

Back in the day: *A roman á clef*

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There was a time, back in the early days of the AIDS epidemic in the United States, when Donn Stone, MD, was attending two or three memorial services a week. Stone, the local health authority for Dallas County and the City of Dallas, knew the deceased personally, and professionally—they were co-workers, friends, and sometimes seeming adversaries who had succumbed after grappling with AIDS in ways that were both individual and community-based.

Stone's city and region had been an early focus of AIDS, and the prevalence of infection in the population was thought to be high. The effective work of the county epidemiologist Albert Rainier, MD, identified the extent of the AIDS burden locally. Without a cure, the outlook, both for individual patients and infected communities, was bleak: the case fatality rate approached 100 percent.

The traditional answer to a life-threatening disease in the absence of a cure was prevention. Epidemiological data from the U.S. Centers for Disease Control and Prevention (CDC) showed that levels of what some called "gay-related immune deficiency" (GRID) were found to be high in specific groups—sometimes called "the Four Hs:" homosexuals, Haitians, heroin-users, and hemophiliacs who required blood transfusion. Prevention efforts were developed with particular attention to these groups.

Groups led by Robert Gallo, MD (AQA, Sidney Kimmel Medical College, 1962), and Luc Montagnier, MD, announced the discovery of the Human Immunodeficiency Virus (HIV). With knowledge of the virus came the development of serological tests for antibodies, allowing for the identification of those who had been infected.

Many people were deathly afraid of the disease, now known as AIDS (acquired immunodeficiency syndrome), and there was widespread concern that casual exposure might spread the infection. A degree of panic led to those who were infected being shunned. Epidemiological evidence was demonstrating that the disease was spread only in a limited number of very specific ways, but the fears of the general public were not calmed. Infected individuals suffered from the ravages of the disease, and discrimination in employment and association.

The Food and Drug Administration set new procedures for safety regulation of blood transfusions, and one of the Four Hs dropped out of discussion as it was understood that Haitians were infected only through sexual activity or illicit drug use, and not through nationality. This left sexual transmission, mother-to-baby transmission, and drug abuse as the major contributors to the growing epidemic in the U.S.

A multipronged approach in Dallas

Stone and Rainier approached the problems of health and society through a multipronged program of information and education in Dallas and its suburbs. To lead the Dallas AIDS Prevention Project, they recruited Linda Freebairn, an experienced health services researcher, educator, and disease control program manager to assist with education and prevention efforts.

As was common with programs related to other sexually-transmitted diseases (e.g., syphilis and gonorrhea), the Dallas AIDS Prevention Project was met with resistance as it required a degree of sexually- and behaviorally-explicit language and presentations that made some people, including Dallas County elected officials, anxious.

Based on the new knowledge of HIV and development of a test for antibodies against HIV, it became possible to test an individual for exposure to the infection, and to identify infected individuals.

Some advocates for potentially-affected groups, like



Poster, Dallas County Health Department, circa 1980s. U.S. National Library of Medicine

college math teacher Doug Herring, chairman of the Lesbian & Gay Public Policy Arm, and Aldiss Escobedo, founder of Cottonwood Counseling Center (CCC), were outspoken in support of AIDS prevention efforts. They helped Stone and Rainier design and distribute materials, provided venues for educational activities, and spoke about safer sex practices in the gay community.

Other leaders such as Earl Sinclair and Harold Manor of GUD (Gay Union of Dallas), and Walter “Red” O’Neill, director of AAF (AIDS Assistance Focus), proclaimed discrimination and persecution. Through public pronouncements, printing and distribution of flyers, and community outreach, these groups advocated to contain the county’s education programs, citing invasion of privacy and malicious intent.

Their major issue was the ability to identify infected individuals well before the disease became manifest. The possibilities of personal identification of infected individuals, and the consequent shunning and discrimination, were too terrifying to contemplate.

Getting out ahead of the disease with free, voluntary testing

Rainier felt it was imperative to offer free, voluntary testing before the blood banks started the testing protocols. He wanted to avoid having at-risk individuals donating blood for the purpose of determining their own status.

