MIKE CIMBURA IN THE ELECTRIC-ASSIST CARGO BIKE CALLED THE BOOTLEGGER.

THE BEAST, THE BOOTLEGGER, AND THE DEATH RIDE

HOW MIKE CIMBURA DEFIES THE DEGENERATIVE DISEASE THAT HAS TAKEN ALMOST EVERYTHING FROM HIM—AND BECOMES A CYCLIST AGAIN

BY **CHRISTINE FENNESSY** ▪ PHOTOGRAPHY BY **BENJAMIN RASMUSSEN**

MIKE AND ZACH RIDING IN FORT COLLINS, COLORADO, WITH HORSETOOTH RESERVOIR IN THE BACKGROUND.

HE COULD HEAR THE WIND.

AND DESPITE THE FULL-FACE HELMET that he hated and the goggles that protected the last part of his body that he could still move, he could feel it. On his face like he used to. His cheeks. His mouth. It washed over him in a thunderous rush.

He could feel the tires. The one to his left wanted to rise up, catch the air, obey the physics and send them hurtling over the edge. He could sense that Zach, seated behind him, was pushing with all his strength, digging that left wheel into the ground, steering the cargo bike's 500-pound load like a snowmobile through the left hand turn of the switchback.

They swept through it at 50 miles an hour.

He could hear the smile in Zach's voice as he hollered, "Whoa!" He knew his friend was crouched low over the handlebar of the Bootlegger, trying to get as aero as possible. Trying to go even faster down Red Mountain Pass in Colorado's San Juan Mountains. The goal is for them to one day hit 60 mph. When Mike Cimbura was well, before the feeding tube, before the tracheostomy, before the total paralysis and the wheelchair, before the indignities and the frustration and the tears, before all the bills, he'd hit 62 on his road bike. They hadn't come close the previous year, in their first Death Ride Tour together. They wouldn't today, at this year's event, either. But they will keep trying.

Before ALS, Mike Cimbura was a hell of a rider. With Zach and the Bootlegger and a charity ride called the Death Ride Tour, he still is.

IF CYCLING, A SPORT SYNONYMOUS WITH *MOVEMENT,* EXERTION, AND **EXHILARATION,** HAD ITS POLAR OPPOSITE ***IN A DISEASE, IT WOULD BE ALS.***

If cycling, a sport synonymous with movement, exertion, and exhilaration, had its polar opposite in a disease, it would be amyotrophic lateral sclerosis, or ALS. The neurodegenerative disease weakens motor neurons that deliver messages between the brain, spinal cord, and muscles. As the neurons die, the muscles become paralyzed. People with ALS lose the ability to move, talk, eat, and eventually, breathe; they do not, however, lose the ability to feel. But when they are hot, they cannot sweat, when they are cold, they cannot shiver, and when their feet are placed in a tub full of Epsom salts and scalding water for 20 minutes by a caretaker who neglects to check the temperature, they can feel themselves burn but cannot escape their pain. In perhaps the cruelest twist of all, ALS mostly leaves their brains alone. They know their bodies are holding them hostage. They typically die of respiratory failure. If they choose to get a tracheostomy—a surgically created opening in the neck through which they breathe via a tube connected to a ventilator—they usually die from infection, heart failure, or blood clots. Every 90 minutes, someone is diagnosed with ALS. The average life expectancy after diagnosis is two to five years, it tends to strike those between the ages of 40 and 70, and it occurs more often in men. There is no known cause or cure. Nicole Cimbura, Mike's wife of 24 years, calls it "the Beast."

Before the Beast caught him, Mike, 52, lived a life of constant motion.

He began road racing as a freshman in college. After graduating from the University of California Santa Barbara, he moved to Lakewood, Colorado, where he and his younger brother John started their own racing team. They handpicked the guys, kept it small, found a few sponsors, and did pretty well.

