

Children's Vision Massachusetts Story Bank

Samantha's Story



I asked my husband, “Do you see her squinting?” In sharing this concern with Samantha’s pediatrician, we were referred to an ophthalmologist at Boston Children’s Hospital who diagnosed her with Hyperopia (far-sightedness), and prescribed eyeglasses. We sat at the kitchen table, put a pair of pink frames on a squirming, fussing 18-month-old Sam, and instantly saw a child go quiet and become enthralled with the book in front of her. Magic.

Or, if you have normative vision - Sight.

In preschool, the questions were more complex:

“Why is she staring at light/windows?”

“Why does it seem like she’s looking right through us?”

“Why does she struggle so much in new places?”

Sam couldn’t talk about what she was seeing. She is non-verbal. So the visual behaviors we saw were the only indication that something was amiss. I did what any concerned parent of a child with a dozen specialists would do . . . I Googled. My search brought me to the American Association for Pediatric Ophthalmology and Strabismus. Sam’s visual behaviors were indicative of Cortical Visual Impairment (CVI), a brain-based visual impairment.

Sam’s ophthalmologist heard our concerns and referred us to Perkins School for the Blind. We held our breath for six months awaiting the Clinical Functional Vision Evaluation. Ultimately, at age three, we received the diagnosis: CVI.

While Sam’s ocular vision was corrected with glasses, with CVI, the visual pathways in her brain were not able to process what she was seeing. After connecting with the Perkins’ Evaluation team, Sam’s level of visual functioning, and the accommodations necessary for her to be able to visually access her world, were determined.



Children's Vision
Massachusetts

Open Eyes. Open Doors.

Our sense of urgency in supporting Sam's visual development comes from knowing that *the vision of children with Cortical Visual Impairment can be expected to improve*. Thanks to neuroplasticity, our brains, and especially young children's brains, keep forming neural connections in response to visual access and skill building. With effective interventions, accommodations, and teaching modalities, *Sam's vision will improve*.

We modify her physical environment and our interactions with her, so she can best process what she is seeing. We connect with community supports such as the Massachusetts Commission for the Blind. A prime example is using Sam's love of water to build on her strengths, motivation and interests, to teach skills. Sam has developed her visual and physical abilities while learning water safety/skills in Adaptive Swim Lessons at our local YMCA. Her new prescription goggles are perfect for this mermaid of a child. These interventions make an enormous difference to Sam's visual progress.



Cortical Visual Impairment is the most common cause of children's visual impairment in the United States. Children with visual impairments need timely assessments, diagnosis, approvals and interventions by qualified professionals, and the necessary funding to support them. While CVI cannot be cured or fully resolved, Sam and all children with CVI deserve to grow and develop their vision to their fullest potential.

Sam is now five years old. Sometimes her progress can be frustrated by wait-times of 6 months or more - from gaining school district support, identifying and accessing appropriate teachers (CVI-trained Teachers of the Visually Impaired), to health insurance approval of medically-necessary transition lenses – the latter of which literally “transitioned” Sam from months of eye-rubbing and averting her gaze, to playing outside with eyes wide open, using her vision to more fully enjoy her favorite playground activities with sunshine and smiles.



Through our experience, we realize more needs to be done to raise awareness and address system-wide barriers to vision care. For children with CVI, this includes establishing diagnostic protocols and data collection, decreasing evaluation wait times, upholding the educational rights/needs of visually impaired students in schools, addressing the shortage of TVIs thoroughly trained and experienced in brained-based visual impairment, mandating CVI coursework in TVI graduate programs, and establishing adequate health insurance coverage for TVI and Orientation and Mobility (O&M) services.

Our children's vision cannot wait. This is why we advocate daily for our child's needs at home, school, and in the community, and it is why I became connected with Children's Vision Massachusetts, a state-wide initiative to improve vision care for all children. Join us! It is our children's right to visually access and participate in their world.

Story by Samantha's Mom: Stephanie