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How a Miami school helps kids with a visual impairment see better and improve skills

Miami Lighthouse has a new initiative to help kids diagnosed with CVI, the No. 1 cause of bilateral visual impairment in children in the developed world.

by Michelle Marchante

Lorenzo reads out loud from an iPad inside a classroom at Miami Lighthouse Academy. "Pete was getting more ..." He pauses, sounds out one of the large, yellow words, then starts reading again.

Francesca Crozier-Fitzgerald watches with pride. She is director of Miami Lighthouse's CVI Collaborative and one of Lorenzo's teachers at the school in Little Havana.

Lorenzo, a second-grader who has attended Miami Lighthouse Academy since pre-K, began working one-on-one with Crozier-Fitzgerald in September. The school is managed by the nonprofit Miami Lighthouse for the Blind and Visually Impaired. He was previously learning braille and print. Now he's learning exclusively with large print – and is reading at grade level.



photo credit: emichot@miamiherald.com Miami Lighthouse for the Blind and Visually Impaired secondgrade student, Lorenzo, reads a story aloud using an iPad with enlarged, bright yellow letters on a black background. Lorenzo is a student who is part of a new initiative Miami Lighthouse is using to help kids diagnosed with CVI.

For his mom, Caterina Sastri, who was told by an ophthalmologist that nothing could be done to help Lorenzo's vision, it's an emotional journey. "It's really a godsend to have the Lighthouse because they've helped so much from where he started to where he is now," Sastri said.

The 7-year-old was diagnosed with cortical visual impairment, or CVI, when he was a baby. Unlike other visual impairments, CVI isn't caused by damage to the eyes, but rather an injury to the part of the brain that processes vision. Kids with CVI can have difficulties recognizing and understanding what they're seeing.

So they are getting training in how to use their vision. Teachers work with the kids to figure out if they see some colors easier than others or if a specially lit work area helps them to see better.

CVI is the No. 1 cause of bilateral visual impairment in children in the developed world, including the United States. About 30% to 40% of children with visual impairments is a result of CVI, said Dr. Luxme Hariharan, chief of pediatric ophthalmology of Nicklaus Children's Pediatric Specialists, a physician group at Nicklaus Children's Hospital near South Miami. She's also Lorenzo's ophthalmologist.

Children with CVI are often undiagnosed, misdiagnosed or do not get the proper care or educational intervention that is needed, according to Miami Lighthouse. It hopes to change that with its new CVI Collaborative Center, which it describes as a collaboration among educators, service providers, doctors and researchers, including Nicklaus Children's and the University of Miami's Bascom Palmer Eye Institute.

"We're addressing a critical need that has been overlooked," said Miami Lighthouse CEO Virginia Jacko. "This is the first time in Florida that there is a center devoting its learning modalities, its assessment, specifically, on students with cortical visual impairment."

Miami Lighthouse says the center will help students with CVI who are enrolled in Miami Lighthouse Academy, 601 SW Eighth Avenue, build their literacy and math skills and meet their full learning potential by teaching them how to use their vision and interpret what they're seeing. Some students might see letters and numbers better, for example, if the font is yellow or if their worksheet is backlit.

In October, the nonprofit received a \$1 million challenge grant from an anonymous donor to encourage matching donor support for the nonprofit's new CVI center, which is housed inside Miami Lighthouse Academy.

WHAT IS CVI? HOW DOES IT AFFECT KIDS?

"CVI does not impact how the eyes see, but how the brain interprets what the eyes see," Crozier-Fitzgerald explains. Kids with CVI usually have some level of vision and can sometimes see improvement over time, according to the American Association for Pediatric Ophthalmology and Strabismus.

The condition is caused by a brain injury that occurs before, during or shortly after birth. The injury could be from lack of oxygen and blood flow, twin pregnancy or metabolic disorders. Babies born prematurely also have a higher risk for CVI.

