



# WHAT TO KNOW ABOUT CVI:

THE LEADING CAUSE OF VISUAL IMPAIRMENT IN KIDS

BY VIRGINIA A. JACKO

*When Caterina's son Lorenzo was just an infant, she noticed something was off. He was slow to meet milestones. He did not recognize her when she walked into the room. He would not even look directly at her.*

Concerned, Caterina sought medical attention, and soon enough, Lorenzo received a diagnosis of Cortical Visual Impairment (CVI). At just three months old, Lorenzo faced a harrowing prognosis: He was effectively blind and, according to his doctor, there was nothing anyone could do to change that.

**L**orenzo is one of thousands of children across the US with CVI, a condition that affects approximately one-third of children with visual impairment. And it is increasing at an alarming rate.

Often, blindness is associated with ocular impairment, but CVI is caused by injury to the visual processing centers and pathways of the brain. This means that kids with the condition do not necessarily have trouble seeing with their eyes, but rather interpreting with their brain what their – *sometimes perfectly healthy* – eyes are seeing. This also means that CVI is often not picked up in a regular eye exam.

For a child with CVI, processing visual information takes effort. Some children with the condition see a swirling mass of color that doesn't have any meaning to them. Some are so inundated with excess visual stimulation that they cannot focus on objects or people's faces – even their own parents'. Other kids may be able to look directly at objects but fail to understand what they see. Often, children with CVI become anxious in new learning environments

and have meltdowns or demonstrate frustrated behaviors due to challenges with sensory integration.

While there is no one-size-fits all experience when it comes to this condition, one thing remains true: CVI is *frequently* underdiagnosed and misdiagnosed.

Despite what she was told, Caterina was determined to get her son help. She took him to our own facilities at the Miami Lighthouse for the Blind and Visually Impaired, where he joined our inclusive preschool program and began educational interventions, such as learning braille. Now, as an elementary school student, he is reading adapted text at grade level, with appropriate spacing between words and lines to reduce complexity.

Caterina's and Lorenzo's story is a testament to the power of early diagnosis and intervention, two things that are critical when it comes to CVI. Research shows that functional vision in children with CVI can improve with early diagnosis, appropriate functional vision assessment, and individualized intervention. With proper care, children with CVI can improve their ability to access their world visually. This is tremendously hopeful news for families everywhere who are affected by CVI. •

#### ABOUT THE AUTHOR:

Virginia A. Jacko is the President and CEO of the Miami Lighthouse for the Blind, where she provides equitable access to education, blindness prevention programs, and vision rehabilitation training to nearly 25,000 people annually, from blind babies to low vision seniors and their families.

### NO TIME TO WASTE : TAKING ACTION NOW CAN HELP CHILDREN REACH THEIR FULL POTENTIAL

If you think your child may have CVI or are newly coping with a diagnosis, here is guidance for taking timely action, so that your child can reach their full educational potential.



#### LOOK FOR CLUES

For so many children with CVI, the signs are there, but parents don't know to look for them. Pay attention to any developmental delays, like the inability for your child to self-feed or crawling, walking, rolling over, and other fine motor movements starting later than expected. Do you notice anything peculiar about how your infant or toddler looks at objects? Are they fixated on lights? Do they have difficulty recognizing things in cluttered spaces? All these behaviors, among others, could be indicators of CVI.



#### SEEK MULTIPLE OPINIONS TO GET THE RIGHT DIAGNOSIS

Because CVI is brain-based, it is often not picked up in regular eye exams. As a parent, you know your child best and are on the frontlines of their healthcare. Advocate for yourself. Do your own research and bring what you have learned about CVI to your child's pediatric ophthalmologist. Ask for specific assessments to diagnose CVI, or whether your child should be evaluated by a pediatric neuro-ophthalmologist.



#### ACT SWIFTLY

Because CVI involves the brain and not the eyes, we can harness the brain's ability to change, known as "neuroplasticity"—to improve a child's functional vision. Thanks to the Individuals with Disabilities Education Act (IDEA), your family has a right to early intervention, which includes developmental, occupational, physical and speech therapy. Seek out educators trained in visual impairments (TVIs), who can continually assess your child's needs and make customized learning programs.



#### FIND COMMUNITY

If your child has been diagnosed with CVI, you're probably experiencing a wide range of emotions. You are likely anxious and fearful about your child's future. Maybe you're frustrated at the obstacles you faced to receive a diagnosis. Often parents say that they are relieved to have a diagnosis at all. Whatever it is you are feeling, connecting with other families can help. Time permitting, you can get involved in advocacy groups and empower yourself as much as possible. The CVI community is here to remind you that you are not alone.