

Zach Thibodeaux is an enduring reminder of the gift his parents received a decade ago



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This is what life looks like on a typical morning: pulling onto the expressway with her notebook open in her lap, a pair of cellphones alternately called into duty, a half-eaten muffin at her side.

Johanna Uek was en route on this mid-December day to pick up her son, Zach Thibodeaux, a fourth-grader at Mary Immaculate Catholic School in Farmers Branch. Their goal: a 1 p.m. date at the offices of Reading and Radio Resource in downtown Dallas, where radio host Donna Miller had invited them to discuss Zach's story on her weekly show, *Infotalk*.

Two years ago, Zach found out he had cone-rod dystrophy, an incurable eye disease gradually killing his retinas. Since then, he's made great strides in his efforts to cope with imminent blindness.

In this holiday season, as much of the nation celebrates the historic birth of one child while grieving the recent loss in Connecticut of many more, Zach is an enduring reminder of the gift his own parents received a decade ago.

Earlier this month, he marked his 10th birthday at home with pals, presents and homemade pies, midway through his hardest school year yet.

He earns top grades. He stays upbeat. Though his parents are divorced, they've enabled his ongoing success, their duties magnified by the challenge of raising a special-needs child, fighting for his academic and social needs to prepare for his future in a visual world.

But as he grows up, there are emotional needs, too. They've helped him confront the tough questions he asks as his window to the world closes: *Why me? Why is this happening?*

"He just doesn't know why," Uek said. "He gets sad. He really wishes he could read and play sports with his friends."

She and Zach's father, Adam Thibodeaux, have each strived to bolster their son's esteem, even as they face their own fears and doubts, hectic schedules and the needs of their other kids.

As they help Zach through bouts of isolation or insecurity, they're readying him for the day he'll have to get by on his own.

"Even though I treat him like a little boy, I have to strengthen him up," Uek said. "Because I'm not always going to be there."

Thibodeaux, a digital strategist for J.C. Penney Co., straddles a tough-love line, aiming to get Zach to think critically, to develop street smarts and discipline. For example, he's taught his son to put his shoes in the same spot nightly so he can find them in the morning. But sometimes Zach forgets.

"He'll be, like, 'Dad, do you know where my shoes are?'" Thibodeaux said. "I say, 'No, I don't.' And I let him struggle for a bit until we have to go. Life is a strong teacher."

"I have the same goals for Zach as any of my children. I want him to be a good, contributing adult, to make others' lives better, to follow the path God sees fit. I've got to help him become a man."

First, she wants to make a stop: The chocolate bars Uek custom-ordered from a Plano chocolatier with Brailled holiday messages molded on back are ready. It's almost noon.

"I think we can still make it," she said.

It's the suburban SUV mom routine — running among her Lewisville home, Zach's school in Farmers Branch, her part-time job selling cosmetics at Neiman Marcus in Dallas with assorted errands in between.

But always, Zach, his older brother Josh and stepbrother Connor are foremost on her mind.

The other boys need attention, too. It's not easy. And one night, when Zach was eager to play a knowledge game he'd gotten, he had no one to read him the questions. His stepdad was busy, his brother was researching colleges, and Uek was cooking dinner.

"He was like, 'Hey, I need somebody!'" Uek said. "But by the time we were done, it was time to put him to bed. His time is so limited.

"I just want to be there for him more than I am."

Zach talks of pursuing a science career, and Uek's goal is to get him into Jesuit College Preparatory School. Among the concerns that flood her mind are the costs of his Braille and cane-mobility classes and translation of his textbooks and tests into Braille, which ran nearly \$5,000 this year alone.

While many services and textbooks would be given in public school for free, she and Thibodeaux opted to keep Zach at Mary Immaculate — in the building, and in the community, that he already knew.

That has created challenges, with tangles over government aid, for instance, if the Catholic school's books aren't state-adopted. Sometimes, because Uek has to order them herself, the books arrive late. Now and then she wonders why it has to be so difficult.

"If my son wasn't going blind, he'd be able to get the education he needs, and no one would be fighting about it," she said in one frustrated moment earlier this year. "If my son wants to be a chemist, I want him to be able to.

