that are constantly repeated by everyone, it's just a precaution.

We had our physio technique checked to make sure we are doing it ok. Physio said to let him be as active as possible to strengthen his chest and arm muscles.

Later today Rhys rolled over for the first time, I think he was listening to the physio!

You can't help but wonder if you are sitting next to another child with CF, how would you know?

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Saturday

We had a little family BBQ today, just me, Dan, Rhys and the pets!! It was good family time, things seem to be getting a lot easier now. Are they getting easier or are we finding ways to cope?

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Sunday

Bad start to the day, Rhys was sick after his first feed so all of his daily meds come back as well.

But the rest of the day was a great day. Rhys was a bit grumpy, I think he might be teething. Now thinking about what he can have for teething and whether anything will affect his medication, I have learnt now to always think about CF before doing anything. It is a bit frustrating, I just want to do normal baby things.

Rhys had a bit of a sicky day and coughed after being sick but not real coughs today, I think new meds are working.

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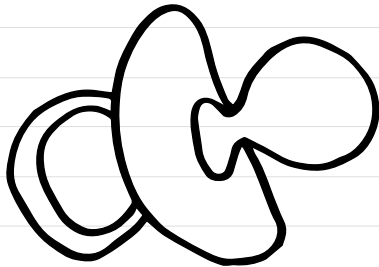
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Monday

We all went to Toys 'R' Us today, now that Rhys is getting bigger he wants to be entertained. We also want to get him mobile as soon as possible to strengthen his chest muscles and we think toys will help.

First encounter with a toddler!! We were happily looking at the toys on the shelves, Dan was slowly pushing Rhys in his pushchair. We both looked at him to find a young boy, maybe 3 years old putting Rhys' dummy back into his mouth. Rhys must have dropped it. The young boy was only doing what he thought was right but my stomach somersaulted and within a second I felt sick with worry.

Dan took over from the little boy who strolled off thinking he had done his good deed for the day. I don't know how I didn't scream out 'don't touch him', I'm glad I didn't. This will be the first of many moments I will feel like this I'm sure.



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Tuesday

Today was a really good day. Meds and physio done early. Our friends came round and played with Rhys with Kayleigh their 7-month-old daughter. They are such good friends of ours. When we told them about the CF, they were so supportive.

Aimee has made a point of researching CF on the internet, she is such an amazing friend. I don't think she realises but it helps so much to talk to her, sometimes about the CF and how I'm feeling but also we can sit for hours and just talk about babies which is a great break from CF.

Rhys rolled over again today, I am trying to get as much movement out of him as I can. He is my little star.

Today I feel that I have now cracked the meds routine, it's only taken me 9 weeks!!!!

I now give Rhys his antibiotics with his late feed and at the same time put all his meds in the syringes and keep them in an airtight container for the following morning, this way I don't have to mess about when Rhys is hungry in the morning.

Pat on the back for me I think!

I am trying to get as much movement out of him as I can. He is my little star.



13

Wednesday

I'm sure it's getting easier.

I am now seeing Rhys as a little boy and not a condition. Rhys is a happy baby who happens to have CF, wow I really didn't think I would adapt this quickly but I must admit Rhys is making it easy, each smile just melts my heart.

The health visitor is coming tomorrow, Dan and I have made bets on how much weight Rhys has put on this week. I'm saying 8oz, Dan is saying 9oz.

We seem to be getting a bed time routine which is great. Rhys is still waking in the night for a feed which is good for me because if he didn't I would have to wake him anyway because I need to make sure he's getting those extra calories. I wonder when I will get a full night's sleep.

Can't remember the last time I cried!!

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Rhys had his second set of jabs today. Had to mention that he was taking Augmentin for 2 weeks for a bug that was found on his caught swab test, it was fine, we still went ahead.

Booked jabs for 4 weeks' time, the receptionist booked us in for the same day as baby clinic in case I wanted to catch up with HV with any questions. Had to ask her to change that day because we cannot attend baby clinic in case the other babies have coughs and colds. Remembering things like this are now becoming second nature but strangely not a burden.

Rhys slept for most of today, must have been the jabs.

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Sunday



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Friday

I am going away this afternoon for the whole weekend. Dan will be looking after Rhys I hope he will be able to cope with the meds and feed and physio. It's not easy and it's taken a long time for me to get some sort of routine. I'm sure they will be fine, it's father, son bonding time!



