Fear of Disclosure

Why Tom Stoddard, a man largely responsible for inventing the field of AIDS law, kept his HIV status to himself

October 1, 1995 By Robert Murphy

Tom Stoddard is moving.

He and his spouse, Walter Rieman, stand amid piles of books and clothes in the spacious but slightly shabby Upper West Side apartment where Stoddard has lived for 15 years and Walter for almost half that. They've taken a 30-year mortgage on a prewar apartment a few blocks away, overlooking Riverside Park and the Hudson. "My mother thought that the move itself was something for me to look forward to," Stoddard says. "But I'm actually planning to live there for quite a few years."

In 1980, when Stoddard last moved, all the world lay before him. Stoddard was 32, a talented public-interest lawyer clearly on the way up; handsome and sexy and in the right city to enjoy it. What occurred during the next 15 years was the bulk of the gay-rights movement to date and the advent and endless stretch of the epidemic, tides of history which Stoddard has ridden to many triumphs, but which have quite roughly scraped and scoured him in the sand.

For months now, Tom's face has looked as though it bore the brunt of the scraping. Though Stoddard concealed his HIV from all but his closest friends and colleagues at Lambda Legal Defense and Education Fund for over two years after diagnosis before going public, there could be no hiding the illness today even if he wanted.

After alternating bleomycin with vinblastin for almost three years to treat Kaposi's sarcoma (KS) -- "it was pretty effective, and kept the lesions at bay" -- this past spring the bleomycin finally began impairing his lung capacity. "So I stopped it, and my lesions flowered."

Dull smeary purple petals bloomed like springtime on his face, chest, groin and legs. (In truth, one large round lesion on his right thigh resembled less a flower than, in appearance and to the touch, a lichen on a log.) Stoddard readily confesses to a strong streak of vanity, and the condition of his face bothered him no end. In mid-May he was scheduled to receive awards and give addresses before large groups in Philadelphia and Washington, and was distressed at the prospect of looking sick. As he complained to Rieman at the time, "I really resent having my illness speak to everyone I meet through my skin."

Worse, his feet and legs developed a painful edema that reduced him to hobbling. “I thought that might make me housebound, and that scared the hell out of me. And I didn’t know what was causing it.” Later he learned that the KS was damming the lymphatic fluids in his legs.

But now he feels much better. “I learned about a drug called Doxil, which is in experimental form, and pushed to get myself admitted to the protocol at New York University [NYU] Medical Center. That drug is so powerful that with only three infusions over a period of a month and a half, virtually all my lesions have very significantly faded, and my legs have returned almost to their healthy state. Yesterday I ran a mile.”

During his last year at NYU Law School in 1976, Stoddard began working for the New York affiliate of the American Civil Liberties Union (ACLU), and for the next eight years he lobbied before the New York legislature in Albany. He and his colleagues fought a never-ending battle for freedom of speech and religion, women’s reproductive rights, due process in criminal law, gay rights and a host of other issues.

Albany was also the training ground for many young reporters and Stoddard developed a brilliant talent for promoting his causes by getting quoted in their stories. As Bob Keeler, a former Albany bureau chief for *Newsday*, put it: “Stoddard was good. He always returned phone calls right away and he was always able to encapsulize an issue for you. I can’t recall a time that I called Tom Stoddard that I didn’t end up quoting him, often for the kicker, because he was always able to put it in the simplest and best possible terms.”

Rich Meislin, a former *New York Times* bureau chief in Albany who, very briefly, dated Stoddard, thought “he was a terrific lobbyist. Very smart, very well spoken, very earnest -- always very earnest -- and a very straight shooter, not a lot of bullshit. He knows how to sell a story the way you should do it, which is with facts. He’s gotten better over the years, but he was already very, very good at it. People listened to him.” As a result of Stoddard’s press skills and contacts, says former *Times* reporter Phil Gutis, "Tom became ’Mr. Gay.’ Every time there was a story about gay rights in *The Times*, Tom was quoted." For years, much the same was true for HIV-related issues.

Throughout his career in Albany, Stoddard also lived and maintained a private law practice in New York City. There, in the late 1970s, a repressed young man from the Midwest could make up for years of emotional and sexual deprivation. “To say that I dated heavily would be an enormous understatement,” Stoddard recalls with a bit of eye-rolling at the antics of his youth, but with evident pride and satisfaction at the glandular gusto his former self displayed. “I dated an extraordinary variety of people. Some of it was glamorous, some of it was exotic, some of it was sleazy.”

After several dates with a stunningly handsome Englishman named John Curry, Stoddard found out that he was an Olympic gold-medalist skater. "I remember how thrilling and glamorous it seemed to me to leave his house one morning, walk to the newsstand, pick up a *Newsweek* and see his photo in it. I thought I could never reach that pinnacle again."