As a Category 3 rider, Mike wasn't the fastest. But he was dedicated. Even while married, working full-time as an accountant, and starting a family, he still averaged 30 hours of training and two—sometimes more—races a week between March and September. Mike was just as driven in the off-season, picking John up at 5 on Saturday mornings to snowshoe up nearby Loveland Pass. They'd spend two and a half hours climbing through thigh-deep snow, then snowboard back down. Then they'd do it again. And often a third time.

"He always had a massive amount of energy," says John, 46, who raced as a Cat 2 on the team. "To sit still and not do something physically active I think just drove him nuts."

His work ethic paid off, especially on the hills. Mike's teammate and friend Leonard Callejo nicknamed him "Blade."

"Regardless of how in shape I was, I could never outclimb Mike," says Callejo, 50. "He was so narrow and thin, I couldn't draft off him and I would just see this tiny blade pedal away from me."

If he didn't drop them on the climbs, Mike would crush them in other ways. "We'd all be in pain and Mike would just not stop talking," says Duane Marlatt, 50, another former teammate. "He used to annoy us all, in a good way."

Cycling tapped Mike's essence. It channeled his drive, his energy, his analytical mind, and his ability to mentor. He taught pack etiquette, tactics, and training concepts to new racers, built up bikes for them, then taught them how to wrench on their own. He was always taking coworkers or neighbors out on the road, hoping they'd find their bliss there, too.

But he was more than a cyclist. He was the barn dad who taught his eldest daughter how to drive an F250 attached to a horse trailer. He was the science geek who helped his two girls win awards for building bridges that weighed ounces yet could hold 50 pounds. He was the breadwinner who passed up the promotion that would have meant missing his son's football games. He was the partner who always had Nicole's back. He was the friend who loved music, mosh pits, and playing drums. So when the Beast came for him on that October day in 2014, the day he did not have the strength to clip his own fingernails, there was so much for it to take.

The neurologist assured Mike and Nicole it was not ALS, and even wrote as much in a follow-up letter. Mike went on weekly business trips that November and December, and while he was gone Nicole would read the letter every night before bed to calm herself down. She prayed for cancer. Something they could beat. Until Mike called her and said he couldn't lift his carry-on, couldn't make it up the stairs, was starting to stumble.

"I feel like every day more of me is dying," he said. "My body feels like it's changing."

And she knew.

Mike and Nicole still sleep in the same bed, on two twin mattresses that fit perfectly inside their king-size frame. Her side is covered in a pink One Direction blanket not because she's a fan but because caring for Mike often requires a person working on either side of him and so it's something she lays out every morning for people to crawl all over. Mike's side is an air mattress that hums constantly as the cells within it alternately inflate and deflate to relieve pressure on his body.

On Nicole's bedside is a small table with, among other things, a Bible and two photos of her and Mike. One is his college graduation in 1992, the other from a Christmas party in 2009. In both, they are smiling broadly. On Mike's bedside, among other things, is a rectangular ventilator, a humidifier, a small oxygen canister, and a tall IV pole holding a plastic bag filled with mustard yellow liquid. The liquid is his breakfast and the monitor on the pole says it's feeding him at a rate of 200 milliliters an hour through a tube that snakes across his purple comforter and into his gut. Behind him, a gray, padded sling with adjustable yellow straps hangs flat against the wall. The straps connect to a plastic hanger that hooks to a mechanical track in the ceiling that travels across the room and into the shower.

Mike is propped up in bed. He has brown hair, a brown beard, and he's wearing a blue vest over a Denver Broncos shirt. The vest is inflated with air and vibrating with a loud *chug-chug-chug*, shaking loose mucus he can't cough up on his own. He's staring up at Nicole, who is standing by his side. He's trying to say something.

Nicole, 48, is tall and blond and almost always moving. She gets up every two hours during the night to care for her husband and works full time as a teacher during the day. She rarely yawns. She calls Mike "babe" and the people around her "hon." She says "blessed" often.

Now she is still, her arms crossed, her blue eyes locked onto his blue eyes. She slowly begins to recite a series of numbers that each represent a series of letters, pausing whenever he responds with a single, slight blink.