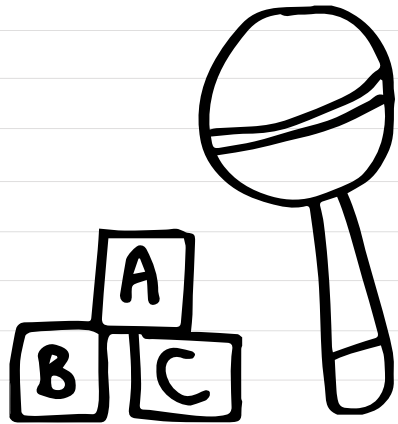
24
Sunday

Back in Birmingham and glad to see both my boys. Dan coped better than I thought he would. He did admit that it was hard work though but we both agreed that when Rhys shows that perfect smile, its all worth it x

Dan coped better than I thought he would. He did admit that it was hard though.

27
Wednesday

Although we had a good day today with lots of playtime, good naps and Rhys took good feeds, he has been coughing a bit today. Hopefully nothing to worry about but we all know it can't be ignored.



13
Saturday

Rhys stayed with his nan today while we went to a wedding, first night with us both being away. As much as I enjoy every minute with him, I think it was just what Dan and I needed.



24
Wednesday

Genetic meeting

Meeting left us with some tough choices but I'm glad we went to see them. At the moment another child is not really on the agenda. I'm enjoying my time with Rhys, he is my life at the moment. Maybe another baby at some point. It's not going to be easy though.

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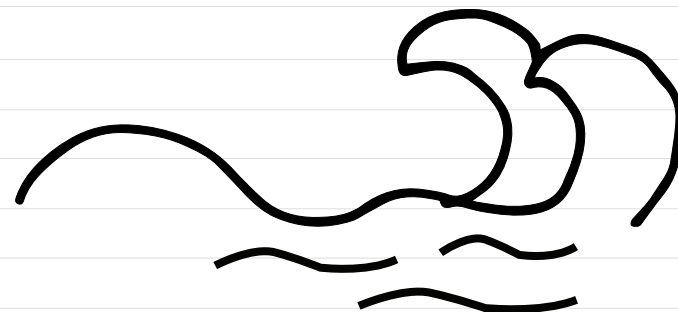
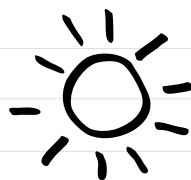
27
Saturday

On holiday!!

Rhys's first trip to Cornwall.

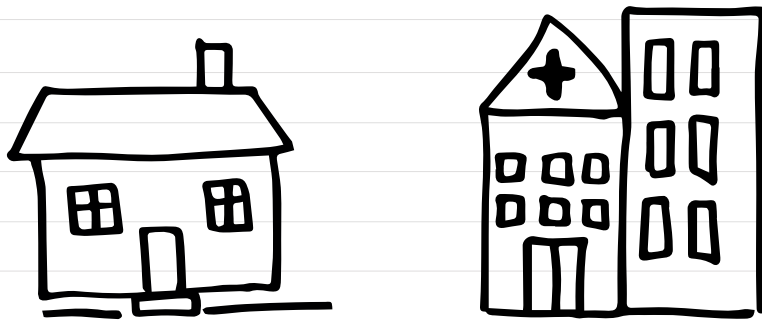
We were very excited to go away, partly because Dan and I love Cornwall and hope to move there some day but mainly because we have been told that the salt in the sea air is very good for CF patients.

Can't wait until Rhys is old enough to surf. Get those lungs going!



29
Monday

Rhys's cough got worse today and he has been sick again. We decided to leave Cornwall at 10pm on the evening instead of tomorrow. I just wanted to get Rhys home, I felt better knowing we were closer to the hospital if we needed to go in.



6
Tuesday

Best baby clinic so far.

We went to baby clinic for Rhys's monthly check up. Everything was excellent. Weight and height good, chest was clear, last cough swab came back clear too. Dietician is ready to start introducing milk so she gave us some to try, also can try meat and dairy,

Best clinic to-date, we can only hope for many more. I know they won't always be like this so I am going to try my best to remember the good ones to help with the not so good ones.

Well done Rhys, Mommy's very proud of you x

I am going to try my best to remember the good ones to help with the not so good ones.

7

Wednesday

Today Rhys and I spent the whole day together. I had decided to stay in today because it was Rhys's first day with the new milk and I wasn't sure how he would take it. It went well, no sickness or runny nappies.

We had fun playing with toys and trying to get Rhys to play on his front and roll over.

Rhys coughed at about 5.30 for the first time all day and this is the first point in the day I thought about his CF. Is this a turning point? I think so, he is no longer in my eyes, my CF son, he is my son who has CF. I am so proud of him x

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who has CF.



Notes



**Special thanks to Sarah
for sharing her diary
entries with us.**

cysticfibrosis.org.uk