Stone, Rainier, and a team of educators, outreach workers, and epidemiologists developed a system to offer free anonymous HIV antibody testing and counseling. No names, no numbers, no way to identify the person being tested, no discrimination. Those who tested positive would be offered counseling about avoiding further transmission of the infection.

The protections offered were not enough for Earl Sinclair, O’Neill, and their colleagues at GUD and AAF. Their outspoken opposition to the county’s testing and counseling program was loud and aggressive. GUD sponsored an advertising campaign urging people to refuse testing.

Sinclair advised testing “Only for people with symptoms, not for those at risk.” He argued, “Widespread testing is a waste of money.”

Rainier responded:

AIDS isn’t just a gay man’s disease. We must educate others, as well. There’s a five-year lag between virus transmission until we see the cases. Consider intravenous drug users often sharing needles. Prostitutes, others. Most gay men already know about AIDS, but other groups aren’t aware. Testing is the way to prevent disease!

In the first weeks of the county’s testing program, every afternoon after the last patient had left the clinic, Rainier gathered the clinic staff in his office for an informal debriefing. In those early days, the patient counseling sessions involving an invariably fatal disease were extremely stressful for the nurses and counselors. Freebairn reported that clinic staff were telling one out of four patients they were HIV-positive. The group debriefing sessions helped to create a strong camaraderie among the staff. While stress was high for these care providers, so was morale.

Rainier noted that communicable diseases nurse Nelda Munford, RN, played a critical role in building relations with the gay community. Outgoing, warm, and frank, she had what Rainier described as “a knack for finding information on the grapevine, and for communicating difficult or stressful information to some of the frightened individuals.”

Meanwhile, County Commissioner Filene Franks, an advocate for the County Health Department, was outspoken



Poster, Dallas County Health Department, circa 1980s.
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in her support for testing, even going so far as to ask for mandatory AIDS screening (blood testing) for doctors, nurses, and dentists. Stone reminded her that the current county testing program was voluntary, and that the county did not have the authority to require screening.

Commissioner Franks's colleague, Commissioner Robert Logan, was not satisfied with the

county's program. He told Stone and Rainier, "You've got too much emphasis on education, and not enough on testing. Be active!"

A growing caseload, a survey, and free testing

As the battle against AIDS became more politicized, Dallas County was 10th in the nation in the number of reported AIDS cases, with more than 600 cases.

As the numbers of infected and affected individuals increased across the country, the CDC concluded that more precise data were needed on the magnitude of the infection in the general population. With the newly-developed serologic tests, it was theoretically possible to determine a national seroprevalence rate through random sample testing. With the collaboration of the National Center for Health Statistics (NCHS) and the private, non-profit Research Triangle Institute, the U.S. government prepared to move forward with a national survey, beginning with one or two small pilot tests. The goals of the pre-tests were to determine how widespread the distribution was, and to assess the general public's willingness to be tested.

Political opposition shot down a proposed pilot survey in Washington, DC. A small scale preliminary survey was conducted in Allegheny County, Pennsylvania, but a larger pre-test of the national protocol was needed.

The cooperating federal agencies, taking note of the rigorous local epidemiologic and community work by Rainier and Freebairn, and the pledge of support from Stone, chose Dallas County for a pilot test.

Federal authorities presented a plan to conduct a

house-to-house survey, with in-home blood testing of individuals selected through a stratified probability sampling process. Teams consisting of a trained interviewer and a technician to draw blood would visit 3,400 households in Dallas County, interview 2,200 people, draw small blood specimens, and offer a \$50 cash incentive for participation. There would be no identification of participants, and no communication of individual results. Participants who were interested in their results would be referred to a clinic for re-testing.

When the Dallas County survey was announced, GUD's Manor was quick to proclaim, "We live in a state where there are no protections for people who are infected. We'd have to be assured that this is truly an anonymous study and that people would not be hurt if they agree to cooperate."

To maximize community acceptance and participation, the County Commissioners appointed a 29-person Community Advisory Panel to review the plans and procedures. The panel included school officials, representatives of gay organizations (Herring and Manor), religious groups, and others. The president of Dallas's public hospital, which carried much of the medical load of AIDS patients, pointed out that there were no physicians on the panel.

