

Technology helping boy fill gap as his sight fades

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A Text Size 

Zach Thibodeaux wriggled in his seat, recalling a bittersweet summer vacation in Hawaii.

As his fingers picked at a laptop keyboard, he heard the words he typed read back to him in a stiff, computerized monotone.

We went kayaking and we went snorkeling and we saw sea turtles.

A small bell chimed. "There," said instructor Donna Miller of Dallas Lighthouse for the Blind, head down, blind eyes shut as she sat next to him. "Hear that ping? That means all your changes are saved."

The visual world is fading for Zach, who at age 8 is working with Miller to learn text-to-speech software. Such technology, along with others now only emerging, will aid in his academic success and help fulfill his parents' hopes for a college-prep high school education.

A third-grader at Mary Immaculate Catholic School in [Farmers Branch](#), Zach is facing [blindness](#) as a condition called cone-rod dystrophy gradually destroys his retinas.

Ahead is a life of unknown challenge and promise, one whose historic limitations for people like him could be wrestled aside with the help of technological advances.

"There's new stuff coming out all the time," said Lighthouse spokesman Blake Lindsay, blind since infancy. "Ten years ago, we couldn't even read our mail or a newspaper ad."

For years, many blind people had few career options, opting for assembly work or maybe a job in radio. Now, Internet-reading software, portable scanners that read documents aloud and other innovations enable students and employees to keep up with peers and consider more opportunities.

"Technology has opened a lot of doors, in the last 10 years especially," said Vicki Davidson, a tech instructor at Austin's Texas School for the Blind and Visually Impaired. "It's awesome because it [equals](#) things out a little more. [People are] able to get information and do things for themselves."

Earlier this year, Dallas Lighthouse offered Zach a training scholarship after a fundraiser organized by his mother, Johanna Uek of [Lewisville](#), raised about \$16,000 for the agency.

"This year, he'll be using more tech than ever," Uek said. "Everything is going to need to be available to him audibly."

In addition to his Braille machine and screen-reader software, Zach has a talking calculator, spelling lists converted to MP3 recordings and a Book Port, sort of an iPod for audio books.

Future challenges

Uek is seemingly tireless as she advocates and researches on Zach's behalf, buoyed by prayers and donations that have poured in as his story becomes widely known. She's determined to give him the best opportunities she can, consumed with urgency despite events that are far off in the future.

Yes, he is only in third grade, but high school is just six years away. That's how long he has to adapt to these new methods, to learn how to get around, to advocate for himself — in short, to learn to be blind.

"My goal is for him to carry the same workload [as everyone else]," Uek said. "Tech training will help him become more self-sufficient. ... I just want him to be able to go to school wherever he wants, regardless of his vision."

Rapid decline

Since Zach was diagnosed late last year, his eyesight has rapidly deteriorated. By May, he'd lost 80 percent of his sight; by July, he could barely see two feet directly in front of him.

His fading field of vision is merciless. Sometimes it is stingy, sometimes it teases, and every time he cannot do something as well as he once did is a harbinger of what's to come.

Despite such moments, he is mostly a happy and curious kid, still playing soccer — with the aid of a rattling ball that allows him to audibly track its whereabouts — and eager to learn the piano.

Last month, he checked in with optometrist Stephanie Fleming at Dallas Services' Low Vision [Clinic](#), scrambling onto the leather exam chair and immediately quizzing Uek about his surroundings. *What's this? What's that?*

Fleming appeared, a vivacious woman with a burst of blond hair. "How's things?" she asked.

"Pretty much the same," Zach said. "Except at night. Pretty much the lights, that's all I can see."

She tested his eyes, patching one and then the other as she flashed a series of cards for him to read. He blurted out numbers as soon as he could interpret them, as if he were on a game show.

"Good job," Fleming said. "Can I have a high-five?"

Zach's pupils darted around for a long moment, until he found her hand and gave it a slap.

Uek told Fleming about Zach's piano interest. With everything he has on top of a normal workload — mobility training, Braille class and so on — would it be too much?

"Let him do it," Fleming said. "The upper grades are going to be like that. Some subjects are going to be harder than others."

In other words, if Zach is going to succeed at a college-prep-type high school, versatility is crucial. "They're not going to water anything down for him." But, she added: "Technology has changed everything."

Such innovations make it easier to set up home offices for call-center work and lower the chances that academic or productive potential will go uncultivated.

Awareness of these advances could allay fears among potential employers about hiring blind employees, Fleming said, as they realize that it might just mean adding appropriate software.

Accommodations

As Zach headed into third grade, Mary Immaculate School officials outfitted his classroom with a tech-based workstation.

For now, Zach continues to excel, especially in math. "He's really sharp," said assistant principal Cheryl Eliason. "That's going to carry him far."

Nevertheless, personal and logistical challenges remain.

One day, Zach came into the office, upset because he couldn't hear his teacher from his workstation. "We had to talk to him about it," Eliason said. "We said, 'You have to tell us what you need.'" They found him a desk closer to the front.

"Sometimes he tries to go further than he can with his abilities," said Bill Newman, the school's information technology director. "He's trying to hold on, maybe."

At times like that, it becomes clear there are challenges that technology as yet can't address, such as the frustrations of a boy unable to do the things he used to do.

Uek noted that as the summer progressed, Zach began running into things a little more, and finding things on his own became harder.

At the same time, it was an eventful summer as his family, through the generosity of donations, tried to provide him with the chance to see places such as Disney World and the Redwood Forest before his sight vanished. In Maui, they explored sea caves and kayaked out to view aquatic life.

One morning, they drove to a viewpoint 10,000 feet up to see the sunrise. For Zach, however, the moment's radiance was clouded by the reality of his future.

"I don't want to see black," he said, crying and clutching his mother's arm. "I don't want to see dark."

About the series

Eight-year-old Zach Thibodeaux is going blind, the result of a condition called cone-rod dystrophy, a degenerative disease for which there is no cure. In "Zach's Journey," staff writer Marc Ramirez and staff photographers are chronicling the Lewisville boy's passage into darkness.