



# Chaz

Born September 1993 | Littleton, CO

Living with CMD

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**W**earing shiny blue running pants and a black Team USA jacket, Chaz Davis walks across the parking lot, the ground covered in patches of hardened snow. Ice cracks beneath his feet as his white cane swishes softly in front of him. He arrives at the track and bends down, letting his cane drop to the ground. “Running has always been a huge part of my life.”

Chaz is a competitive runner, holding state titles, medals, and dozens of team championships. As a freshman at the University of Hartford, he ran cross country and finished the year as the team’s top freshman runner. He has run in the Paralympics and most recently the California International Marathon—all without being able to see.

Chaz was born with perfect eyesight. One morning his freshman year of college, his vision suddenly changed. “I woke up one day and my right eye couldn’t see at all,” Chaz says. “My vision was distorted. Light was coming through with some peripheral vision, but my central vision was gone.” He assumed the vision change was associated with recurrent migraines,



but within a week, the vision in his right eye had further deteriorated. The first round of medical tests revealed no answers. It wasn't until a few months later, when the vision in his left eye deteriorated, that Chaz met with experts at Tufts University.

A neuro-ophthalmologist told Chaz he had Leber hereditary optic neuropathy. LHON is a rare mitochondrial disorder that causes degeneration of retinal cells which can lead to a sudden-onset loss of central vision. It affects one out of 50,000 people. Chaz's particular mutation, 3460 (the point of mutation in his mitochondria), affects his peripheral vision as well. Additionally, he has what is known as LHON Plus, a more severe form of LHON which involves extraocular

conditions—in his case, neurological conditions like muscle twitching and fatigue. Although hereditary, no other members of Chaz's family had any LHON symptoms.

"I thought the doctor might say I'd get my sight back," says Chaz. "But he took my parents into his office. When they came out, they were very emotional. They told me that I would be legally blind for the rest of my life. That summer, I began drinking. I went into my room and turned the lights off. I didn't want to do anything."

Chaz describes what's left of his vision in two parts. First, he describes his central vision as a screen-like field of pixelated dots. Occasionally, he can detect blurry images in

front of him that are blue or brown. Second, his remaining peripheral vision consists of narrow slits in which he can make out rough images, such as three fingers he holds out an arm's length from his ear.

A few months into his self-described period of "self-pity," Chaz woke up and thought I'm not doing this anymore. "Somehow, I got my spark back," he says. Newly blind, he returned to school. "Within a week of arriving, the Massachusetts Commission for the Blind (MCB) set me up with computers and assistive devices. But the commission representative warned me that I shouldn't go back to college—that I wasn't ready—and that if I tried, I would likely fail." Chaz disagreed. "With all due respect, sir," he

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said, "I'm going back to school." He found a tutor to teach him about software that converted text to audio files and excelled, earning a GPA of 3.8 that semester, his best up to that point. Years later, when Chaz graduated, his college rehabilitation counselor photocopied his diploma and mailed it to the MCB. The message was clear: Chaz did not accept failure as an option.

Although Chaz was succeeding academically, he missed competitive running. He longed to be a part of a team again, and to feel once more the physicality that was his natural born gift. He was unsure if there was a way to run as a blind person.

The Grafton Gazebo Road Race was a local five-mile race that Chaz had won in the past. The community heard of Chaz's story and decided to donate proceeds raised by the race to fund LHON research. "If they are going to do that," Chaz thought, "I at least have to try and run the race. At that point, running five miles was way out of the question," he laughs. "Five miles! Are you kidding me?"

"My friends from school came to guide me in the race. I had gained 55 pounds; so here I was, this bloated guy trying to run five miles around town. I placed fifth, but more importantly I was able to cross the finish line with my friends. That changed my perspective on everything. I knew I had to get serious about running again, but I had no idea how."

Chaz trained on a treadmill, starting slow and then cranking it up to six-minute miles. "That fall, I tried to run the preseason trials with my team, but I fell down a bunch of

times, tripping on rocks and sticks. It was really disheartening. I felt like I was in good shape, but I had this barrier." Chaz's coach suggested he give indoor track a shot because of the smooth running surface. It was an idea that worked. "With my peripheral vision, I could discern the lines of the track. I didn't fall at all. I could innately sense other runners around me." Running track gave Chaz a boost in confidence. He increased the intensity of his training and soon became the fastest runner on the team.

The following summer, Chaz had a thought: "If I'm blind and running, there have to be other blind runners out there. I want to compete against people that are similar to me." He heard about the Paralympic games and got in touch with the coaches of the United States team. The national trials were just one month away. "I said, 'Well, I'm going!' Me and my parents hopped in our

car and drove straight to Minneapolis. I ran the 5K and won. I qualified for the team."

Back at school, a new coach was hired. Coach Roger Busch was excited to train Chaz for the Paralympics, but he also wanted Chaz to return to cross country. "I just looked at him and said 'What?' Cross country is trails and uneven terrain. How is that gonna happen?" Coach Busch insisted and a teammate guided Chaz, alerting him to obstacles along the way. For the first time since he became blind, he felt the rush of running past trees and the textures of earth beneath his feet. Chaz says, Coach Busch "was the first person to not mention my blindness as a defining characteristic of who I was."

The 2016 Paralympics in Rio de Janeiro were on the horizon. Chaz would be competing on an international stage with other visually-impaired runners from around the





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world—people who struggled like him and trained like him. But the morning of the first race, his neurological symptoms flared up. “I was extremely fatigued and I had muscle twitches. I was really worried.” When Chaz arrived at the stadium, however, he heard something that gave him new-found energy. “It was the sound of 50,000 people. There was this huge roar. You could not hear your feet on the ground. It got me going!”

Chaz speaks with pride about representing his country on the international stage. He also laughs about how unlikely it all seems: Three years after forcing himself out of the darkness of his bedroom, he set an American record, placing 10th in the 1,500m at 3:58, which is roughly a 4:15 mile. He also placed eighth in the 5,000m at 15:15.

Coming off the high of the Paralympics, Chaz says it was a challenge to adjust to everyday life. “I kind of realized then... I’m actually blind. The world around me is a sighted world. It’s not set up for blind people to succeed. I needed more [life] training.” He moved to Denver and enrolled in the Colorado Center for the Blind. There he found a community of blind friends and role models. The center taught independent life skills like Braille and cooking. With hearty laughter, Chaz recalls the day he mastered navigating public transit. “One day the instructors put us in a white van with blindfolds on. They drove all over the city and brought us to some undisclosed location and said, ‘Ok, get out!’ I had to find

my way back to the center. I stood there terrified for two minutes. I heard traffic to my left. On the sidewalk, I tapped my cane on a pole. I could feel it was a bus stop. I took several buses, listening for the stops until I recognized the downtown area. Because I could see before, I could visualize the route like an internal map. That kind of independence was new to me.”

Chaz recently enrolled in a masters in social work program at the University of Denver, where he is pursuing clinical social work within the blind community. He also recently made his marathon debut at the California International Marathon running it at 2:31:48, setting an American record in the visual impairment category. Chaz insists his accomplishments are more than just personal successes. “I want to educate the larger community. I want people to see visually impaired people as assets, not as helpless. I am a representative of the blind community whenever I’m in public.”

Asked if people call him inspirational, he laughs. “Every single day! But don’t call me inspirational if I’m walking across the street. Everybody walks across the street. If someone who is blind finds me inspirational for running, or getting a degree, that’s okay. If I can inspire someone just by being myself, then that’s good.”

