Martin Delaney: An AIDS Warrior Passes the Torch

One of the nation's brightest and most accomplished AIDS activists, Martin Delaney has passed away from liver cancer. His influence on AIDS research and the patient empowerment movement will be lauded for years to come. David Evans, a fellow activist and editor with AIDSmeds and POZ, explains Delaney's legacy and the challenges he left to a new generation of activists.

January 27, 2009 By David Evans

When Martin Delaney, a longtime AIDS activist, died of liver cancer on January 23 at the age of 63, people with HIV lost one of their greatest champions. From the early 1980s—when he became a one-man information clearing house about experimental treatments and started smuggling promising drugs from Mexico to the United States for desperate men and women—until the day he died, Marty never gave up on the hope and possibility of a cure for HIV disease. Though not HIV-positive himself, he kept up the pressure on scientists, politicians and other activists to continue talking about the possibility of a cure, even when such talk became unpopular. The passing of his vision, passion and hope will be impossible to replace.

I had the honor to call Marty my friend. Though he'd be uncomfortable with some of the praise that has been printed since his passing, it is important that people with HIV know what Marty accomplished and what we've lost due to his death. He was a brilliant thinker, educator and, above all, a negotiator; for 27 years, he shared those gifts selflessly and unceasingly on behalf of people with HIV. He was also a complex and imperfect man—just like the rest of us—and like any good activist, he managed to ruffle some feathers along the way.

In the late 1980s and early 1990s, Marty was sometimes at odds with activists on the East Coast about the proper course of AIDS research, how that research should be governed and the most appropriate people to lead the charge. Though they didn't always agree, Marty, along with ACT UP chapters around the country and the Treatment Action Group from New York, played a prominent role in helping speed up access to experimental medications and approval of those drugs for people with HIV.

Over nearly three decades, Marty was a guiding force in research on the immune system, therapeutic vaccines and HIV drug development. He played a key role in the development of protease inhibitors and a number of other HIV drugs. While publicly advocating that pharmaceutical companies continue to invest in HIV research, he led a group, called the Fair

Pricing Coalition, to lower or freeze the prices of existing HIV drugs. His skill and experience as a negotiator to big business allowed him to effectively advocate on behalf of people with HIV with the heads of industry and government.

Marty also worked tirelessly to give people with HIV the information and resources they needed to be proactive about their health care. He founded Project Inform, one of the country's first nonprofits devoted to HIV treatment advocacy and information. At the height of the epidemic in the early 1990s, Project Inform's treatment hotline received up to 100,000 calls a year from people with HIV and their friends and family members. I had the privilege of working with Marty to bring informational town meetings to cities big and small all across the United States. Over and above such formal activities, Marty also helped hundreds of people individually who called at all hours of the day and night seeking his help and advice. He used his knowledge and influence to help people access experimental drugs and advocate for better treatment from their health care providers, who were often inexperienced in treating HIV. I couldn't begin to count the number of people who came up to Marty after a town meeting to talk with him in person for the first time and to tell him that he'd literally saved their lives.

Not long after meeting Marty in 1991, he and I took an impromptu road trip in the desert. We were in Las Vegas for some reason, and Marty, being a huge sci-fi and UFO buff, wanted to drive out to a spot that some people claimed was the site of an alien landing in the 1950s, kept top secret, of course, by the federal government. I loved the desert, and adventure, so I was game.

We left the glaring neon monotony of the casinos around noon. About 25 miles north of Las Vegas, Marty pulled off on a two-lane road and started heading into a wilderness of sand and scrub. I happened to glance at the dashboard as we curved around the highway off ramp and noticed that we had less than a quarter tank of gas. I suggested that we drive to a gas station first before embarking on our trip into the desert, but Marty said not to worry. I was skeptical, because he wasn't totally sure where we were going and we hadn't consulted a map, but I decided to let it go.

We stopped now and then to take photos of jackrabbits and mesas and the massive sky filled with winter cloud formations. After a while, we found the mile marker and the dirt road that led to the alleged UFO landing site, but it was gated shut about 100 yards in. We stopped for a minute, and Marty actually contemplated trying to break through the gate, but eventually we decided to get back in the car. It was at this point that I noticed the light on the gas gauge was blinking. We were down to empty. We hadn't seen another vehicle on the road for over half an hour. The only sign of human habitation had been dirt side roads leading off into the desert. I was ready to pull over and wait to be rescued. I didn't say the words, "I told you so," but I came pretty close.

Marty said, "Don't worry," then pulled out onto the road and started heading deeper into the desert. I told him that he was insane and that we should go back to the highway, but he said to trust him. I spent the next 20 minutes fuming, as we slowly climbed up a stretch of low foothills. I was certain that we were going to be stranded, perhaps for hours. Eventually the car coughed and shuddered a bit, and then Marty shifted the car into neutral and turned off the ignition, letting gravity pull us along. The road began to decline, and we coasted quietly, barely making it over the

top of the slight rises, as we rounded the curves of the hills. Then, as we floated around another turn, a gas station sign appeared over top of the next hill in the distance. As Marty gently eased up to the pump at the old station, he pulled the emergency brake, turned to me and cracked a huge smile. I just rolled my eyes, and told him he'd gotten very lucky. But that's how Marty approached everything, including AIDS activism: with a quiet certainty that he was headed in the right direction, even when others raucously criticized him for being on a fool's errand. He also didn't hesitate to break the rules when he felt he was right. The most frustrating and wonderful thing about Marty is that he almost always turned out to be right in the end.

A couple of days before Marty died, when he was still a little bit responsive to our voice and touch, a top AIDS researcher with whom Marty had become friends over the years came to say goodbye. He thanked Marty for all he'd done and promised to keep science moving forward, but Marty protested, "I haven't done enough."

What Marty meant is that we still haven't found a cure for HIV and that millions of people worldwide still don't have access to the treatments we do have. As hard as it will be to move forward without Marty's confidence, energy and insight, those are two battles that we must continue to fight.

With the world economy in shambles, it's going to be tough to keep up the pressure to roll out expanded HIV treatment in the developing world. The pharmaceutical industry is complaining that there's little incentive for them to stay in AIDS research. Scientists have largely given up on a cure, and confidence in finding an effective vaccine has sunk to an all-time low. It is when things seemed darkest, however, that Marty always fought the hardest and stubbornly headed off into the unknown desert instead of toward the safe highway. I hope that Marty's spirit and example will give those of us he's left behind the courage to go in unexpected directions and fight the difficult battles ahead. It's the least we can do.

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