Sweet Chariot

Nelson Figueroa is a fighter: No crippling myelopathy is going to cramp his style.

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When Nelson X. Figueroa first arrived three years ago at Rivington House, a former New York City high school refurbished as a full-care PWA residence, he had been diagnosed with several “untreatable” neurological problems. “They said I had two months to live,” he says. “But I wasn’t ready to die. It wasn’t in my vocabulary.”

Recounting this painful history, Figueroa steers his electric wheelchair expertly around the precarious stacks of magazines, AIDS newsletters and pages of poetry that crowd his dorm-style room. “I fought the residence and Medicare to get this power chair,” he says. “If I’m going to be in one for the rest of my life, I want to be comfortable.”

This tenacity has served him well in his long struggle with myelopathy, a common but little-known HIV-related neurological condition (see “Hitting Below the Belt”). He has fought to see some of the best neurologists in the city. “I like to fight,” he says. “And I like to win.”

Figueroa’s medical history is a textbook case of the progressive symptoms of myelopathy. The born-and-raised East Harlem resident, who says he “used to shoot up in galleries,” began having urinary incontinence in 1992. “It was uncontrollable,” Figueroa says. “I was urinating all over the place—on the subway, in the tunnels, in the streets. It was so embarrassing. I had to start wearing diapers.” A heavy drinker at the time, he attributed his problem to the alcohol.

Within a year, his legs began to give out. “They felt rubbery, like my knees were bending backward. And my feet bloated badly.” Figueroa went from walking with a limp to needing a cane, and then a walker. By 1995, he was in a wheelchair. “I figured I was just going to die,” he recalls. “I felt hopeless.” He had become impotent as well. “I never thought that I’d have another woman,” he says. Later that year, he spent four months in and out of a coma. That’s when he first tested HIV positive and was diagnosed with myelopathy, as well as dementia and peripheral neuropathy.

Yet his Rivington House docs told him only about the latter two conditions. Months later, once his dementia-induced confusion had subsided somewhat, Figueroa discovered his myelopathy diagnosis while studying his medical records. He pored over treatment newsletters and learned everything he could about the condition. “I figured it meant permanent paralysis, but the doctors weren’t taking it seriously,” he says. “So I made a big to-do.”

Finally, he obtained a referral to a neurologist, who in turn referred him to David Simpson, MD, a myelopathy expert at Mount Sinai Hospital. “Dr. Simpson made me feel at ease by just acting human,” Figueroa says. “He gave me hope.” Simpson also linked Figueroa to the Manhattan HIV Brain Bank, a research project that now regularly gives him neurologic tests, and enrolled him in a dementia trial.

But that very enrollment blocked his efforts to join a trial for a possible myelopathy treatment—the amino acid methionine, sold in health food stores. (For fear of generating confusing data, researchers often exclude those already enrolled in other trials.) And with the product not covered by Medicaid, Figueroa couldn’t afford the $25 monthly expense. Finally, last summer, he managed to obtain a supply of methionine after a friend died. Results came quickly. “It was fantastic,” he says. “The bloating in my feet went down, and I could wear shoes again. I was wheeling around without my urine bag or my catheter. It was freedom.”

After six weeks, though, his supply ran out. Now his feet are swollen again, and his visions of freedom remain just that—at least until he can get his hands on more methionine.

The seven years since Figueroa’s first myelopathy symptoms have been a constant roller coaster. He’s been through 14 antiretrovirals in various combinations since 1995 and had to stop his last six-drug combo three months ago because of liver damage. But with a viral load of 5,000 and a CD4 count above 600, he is doing well by anyone’s standards. “My body has been good to me,” he says. And with the advent of Viagra, his impotence is a thing of the past. He delights in introducing visitors to his new girlfriend.

Figueroa, 42, is busy planning a move to a new apartment—and more. “I’m going to get married when I’m 50 and die when I’m 80,” he declares, zigzagging his wheelchair through the corridors like a bumper-car champ. “I want to be independent again. I want to live my life. I’m going to see my poetry published.” He smiles broadly. “There’s no stopping me now.”
