It’s His Party

Rob Phelps flacks for the drug that saved his life—and cries ’cause he wants to.

July 1, 2003 By Rob Phelps

The limo’s windows, dark as Jackie O’s sunglasses, shaded me from the 88-degree Fort Lauderdale afternoon—a far cry from the Cape Cod winter I’d just escaped. As the chauffeur pulled up to the seaside hotel, a liveried doorman helped me get out. The star treatment put me on edge—especially when I considered who was footing the bill.

You see, Fuzeon (T-20) had finally been approved, and I was one of five clinical-trial successes its makers, Roche and Trimeris, had flown in. We were to educate—and motivate—their sales force about the drug that’s many HIVers’ last hope. I couldn’t help thinking of PWAs who don’t have access to lifesaving meds, let alone get put up in fancy hotels to rave about them. And here were Roche and Trimeris hosting this gig—even as they priced Fuzeon higher than any AIDS drug ever, claiming it was so hard to make that there would be a limited supply. Were they behaving responsibly? Was I?

I know this much, even if I sound like Big Pharma’s ideal Stepford Patient: I’m grateful to the makers of Fuzeon. Four years ago, my meds were failing—badly. CMV had blinded my right eye and MAC had wasted me to 113 pounds. Eight weeks after adding Fuzeon, my viral load plunged from one million to undetectable. My T cells, once in the teens, climbed slowly into the 500s. Today I feel my best in years. Right or wrong, this trip felt like a party to me—a celebration of life regained.

In the elevator en route to the opening dinner, a man with a Roche badge like mine asked what I did. I told him I was a study participant. He nodded politely, wished me well and headed off.

Moments later I sat at one of countless tables in an enormous function room. The scene was surreal. Indoor kliegs threw colored light beams. Over fancy meals and live music, a sea of sales reps lived it up, oblivious to me and my four fellow Fuzeon miracles: a self-proclaimed ex-hippie from upstate New York; a handsome Baltimore hairdresser with a German accent; a Mexican-American grandma from Fresno; and a 6-year-old girl and her adoptive parents from the South. We five regarded one another respectfully, not saying much. If we were all at this table, I figured, we must have had similar struggles.

Dessert plates were cleared. The lights dimmed; the audience hushed. New Age-y music swelled

from a violin, guitar, drum, bass and a huge thing called an Earth Harp. My face reddened. Would they turn us into a sideshow?

Over the music, one of three actors stepped forward onstage and recounted how Fuzeon had brought me back from near death. On a giant screen behind him, images of hospital beds gave way to that of a sloop, to show how Fuzeon had returned me to my great love, sailing. The boat was bigger than what I usually sailed—otherwise my story wasn't exaggerated. I stared into my plate to conceal tears. I hadn't known how much my own story would move me. In fact, everyone's did. We'd all joined the trial hardly daring to believe it could help us.

The lights came up. Awed sales reps crowded our table. One stood before me, eyes welling. "I didn't realize," was all he said. It was the man from the elevator.

The next morning found four of us onstage (the little girl played with her mother just outside the hall), perched on tall director's chairs beneath giant onscreen images of ourselves. For an hour, we told the reps of the pain, drudgery and miracle of injecting Fuzeon twice a day.

Questions followed. "There's such a limited amount of this med," one rep began. "How do we decide who gets it? People with poor adherence—should they?"

Awkward silence. Then the ex-hippie blurted out, "Everyone gets it. It's your job, man. To teach everyone who needs it how to use it. If there's a limited supply, let the doctors decide who needs it most—but please, not because someone doesn't know how to use it properly."

Silence. Then the room burst into applause. Someone even hooted.

The four of us spent the rest of the day poolside, drinking virgin coladas. (Word was that the little girl went to visit an alligator farm.) "It's not fair, man," the ex-hippie joked. "They hold this meeting in paradise and those reps have to sit up there in windowless rooms." "Yes," the hairdresser replied, waving at the luxe hotel, "but everyone knows how stingy the drug companies can be." His irony was as thick as his accent.

The surf was coming in. The ex-hippie and I dove into bathwater-warm waves. "This is the life, man," she exclaimed, bobbing out into deeper water. Then she turned back to me. "This," she amended, "is life."

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