

Children's Vision Massachusetts Story Bank

Josh's Story



Hospital doctors noticed Josh's coloboma when he was born but everything checked out OK. At the time we were dealing with other health concerns, so vision wasn't a priority. At his 18 month old visit, his pediatrician thought he had a neuroblastoma. Luckily that wasn't the problem, but the eye doctor did find his left eye wasn't tracking as well as his right, and he was prescribed glasses.

We instantly noticed an unexpected difference. Josh stopped talking, being silly, being sassy, all the things that made him Josh – his character stopped and he had a flat affect. My husband, Dan, would take the glasses off and I would put them back on because they were prescribed for full-time use! It caused stress between the two of us because we disagreed on his glasses wear. Dan just felt so strongly that it wasn't Josh anymore, that he was a different kid.

After two more follow-ups both eyes were tracking together, but Josh had to keep wearing his glasses. We continued to be concerned - he fell down and tripped a lot. His pediatrician told us toddler's trip, but we didn't want this to be for the rest of his life.

Other people were noticing the difference with Josh's glasses. Our Early Intervention team suggested contacting Perkins School for the Blind. At his vision assessment, a Teacher of Students with Visual Impairment (TVI) recommended obtaining a new comprehensive eye exam. We trusted our baby was trying to tell us something!

The new eye doctor was a pediatric eye doctor, experienced in treating children. He explained details of Josh's vision we hadn't understood before. Josh's colobomas were not affecting his vision. His eyes were not tracking together and he had low visual acuity, making his vision blurry. The eye doctor wrote a new prescription and said Josh may not need glasses past his toddler years.



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Massachusetts

Open Eyes. Open Doors.

The day we put his new glasses on, I can't express the difference in Josh. After a moment of surprise – he didn't want them on at first - and then something clicked. He immediately began exploring everything in a new way. I texted his TVI, "Not even joking it's like a different baby in the house. He even pointed to the bag that held his glasses - the first time he's pointed at something. Ever. He's smiling huge smiles and making eye contact, lots of happy eye contact. His eyes are smiling. I'm seriously going to cry. He's joyous. I never realized that he didn't smile with his eyes. He's smiling with big, happy, smiling eyes!!!!!! And he's laughing and squealing."

Over the next couple of days it was like he was born again. He explored the whole house in ways we'd never seen. He climbed up and went down the play slide all by himself. He actually stood up on it, turned in circles, and went down on his belly! He found a mirror and loved spending time looking at himself, kissing his reflection. He began clapping and doing less flapping. He actually explored, instead of running mindlessly. It was so wonderful to see him filled with wonder and exploration!

There are just so many examples of his little life being changed. Before, he wouldn't jump into the pool, and now he goes off the steps and swims back on his own. He interacts with others, and approaches and cuddles with our dog. Dan is happiest because now Josh will see him across the room and run towards him. If we make a funny face at him he laughs. Before, he never made eye contact, and didn't notice details like expressions.

We didn't know before this, that vision can affect speech. When we put his new glasses on, Josh didn't stop talking, he was just babbling and babbling with a permanent smile. Now when we say it's time to put your glasses on he waits and puts his face up with a big grin, which for me is so validating. He doesn't run away like he used to. He doesn't try to take them off. He's a whole different person. He's re-born.

Everything is improving in leaps and bounds. He's a miracle on many levels. We are a thousand times lucky to have our Early Intervention team and Perkins working with Josh. Recently, we went to the fireworks. Josh had never seen them before this year. That was pure joy.



Here he is reaching out to touch the flash on my phone right after he put his new glasses on



Then he noticed the lamp in my bedroom that's been in there for years and years. He started reaching for it. Before, the light was low contrast against the wall, so he could not see it.

Story by Josh's Mom: Michelle