



A Mother's perspective: Rebecca Sutton

Hearing those words “He’s going blind”.... somehow I managed to keep it together for the rest of the phone call. Kaileb’s Dad walked into the room as I put the phone down, we looked at each other and I crumbled, he didn’t need to ask me why, in that moment our son’s life had changed forever. The next thing I remember was it raining outside and me asking “how does a blind person know it’s raining, they can’t look out of the window and see it?”

I was right back to those early days, where I held my nearly 4 week old baby on my lap for hours as he had hearing tests, to be told he was profoundly Deaf. The first thing I said then was “he’s never heard me tell him I love him”, but I wasn’t just back there, I was further back, a place I’d never been, a place I could not accept.

I felt 6 years of my son’s life had been wiped away, wasted. We had been so happy, he was Deaf, there was no mountain he couldn’t climb, he had defied everything thrown at him, that he probably wouldn’t learn speech - he doesn’t stop talking.



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We had spent 6 years living, knowing our son was Deaf, never to hear a natural sound but doing fantastic with Cochlear Implants. Kaileb had spent 6 years living life, loving life. Now we had a different life, isn't never having the use of one sense more than enough but to lose two senses is beyond cruel.

Kaileb's diagnosis was not meant to happen. He had a diagnosis for his hearing loss, he has BOR Syndrome. In trying to pin point the gene causing his BOR Syndrome they found he had other genes that had mutations that could be causing havoc, the MYO7A gene, but he needed an ERG test to either dispel or confirm that these mutations were trouble. Our brave son underwent that horrid ERG test, not once complaining or giving up. That phone call was giving the results, it had shown his rods and cones were already severely affected. He was already going blind, the cruel irony that in front of our very eyes he was losing his eyesight.

In that instant we were thrown into a world that we knew nothing about, a scary world where there was no one else.



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That phone call was now nearly a year ago and his diagnosis is still heartbreakingly raw but life carries on, and it sure has carried on a great speed this past year. The one thing we don't have is time on our side so through the heartbreak, the hot painful tears, the despair, we plough on.

Making visual memories is the thing I'm striving to do. Kaileb has had a very busy year and has had lots of experiences. He's spent a day with the Police, where he had an amazing time. He had a chat and biscuits with the Chief constable, he got to experience many areas of the police force and got to make lots of noise with the sirens - he loves making noise! He spent the evening with the Fire service and had the brilliant opportunity to go up in the Ariel ladder to look at the views! Kaileb has also climbed Scafell Pike, England's highest mountain. He got to the summit, his little legs were very tired but the views and the experience were more than worth it.





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He's just been having a fantastic time being a child. And yes, there have been changes, he knows his eyes struggle, that he cannot see at night and in difficult lighting, he knows he trips over and bumps into things because of his eyes. He knows that sometimes when someone's ears don't work that their eyes also don't work, but we haven't used that word yet – Blind. I do not want him having that burden yet, that word is too final for a 7 year old I feel. We will have to use it one day, but for now we are drip feeding and taking it all day by day, and preparing as we go on this new journey.

Even though I cannot accept that my beautiful son is being robbed of his most precious sense, I am glad that we found out, as it means we can prepare. Kaileb recently finished his long cane training and is now a long cane user. Whilst we prepare and learn, Kaileb carries on doing what he does and that is living life to the full. Just last night he got invited to join the Rookie disability swimming squad, and very soon he is starting Piano lessons.



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In the past year we have found that there are others, there really aren't many of us but we are not alone and Kaileb has had the wonderful opportunity to meet other children and adults and so have we. I'm still going through a range of emotions and I think I always will do, but I watch my son tackling life head on with a strength I've never seen before and sheer determination and I know he will achieve absolutely anything he wants to do in life. Kaileb is showing Usher who is the boss and he is also showing us the way. My amazing son, Kaileb.