County and federal officials, including Rainier, Stone and Freebairn, worked long hours over several months, developing a plan that they hoped would be both scientifically valid and widely accepted. After receiving input and discussion from across the county as well as volunteer speakers and consultants, the Community Advisory Panel voted to proceed with the study. Only one member voted in opposition: Manor, who vowed to "campaign to refuse participation!"

As interviewers and technicians were trained in the prescriptive study protocol, the public relations battle intensified. *Adweek's* headline read "AIDS Study Prompts PSA Duel," with print and broadcast advertising both supporting the survey and opposing it.

A letter from Surgeon General C. Everett Koop (ΑΩΑ, Weill Cornell Medical College, 1989, Alumnus) urged participation. Local advertising agency Knappe & Knappe developed commercial spots, ads, and lapel pins asking people to "Be Part of the Solution!"

In opposition, GUD offered a campaign including mailings, posters, "Just Say NO!" buttons, and radio and television ads encouraging a boycott of the survey. It was reported that there were efforts to urge sabotage of the survey through the falsifying of participant presentations.

One of the survey designers from Research Triangle



Poster, AIDS Resource Center, Dallas, Texas, circa 1980s.
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Institute expressed concern that strident public expressions of opposition “may encourage people to grab survey materials away from the teams,” and there were rumors that bounties were offered for such materials.

While federal authorities had authorized a \$50 incentive to encourage participation, Manor announced, “We’ll pay \$100 for the first person who can prove that they rejected this test. After that, we’ll donate \$50 to AIDS research for anyone who turns it down.” GUD continued to challenge the need for the study, citing invasion of privacy and a waste of tax dollars.

The anti-study campaign peaked when a loud commotion was heard outside the front entrance to the health department. Hearing the clamor, Stone rushed down the stairs from his office to find a perplexed security officer Joe Schuster scratching his head as he looked through the glass door entrance at a panoramic scene of mass disaster. There at the entryway to the building were 90 human-like bodies—shirts and trousers stuffed with rags and old newspapers to simulate dead bodies. Standing behind the ersatz corpses was a crowd of 40 to 60 people of the Gay Action Squad chanting, “These studies are killing us!”

News media had been alerted, and newspaper, television, and radio reporters were on the scene as Stone came out to view the spectacle. (When a clean-up crew came later to remove the dummies, it was noted that some were dressed in fine designer clothes. Several not-so-well-paid county employees were quick to assist with removal of the exhibit.)

The survey continued through all of the publicity. Strong support for the study came from courageous gay leaders including Escobedo and Herring.

Survey results

When it was done, Nathan Cordray from NCHS provided a report and analysis at a press conference in Dallas. More than 1,000 Dallas County residents had participated, at an overall rate of about 80 percent, enough to call the study a modest success. The data analysis allowed a statistical inference that between 4,000 and 7,500 people in Dallas County were infected with HIV. Stone said, “We’re eight years into the epidemic. We’ve been looking at the tip of the iceberg. Now we have an idea of the general size of the iceberg itself, and we can develop appropriate ways to deal with it.”

We’re all in this together

Several months after the survey, a group of interested parties from throughout Texas came together in the State Capital to discuss the HIV/AIDS problem. O’Neill, an ever-present outspoken critic of the Dallas County Health Department’s HIV testing and counseling program, and vocal opponent of the now-completed survey was also at the meeting. During a break in the meeting, Stone asked O’Neill, “How’s it going, my friend? Can I buy you a cup of coffee?” O’Neill looked up, flashed a tentative smile, and said, “Sure thing!”

The two men spoke casually about the conference, then O’Neill remarked, “Ya know, I was absolutely amazed that you came over and talked to me. After all we’ve both done and said over the last couple of years, I was completely bowled over that you would even speak to me!”

Stone smiled, and after a brief pause said, “I do my job the best that I can. You do your job the best that you can. But, ultimately, we’re all in this together.”

A few months later, Stone attended a memorial service for O’Neill, who had died of AIDS.

Editor’s note: This story is based on Dr. Green’s personal recollections and conversations from his time as Director of the Dallas County Health Department and Health Authority for the City and County of Dallas. Most names, characters, agencies, and incidents are used fictitiously and represent composites.

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