

Johnny Five fights back

Trucker refuses to be parked by Lou Gehrig Disease

By Harry Rudolfs

ORANGEVILLE, Ont. – John Van Lubeek is fighting a monster of a disease – and he’s winning. Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig Disease, is a progressively degenerative disorder that affects control of voluntary movements. It disables the neurons relaying signals from the brain to the muscles, and strikes six out of 100,000 people. “How come my luck doesn’t work like that in a lottery?” quips the 51-year-old driver on the phone from his home in Orangeville, Ont.

The condition is often difficult to diagnose. Van Lubeek was undergoing therapy for a back ailment when his physiotherapist alerted his doctor to the fact that something was wrong.

“They figure I’ve had it for about two years,” he says. “I, myself, noticed the speech problem first – slurring my words although no-one else noticed it. I also found it difficult to separate sheets of paper, and a little thing like threading a nut onto a bolt became a hard thing to do.”

Known around the yard as ‘Johnny Five’ (his shunt call number for over a decade), Van Lubeek has been driving for Purolator Courier for over 20 years, beginning his career as a step-van driver at the Morse Street terminal in downtown Toronto.

He then drove five-tonnes for a couple of years and switched tractor-trailers soon after, specializing in yard shunting as the courier giant was growing its operations and opening new facilities in the west end of the city.

Despite the diagnosis, Van Lubeek is still doing the job he loves. These days he’s working the midnight shift out of the company’s Metro West hub on Kipling Ave., shuttling trailers between depots around the GTA. Management has been compassionate and understanding, supplying him with a dedicated International ProStar with an au-



SURVIVOR: John Van Lubeek has managed to keep trucking, despite being afflicted with ALS, a degenerative muscular disorder. *Photo by Harry Rudolfs*

tomated 10-speed Eaton Fuller that he praises highly.

“I’m fine to drive and all my senses are there,” says Van Lubeek. “The only thing I have wrong is my one arm is weaker than the other and I’m left-handed anyway. So driving the automatic makes it no problem to shift gears.”

To be absolutely clear, Johnny Five has the green light to drive commercially as certified by his doctor and specialists. I got behind him in the line-up leaving the Ontario hub the other night, and he steered straight as an arrow down Hwy. 427. Van Lubeek has excellent driving skills, as anyone in the yard will attest.

“I’m in the top 10% that seems to take longer to be totally disabled.” He’s also taking Riluzole, a drug that seems to

effectively slow the progression of the disease.

Those affected usually remain clear and cognizant, often with no loss of sensory ability, while the voluntary muscles get less and less work and eventually atrophy. But regular exercise can strengthen those muscles not affected and reduce spasticity.

The best therapy might be to keep moving, using low impact workouts like stationary cycling – or shuttling trailers.

The disease is completely non-contagious. To date there is no cure available, nor is there any way to prevent getting ALS.

For the most part, science is in the dark about the cause, and only 10% of the cases seem to have some hereditary component.

Well-known sufferers of ALS, besides baseball great Lou Gehrig, include the late Charlie

Mingus, virtuoso bass jazz artist, and scientist Stephen Hawking, arguably the smartest man in the world.

Van Lubeek attends Canada’s top ALS clinic at Sunnybrook Hospital in Toronto every three months. “They’re amazing people,” he says. “They make you feel like there’s hope.”

He lives with his wife and three daughters, aged 14, 16, and 20 in an Orangeville townhouse.

“Have you ever tried to stay home with four women in the house?” he jokes. “Seriously, I love driving. And the truth is that disability doesn’t pay all that much.”

In fact, he hasn’t missed one day of duty since his diagnosis.

He even works some overtime when Purolator is stuck for drivers. “Let me tell you something, when I work overtime the company is getting its money’s worth,” he says.

Johnny Five admits to getting depressed on occasion. “Everybody gets depressed at times,” he says.

“I can’t say I don’t get depressed, but apparently many people who get this thing just crawl in their house and think it’s over. In this world there are too many people who just give up. I’d like to be an example to give people some incentive to go on.”

No one knows what our purpose is on this planet, but I caught a glimmer of it talking to Van Lubeek.

Simply put, our function is to be the best people we can possibly be, living up to our potential. And there is some measure of redemption available to us truckers, especially if we can bring a fraction of the character and dedication to the trade as does Johnny Five. In an interesting footnote, he was cited for bravery in 1994 when he rescued an elderly man from a burning car in a Scarborough parking lot, just seconds before it exploded.

Johnny Five, himself, supplies the best reason for keeping on trucking. Although he insists his daughters are too young to be partnered, and he wants them to see the world before settling down, “I really want to be around to see my grandkids,” he says. □

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