"He should have the right to decide. He's not asking to be a rapper. He's asking to be a chemist or an engineer. I need these materials so when he goes to high school he'll be able to keep up."

Back to mid-December: in the car, on her way to Plano. Uek had finished three phone calls by the time she reached The Shops at Legacy, with another coming in as she parked.

The chocolatier showed her the bars. She checked the design. All good. She paid up and hit the road to Farmers Branch.

On the phone again: "Hi, this is Johanna Uek. I'm picking up Zach Thibodeaux. I'll be there in five minutes. Can you have him wait in the office?"

She hung up. "We're going to be cutting it close," she said.

It's nearly 12:45 by the time Zach exits with his cane and backpack, the skies spilling rain. One more phone call to radio host Miller, informing her of the delay.

"I knew I should have done the candy later," she lamented. "I just wanted to bring Donna a candy bar."

Every week, Zach works on his cane skills, part of his path to independence. Crossing busy streets: that's the challenge his parents worry about most.

"It's not that I don't trust him," Uek said. "I'm worried about that driver that's not paying attention. ... The hardest thing for me to do is let go."

Earlier this month, Zach was at his dad's home in Addison, where mobility teacher Rhonda Miller prepared to direct them on a trek to the adjacent shopping plaza.

First, they would go to the pet store, where Zach wanted to buy a fish. On the way, he'd focus on his cane, aided by his limited sight but hampered by the dark. Then, blindfolded, he'd continue to the nearby market, where his mission was to buy milk.

The outing was long and laborious. Thibodeaux had to hold back.

"Rhonda says the best way for him to learn is for me to just shut up," he said. "It's tough — because you want to help."

Recently, Thibodeaux recruited Zach to be a greeter at church, welcoming congregants as they enter. It's a way of helping Zach recover the enthusiasm he's lost when meeting people because he can no longer discern their expressions.

On duty, Zach recalls his dad's advice: *Keep your shoulders straight. Keep your chin up. Interact.*

But one Sunday, an older man said to him: "Hey, you need to look a man in the eye when you shake his hand."

The man listened as Thibodeaux explained that Zach was mostly blind. Then the man told Zach, "We're glad you're out here. You're doing a really good job."

Such interactions are good for Zach, Thibodeaux said, as he learns to believe in himself.

It's hard, though, for Zach not to feel left out when other kids play video games or when former soccer teammates take the field, hard

not to pout when friends laugh at something he cannot see.

Whining, his dad warns, will only make his friends uncomfortable and less likely to come over. Instead, Zach needs to learn to ask: "Hey, what were you guys laughing at?"

It's those difficult truths Thibodeaux vows to deliver.

"That's a hard thing for a kid that age to hear," he said. "But he needs to know I have his best interests in mind."

Mom, are you going to love my brothers more than me? Do other people think they're better because they can see?

Why would you think that?

Because no one would ever want to be blind like me.

No, Zach. You are special. You will know things other people don't because you are blind.

He doesn't like it when people feel sorry for him; neither does she.

"He is more than just blind," Uek said in an email last spring. "He is going to change the way people see the visually impaired.

"Any way that God gave him to me is more than good enough. He is no less than anyone else, and I count my blessings every day that he is my son."

Back in the SUV, Uek zoomed down the Dallas North Tollway, arriving at the offices of Reading and Radio Resource at exactly one o'clock.

In the studio, Zach bubbled in his chair. Oops, gotta go to the bathroom first. Then back again, headphones on, jazz-dancing in place as the show's introductory theme played.

Before long, he was practically directing the exchange, suggesting questions, taking opportunities to reiterate points he'd wanted to make earlier.

Charming. Assured. Articulate. His own person.

On a December afternoon in 2002, a baby boy is born to a young couple. Nineteen inches long, the chart says. Six pounds, 11 ounces.

His parents embrace him. His grandmother cries.

The boy looks around, sensing, exploring, discovering the world with new eyes.

ABOUT THE SERIES: Zach's Journey

Ten-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 our photographers are chronicling the Lewisville boy's passage into darkness.

Did you see something wrong in this story, or something missing? Let us know.

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