Some kids with CVI may also have other disabilities or health problems, including developmental disabilities, cerebral palsy, or hearing loss, according to the National Eye Institute. And while CVI may have a "clear medical definition," every child's experience with CVI is unique, making it a "complex issue with a complex diagnosis and treatment that is not always clear-cut," Hariharan said.

"The reason we're developing this partnership with Miami Lighthouse ... is because it has to be a multidisciplinary approach," added Hariharan, who alongside a team of Nicklaus ophthalmologists and neurologists will be part of the collaborative. "It's not just an ocular problem. It's not just a brain problem. It's not just a learning problem. It's a combination."

That means every child with CVI needs a personalized approach to learning, with their own individual goals, Crozier-Fitzgerald said. "It's really my life mission, my passion ... to see these kids start to recognize in themselves that they can read or they can recognize that letter," she said.

ACCESSIBILITY IS KEY

Teaching kids with CVI to interpret what their eyes see takes time, effort and some trial and error to determine what works best for each student. Miami Lighthouse will first give the students a CVI Range Assessment, developed by Dr. Christine Roman-Lantzy, to determine what type of support they need.



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Miami Lighthouse for the Blind and Visually Impaired second-grade student, Lorenzo, works with Francesca Crozier-Fitzgerald, the director of the CVI Collaborative Center and teacher of the visually impaired at the school. Lorenzo was reading a story aloud using an iPad with enlarged, bright yellow letters on a black background.

"A lot of times, it's the complexity of accessing what you're doing visually, rather than the complexity of the concept ... and its been called a disability of access for that reason," Crozier-Fitzgerald said. "It's not what the material is, it's how this child is able to access it, and interpret it and learn."

With Lorenzo, part of making his classwork accessible requires reducing things that are "visually complex" to him, Crozier-Fitzgerald said. Lorenzo is learning keyboarding, for example, and has purple tape on all of the keys, except



the home row. While reading books on his iPad, he may have the text in large, yellow or white font with a black background on Google Slide to help him focus his vision. Like other CVI students, Lorenzo is also a "multi-sensory learner," and has audio tools, such as videos and devices that read text to him, incorporated in his curriculum to help him avoid vision fatigue, she said.

Crozier-Fitzgerald and Sastri, Lorenzo's mom, say his self-motivation to learn has played a big role in how far he's come. He also has found a new passion. "I like to read!" Lorenzo said.

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Miami Lighthouse for the Blind and Visually Impaired second-grade student, Lorenzo, sings a song in his classroom.

HOW TO GET SUPPORT

Hariharan, the Nicklaus ophthalmologist, says that the earlier a child with CVI is diagnosed, the faster they can get the support they need. CVI can cause a variety of vision problems that range from mild to severe.

Kids with CVI could have trouble recognizing faces and objects, especially in cluttered spaces. They might struggle with seeing certain things that are in front of them, like if they are in a busy place with lots of movement, according to the National Eye Institute.

Some kids may also prefer to look at things a certain way such as with their peripheral vision. Again, every child's experience with CVI is different.

"CVI can be hard to diagnose, but the right diagnosis is key to getting your child the help they need. So if your child has vision problems that can't be explained by a problem with their eyes or fixed by glasses, ask your doctor if it could be CVI – especially if your child has had a brain injury," according to the National Eye Institute.

Parents interested in learning more about the Miami Lighthouse Academy and its CVI Collaborative Center should contact Miami Lighthouse CEO Virginia Jacko at 305-856-4176 or vjacko@miamilighthouse.org. Its inclusive pre-K is for students with and without visual impairments and its K-2 classes are for students with visual impairments.

To learn about Miami Lighthouse's other services and program, visit miamilighthouse.org



photo credit: emichot@miamiherald.com Second-grade students at the Miami Lighthouse for the Blind and Visually Impaired eagerly leave their desks to visit with CEO Virginia Jacko and her dog guide, Eva.



photo credit: emichot@miamiherald.com Second-grade students take a break from classwork to dance and sing a holiday song



THE VIRGINIA A. JACKO CORTICAL VISUAL IMPAIRMENT (CVI) COLLABORATIVE CENTER