The First AIDS Treatment Activist

June 26, 2008 By Peter Staley

Last night, Martin Delaney was honored at an event in Washington, DC. Marty is one of my heroes. He was the founder of Project Inform, and has been an AIDS treatment activist longer than anyone I know.

Back in the late 80's, when ACT UPers like myself starting pushing the government and big pharma to move faster in finding treatments for people living with HIV/AIDS, we quickly discovered that a great deal of groundwork had already been laid by Marty and one or two other gay men (notably Jay Lipner, a Manhattan-based lawyer -- see his NY Times obit). They had the smarts and patience to teach themselves about the scientific process and the inner workings of the bureaucracies involved in AIDS research.

They created AIDS treatment activism. I'm alive today because of gay men like Marty.

In addition to AIDS bigwigs like Robert Gallo, AIDSmeds.com's very own David Evans paid tribute to Marty last night, with these wonderful remarks:

> They say if you want to get to know someone well, you should spend several hours in a car with them. Since 1993 I've taken hundreds of car trips, dozens of plane rides and even spent a few hours in an indigenous canoe in the Caribbean just off the coast of Panama with Marty. I've come to know him well. It would take 100 hours to go into even half of it, but I've only got a few minutes and I want to take this time to tell you a few things about him that others may not know or mention.
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> There is a political Marty. He's definitely left leaning, but he's rarely partisan -- particularly when it comes to HIV. He's equally generous with his criticism and praise of both Republicans and Democrats. This isn't Machiavellian political gamesmanship. Speaking the truth is very important to him, and damn the politics, and damn what's expedient or polite. This hasn't always made him popular with politicians, government officials, or pharmaceutical executives—or even other AIDS activists. In fact I've watched him get beat up over his work

many times, both publicly and privately.

Marty is not a typical activist. He's unlikely to get arrested in front of the New York stock exchange or the Capitol building. Yet he repeatedly risked arrest and prison in the late 1980s, smuggling in drugs from Mexico that we once hoped would effectively treat HIV. He helped with the founding of the first buyers clubs that worked on quasi-illegal generic formulations of AIDS drugs in development. Marty will gladly buck authority and break the rules when he believes that there's no other rational way to accomplish his goals.

Marty isn't much of a yeller and screamer. When he sees a problem his first instinct is usually to figure out who is the person with the most power to effect the change he wants and then to pick up the phone and call that person, and to keep calling until he gets what he wants. This means that his advocacy work is often private, rather than public, and that much of his work has gone unnoticed and unacknowledged.

When I first met Marty in 1991 I had no idea who he was. I was a Project Inform volunteer and he was a guy with a briefcase who swooped in and out of the office once or twice a week. I didn't get to know him well until we went on a road tour together of town-hall style meetings in 1993. We hit about fifty cities a year over the next three or four years. I'd do the legwork - fly in, rent a car, find a map – this was way before online driving directions or GPS – and get things set up. I'd pick Marty up at the airport the next day and we'd spend the next two to five days together, sometimes doing meetings in three or four towns in a row.

All of this began soon after the depressing results of the Concord study, which found that AZT all by itself didn't increase survival. They were lean years, with far too many funerals. But Marty, privy to the earliest exciting data on the protease inhibitors in development saw it as his personal mission to keep people hopeful and healthy long enough for the drugs to become available. From 1993, until protease inhibitors became available at the end of 1995, Marty spoke in front of thousands of people, some of them terribly ill, and urged them to hang on just a little longer. Though he's not a religious man, and thinks with the intellectual discipline of a scientist, he's often said that when hope is lost, the body usually follows. When all we had to

offer was hope, that’s what he strived to give people.

But his roadshow was just the warm up to some of the most intense, private work that took much of his personal time. At the end of each town meeting people lined up to talk to Marty. Most just wanted to thank him, or follow up on something he’d said in his talk. But there were always a few who faced profound problems -- sometimes life threatening problems "everything from doctors who kept them on a failing and toxic regimen for too long, or who failed to catch an opportunistic infection early enough, or problems accessing a needed treatment. It was then, with each one of these people, when Marty went into action, usually giving people his private home number so that in the coming days, and nights and weekends, they could together navigate those problems and find solutions. I imagine there are a few of you in this room tonight who are alive because of the direct help Marty gave you.

Marty’s a complicated person, and like any human being he’s not always right, or even in the best mood. But he’s always, always tried to live by a set of principles that include compassion, honesty, responsibility, fairness and what’s right and true.

For each of one of us who’s born witness to the horror and tragedy of this microscopic virus, it’s hard to imagine what it would have been like without Marty’s guiding hand. He’s indirectly helped tens of thousands of people by shaping clinical trials, the development of HIV drugs, and policies affecting treatment access and the price of drugs. And much more personally he’s helped thousands of people one-on-one. He prophesized hope when there seemed none. And more important still he stood with one person after another, taking it on himself to solve problems, overcome obstacles and ensure care in such a way that many came to see him as a kind of healthcare guardian angel. It’s important to honor his achievements, but it’s also important to honor his humanity, and that’s what I hope you will do.

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