Recognizing a Founder

May 7, 2008 By Paul Dalton

Last week I wrote in praise of the early AIDS activists. At the risk of organizational immodesty, I would like to praise one in particular?Project Inform?s Martin Delaney.

Marty is one of the founders of the AIDS activist movement. As chronicled in Jonathan Kwitney?s book, Acceptable Risks, responding to the failing health of his partner and many friends, Marty took action. This model of direct action in the face of despair became the driving principle of the budding AIDS activist movement in the mid-1980s.

He began as a drug smuggler, carting experimental HIV treatments in from Mexico at a time when the FDA dragged its heels as the scope of the epidemic started to become apparent. Marty was not living with HIV himself, but nonetheless had firsthand experience with the very real and personal cost of bureaucratic indifference.

As a participant in a clinical trial for an experimental hepatitis B treatment, he saw a promising treatment denied to folks who needed it. He also suffered the day-to-day consequences of trying to treat a chronic and often debilitating disease?particularly one that was disproportionately affecting gay men.

Marty started Project Inform as a six-month project in 1985. Obviously, it has gone on a bit longer than originally imagined. Quite unintentionally (like many (most?) others in the field) he became an expert in the nascent area of treating HIV. In 1985, HIV was discovered and no approved treatments were available, or even on the horizon. The FDA, under the negligent watch of the Reagan administration, was no friend to people with AIDS. It was up to these burgeoning activists to make change happen. And they did.

As word spread that Marty and others were amassing what little was known about possible treatments for HIV, calls for this information overwhelmed his home phone. Project Inform?s hotline grew out of this need, beginning in his own garage. Today our toll-free National HIV/AIDS Treatment Hotline provides much needed information and support to people infected and affected by HIV throughout the US.

From those humble and quite accidental early days, Marty helped build Project Inform into a leading national HIV treatment and public policy information and advocacy organization. I have been fortunate to work alongside him for the past 6.5 years?first as a trainer, then as a rookie treatment writer, and now advocate.

Marty is now semi-retired ? with an emphasis on the semi. There?s little chance you will find him on the golf course or playing shuffle board in Miami. He is still working as hard as ever to end this epidemic, dedicating this phase of his life to promoting cure-based research. His day-to-day programmatic role at Project Inform is less now. Our new Executive Director, Dana Van Gorder, started in November 2007, and I have assumed leadership of our treatment focused activities.

It is truly humbling (and, I confess a bit anxiety provoking) to follow in Marty?s footsteps?along with Brenda Lein, Ben Cheng and the many other brilliant activists who have worked here at PI. Without Marty?s leadership and mentoring, I wouldn?t be half the advocate I am today. Without Marty?s leadership in the fight against AIDS, I don?t know if I would be here today.

As much as he might want us to, Project Inform cannot let Marty go too quietly. We are hosting two events to honor his vital contributions to the fight against AIDS?one here in San Francisco and one in Washington, D.C. For information about these events, please see our website: https://www.poz.com/article/project-inform-leader-hiv-hepatitis-c-advocacy-likely-close

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