"1, 2, 3, 4, P, Q, R, S...S?" she asks. "5, U...U? 1, A, B, C...C?" She stops the vest. She knows what he needs. She almost always knows. Sometimes when she's really tired she can't store the letters in her head and she writes them on a small whiteboard on his side of the bed. S-U-C. He needs suction.

She flips on a suction machine and it drones like an air compressor. Then she runs a narrow catheter into his tracheostomy. She feeds it into his lungs, gently suctioning up the mucus shaken loose by the vest.

Mike normally communicates using the tablet set up above his bed. It uses infrared technology to track his eye movements so he can do stuff like surf the web, watch Netflix, email, and speak. To talk, he locates the appropriate letter on the keyboard with his eyes then blinks to select it. After he composes a word, a male Siri-like voice speaks it for him. It's slow and imperfect and usually it works. But not lately. Not since one of his caregivers (Mike has several) accidentally scratched his left cornea while dressing him. Because of the disease, his blinks are no longer rapid and reflexive but perilously slow, leaving his eyes vulnerable, and when the caretaker pulled his shirt over his head, the collar got him. Now the machine isn't calibrating right and they must rely on their number and letter system of communication, their "paper" system as they call it, because it's written on laminated pieces of paper that hang everywhere—in the shower, in the kitchen, on the window of their wheelchair-accessible van. When technology fails or is unavailable—or a cornea gets scratched—it is their only means of communication beyond one blink for "yes" or two blinks for "no."

NICOLE AND MIKE, IN ZACH'S GARAGE, GETTING READY TO RIDE.

ZACH YENDRA, WITH HIS 1968 FORD COUNTRY SEDAN WAGON, IN LAPORTE, COLORADO.

But Mike can still trigger certain areas on the tablet's keyboard, like the box that initiates the harsh, pulsing alarm he's now using to get Nicole's attention.

"What do you need, babe?" Again, she patiently recites the numbers and the letters. When he blinks once for 'm' and once for 'o,' she stops.

"Mouth?"

One blink.

"Okay." She inserts a Yankauer—a long, thin suction instrument similar to what the dentist uses—in his mouth and each nostril and suctions them out.

It's 7:50 on a Saturday morning in mid-January and today is a big day. Zach is driving down from Fort Collins with the Bootlegger. Barry is coming over. So are the neighborhood guys. They're going for a ride.

But first Mike must spend these 30 minutes having the mucus shaken and sucked from his lungs. Then his caretaker will fit him in the sling that will lift him by his armpits and knees and take him into the shower. He'll hang like that, quads to stomach, uncomfortable as hell, as the caretaker pulls packing material from inside the pressure ulcers on his backside and rinses the wounds. Next, she'll lower him onto his shower chair and wash him. Then Nicole will be home from the chiropractor, and will treat the hole in the arch on his left foot where the skin graft didn't take. The skin graft that was the result of the caretaker who put his foot in a tub of Epsom salts and scalding water and missed Mike blinking as hard as he could as he sat through third- and fourth-degree burns.

After that, he'll go back up in the sling so his wounds can be washed again, repacked and re-bandaged. The trash can in the bathroom will slowly fill up with gauze, wipes, plastic, and adhesive backings. Then they'll dress the guy who used to nail the rockabilly look—slicked back hair, long sideburns, English Laundry and Ike Behar dress shirts—in sweatpants, a long-sleeve T-shirt, and untied silver Nikes. Nicole will give him stomach meds, a probiotic, and a blood thinner through his feeding tube.

Four hours and 21 minutes later, Mike will be ready to ride.

Zach Yendra was used to fielding crazy requests, but nothing like the email he got on April 17, 2016. He read through it again. *I'm the president of the Death Ride Tour, a charity cycling event to support the fight against ALS. I have a friend with ALS who would like to join our tour this year and we need to build him a custom bike similar to the Bootlegger.*

The email was from a guy named Barry and he'd sent it at 5 a.m., just hours after leaving a voicemail the night before. Zach