

Seb's Story



PATIENT AND FAMILY ENGAGEMENT GROUP

Seb was born with Tetralogy of Fallot's. It wasn't picked up in pregnancy, it was picked up about 14 hours after he was born. Absolutely brilliant pregnancy, fantastic birth. But when he was born, he was quite small, weighing 5lb11.5oz and the placenta was quite small and grainy and Seb was cold, so it started ringing alarm bells to the Consultants.

When he was diagnosed it was a big shock, we weren't anticipating it at all. We were told he was quite pink for a blue baby and not to worry too much, that the aim would be surgery at around a year old. So, off we went home thinking everything would be fine. Seb started spelling quite early on, just some small spells initially. We had a specialist nurse at the Freeman on speed dial.

The whole goal was to get as much weight on Seb as possible before the surgery but because he was so small and quite weak breastfeeding didn't happen for us so feeding was a real struggle. The spells became more frequent, and it was decided that Seb needed his surgery more urgently than anticipated.

As you can imagine, the whole period for us was traumatic. But, thankfully, the team at the Freeman were fantastic and looked after us. We actually got to a point at the hospital, when Seb had his surgery at 16 weeks, and we'd been in PICU for a week and they started talking about us going home, we actually got quite worried about leaving and what that would be like. I think we became a little bit institutionalised, where outside was bad and inside was good. We did manage to get over this feeling and get home and get back to normal, with the reassurance of six-monthly checks at the Freeman keeping a close eye on Seb and his heart health. Seb has just undergone further surgery at the Freeman, now aged 13 years old. He was incredible and was in and out within 5 days. He is now back at Taekwondo doing what he loves.

It does not stop me doing anything, I think the reason I just struggle in PE is because of my low stamina or something. I don't know... Or I'm just not that fit of a boy, but I do try my best



On Wednesdays I now do sparring which I do enjoy quite a bit. I'm a low budget, off brand Iron Man!



To be honest, it doesn't really affect me emotionally or anything physically that much but what it does is make me feel a bit like Harry Potter because I've got the glasses and I've basically got a huge scar down my chest. So, where's my letter to Hogwarts?!

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