Dubin’s List

The president of the Committe of Ten Thousand reports from the holocaust

January 1, 1997 By Corey S. Dubin

As we enter the 15th year of our holocaust, HIV positive people with hemophilia are a community both devastated by AIDS and on the path to empowerment. We have come a long way from the late ’80s, when the community was mired in hopelessness, despair and an all-encompassing sense that we had been abandoned by society. The Committee of Ten Thousand (COTT)-named for the estimated 10,000 people with hemophilia who were infected with HIV by the blood industry-was formed in 1989 in response to this hopelessness. Through grassroots organizing for economic and social justice, our small community has begun the process of fundamentally altering the blood-products business while working with other communities to demand dignity and human rights for all people with HIV.

At the center of these changes is the question of our identity. For decades, people with hemophilia were defined by the medical establishment; the standard was based on our capacity to be dependent and ultimately, disempowered. We were the “perfect” patients who did what our doctors told us to do, the “happy” wards of the hemophilia treatment centers. And we were ultimately the perfect research cohorts for studying the progression of diseases such as hepatitis C. Our consent in these studies was never sought. It was simply decided for us that the benefits of blood-clotting substances like factor concentrate far outweighed the risks of active hepatitis, even though by 1975 hepatitis C had become the leading killer of people with hemophilia. And by 19878, there existed viral-inactivation technologies such as heat treatment that would have prevented the transmission of hepatitis (and, we now know, HIV), but the blood industry did not implement them. Why? Because it did not want to incur the expense of altering production operations. Company profits took precedence over health and safety.

So it was with HIV. By 1985, when the Food and Drug Administration (FDA) finally ordered testing of the blood supply, some 10,000 people with hemophila had been infected with HIV. Since then, more than 3,000 have died, and the rest of us (as well as hundreds of our partners and children) are at varying stages of HIV disease progression. For years, the manufacturers of blood products and the regulators at the FDA persuaded the hemophilia community as well as the general public that these infections were a “tragic yet unavoidable mistake.” We now know that this is absolutely not the case and that doing business as usual from 1982 to 1985 consigned thousands of people with hemophilia to the ravages of AIDS. By December 1982, there were 12 reported cases of AIDS in the hemophilia community, and the Centers for Disease Control (CDC) was warning that the

disease was probably the result of a blood-borne pathogen present in the blood supply. Internal drug-company memos demonstrate that officials understood the impact that blood tainted by this pathogen could have on people with hemophilia as early as mid-1982, but they failed to warn either our doctors or us.

The industry was also targeting for plasma collection groups with a high incidence of hepatitis B-gay men and prisoners-that the CDC had by then identified as likely to have AIDS. (Donors with a history of hepatitis B are necessary for the production of gamma globulin, which offers antibodies to protect recipients from infection. However, these same donors are considered high-risk for the production of other blood products such as factor concentrate.) Alerted to this correlation by the CDC in mid-1982, the industry should have stopped the use of hepatitis B-contaminated plasma for factor concentrate and recalled all products. This was not done. The industry should have begun to isolate the plasma collected for gamma globulate from the pools of plasma used to make other products, as required by FDA mandate. This was not done either. Internal drug-company memos demonstrate that once again, officials understood that these policies could result in the further spread of AIDS. The hardest aspect of this nightmare for our community to accept is, "How could company executives-fellow human beings-decide that their profit margin was more valuable and important than our lives?" This is none other than the business ethic of viewing human life as a means to an end-financial gain.

The Committee of Ten Thousand, a seven-year-old peer advocacy and support group, is a vehicle for taking control of our lives-something this community had never done. Two initiatives are the centerpiece of COTT's program: A class-action suit filed in September 1993 against four drug companies: Bayer, Baxter/Hyland, Alpha Therapeutics and Armour/Rhone-Poulenc Rorer (see AIDS Law); and the introduction in February 1995 of the Ricky Ray Hemophilia Relief Fund Act in Congress (see Retro *POZ*).

COTT has also had a substantial and defining impact on the business of blood processing and distribution in this country. In 1993, our work resulted in Congress mandating the National Academy of Sciences' Institute of Medicine (IOM) to appoint a blue-ribbon panel to investigate how this holocaust occurred. Its 1995 report, *HIV and the Blood: An Analysis of Crisis Decision Making,* substantiated our claims. And last spring, Congress directed its Subcommittee on Human Resources and Intergovernmental Relations to investigate the safety of the nation's blood supply. Its report found that major problems continue to plague our blood supply. While the blood supply is definitely safer today than it was in the '80s the federal government's and the industry's responses to emerging threats continue to be problematic. Because of the ongoing failure to institute adequate screening for other pathogens, the blood supply remains vulnerable to another viral explosion like HIV.

A major step forward, in response to community pressure, was the 1995, reorganization of the FDA's Blood Products Advisory Committee, which is responsible for blood safety. Since its inception, this committee had been mired in conflict of interest as more than 90 percent of its members were involved in the blood-banking industry. COTT continues to demand a no-fault compensation program for those harmed by blood and blood products in the future.

HIV positive people with hemophilia have demonstrated how a community left for dead can turn disaster into self-discovery. From our perspective, we were considered expendable in the name of both profit and so-called medical progress-like the African American men in Tuskegee, Alabama, who from 1932 to 1972 were used to study the progression of syphilis, or the population of Haiti that serves as a virtual floating drug-company laboratory. We still have a long way to go to free ourselves from the shackles of medical dependency. We must continue to agitate, educate and organize within our community and in alliance with others. Only by building a broad-based, grassroots movement for social and economic justice can we be successful.

The process of working with other AIDS communites has been a profound learning experience. When COTT began, homophobia was a serious problem within the hemophilia community, while the gay community viewed us as concerned only about our own. But COTT has built strong and mutually beneficial relations with the gay community, and this accomplishment has had a substantial impact on changing the way we view each other. Through understanding and supporting each other’s issues, we have strengthened the larger human-rights struggle. And through our activism in Japan, Latin America and elsewhere, we are helping to give birth to an international justice movement for people with hemophilia.

In solidarity with other communities, we must once and for all end the medicine of profit and the use of human beings as guinea pigs. Those who behind the closet doors of board rooms and government offices perpetrated this outrage must be held criminally and financially liable for the death and devastation of three generations of people with hemophilia. And this sordid history must be known worldwide to ensure it never happens again. Otherwise, all our brothers, sisters, mothers and fathers will have died in vain.

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