At a Lambda Legal Defense and Education Fund reception, Stoddard was spotted by noted gay

novelist Edmund White, recently out-of-love and unhappy about it. "I saw Stoddard stride into the reception looking like the young Kennedy, in a white shirt with the tie loose and the sleeves rolled up, and I thought he was really exceptional in his *allure*," recalls White. "I had heard of his good works, and thought that must be an interesting person, so I called him up and invited him to dinner. We had sort of an affair. He would come over (by then I had moved downtown), I would fix dinner, I would ask him questions and we would spend the night together. He would describe his civil liberties work, he would talk about his childhood. One of the things that surprised me about him was that he seemed so much the ideal, together person, but he had deep feelings of insecurity, the fear that he wasn't attractive enough. I was flabbergasted that Tom took any interest in me at all since I saw him as a catch beyond my reach. There was never a question of love between us, alas. I say 'alas' because he was my notion of an ideal lover: Handsome, brilliant, politically engaged, cultured, great sex, fun, sophisticated."

Stoddard dated many of the bright lights of the gay-rights movement in New York as he gradually became an active and well-known advocate himself.

Stoddard made a bid to become executive director of the New York Civil Liberties Union in 1985, but lost out in a bruising battle with homophobic overtones. Not long afterwards Tim Sweeney decided to resign as executive director of Lambda, and Stoddard was asked to apply. By virtue of his years at the NYCLU, he now had more experience than virtually anyone else doing gay-rights work in the country. He got the job running away.

Lambda at the end of 1985 was a tiny impact-litigation organization with an honorable 12-year history working out of a single room provided by the ACLU. In addition to its gay-rights work, Lambda had brought and won the nation's first AIDS discrimination suit and largely invented the field of AIDS law. When Stoddard arrived, the AIDS docket was exploding along with the epidemic -- just when gay-rights work faced its own intensifying challenges as a result of *Bowers v. Hardwick*, the notorious Supreme Court decision upholding the constitutionality of sodomy laws.

Stoddard spearheaded rapid growth at Lambda. In part, AIDS and *Hardwick* propelled the growth, but crucial, too, were the high visibility Stoddard brought Lambda and a talent for fundraising that nearly matched his media skills. Stoddard also attracted much of the top-drawer outside legal talent on which groups such as Lambda depend. William B. Rubenstein, formerly head of the ACLU's gay rights and HIV project, says flatly: "Tom legitimized gay-rights work for the legal community in New York."

Reviewing Lambda's docket for the last half of the 1980s reveals the scope of the legal assault against people with HIV: Discrimination of every kind, attacks on privacy, government coercion and deprivation of health care. Lambda's staff and outside attorneys ceaselessly and effectively responded to the legal crisis. And their accomplishment was profound. As David Hollander, a former co-chair of Lambda notes, "We succeeded in making AIDS discrimination illegal, and Tom deserves the most credit for pulling the effort along."

Skillful public-interest advocacy uses litigation not only to shape the law but, often more

importantly, to shape public debate. Beginning in 1985, Stoddard began to discuss AIDS issues regularly on television shows like *Crossfire, Donahue* and *Nightline*, taking on the likes of Pat Buchanan, Jerry Falwell, Robert Dornan and a multitude of homophobes, victim-blamers, mandatory testers and would-be quarantiners.

A 1987 letter from a *Crossfire* viewer suggests the impact these appearances had on the national debate: "Your presentation, your restraint, your insistence upon being heard, your rationality were very impressive -- and I'm sure to any reasonable open-minded person, *persuasive.* I'm glad you are there doing what you do. I would have exploded in a rage!"

Stoddard's dedication to a rational, civil mode has made for tensions with activists of greater stridency. As critical as anyone of government officials' inaction and worse on AIDS issues, Stoddard would be very unlikely to scream "murderer" at them. But offsetting his genuine belief in respectfulness, Stoddard has an undeniable arrogant streak. And he's not the only one. In a 1990 feud that began with what should have been a principled disagreement over a controversial health department appointment, Larry Kramer dropped his Lambda membership, publicly hurling at Stoddard a couple of his patented verbal fragmentation grenades.

Flare-ups aside, Stoddard and Kramer have usually enjoyed a friendly relationship, and Lambda and ACT UP often cooperated. But the two leaders and organizations make a fascinating comparative study in the aims and strategies of social movements. Stoddard has worked through Establishment channels of power: Courts, cloakrooms, network television and *The New York Times.* Never a street activist, the closest he ever came to an ACT UP demonstration was as an extra in the movie *Philadelphia.*

Stoddard credits ACT UP with great accomplishments in reforming the process of drug development. In general, however, he believes demonstrations have little effect on lawmakers, and rejects a discourse so fueled by fury. "While I respect the anger of someone like Larry Kramer, it's not my perspective," he says. "In the end, I'm always hopeful."

His friend Rich Meislin observes: "In public life reasonable voices are a real rarity. Lambda was a perfect fit for Tom for most of the time he was with it, largely because it was just the right organization for somebody who could make rational arguments. It was not a job where you want somebody who spends their time being angry and screaming. There are places for that, too, but the head of Lambda is not one of them."

In October 1989, Stoddard went to his doctor for a checkup, after which the doctor strenuously, but without explanation, began urging Stoddard to take the HIV test. Not at all sure he wanted to, and quite put off by his doctor's insistence, Stoddard left. When he didn't keep his next appointment, the doctor came to Stoddard's office at Lambda on lower Broadway and told him why he wanted him to be tested: He had found a lesion inside Stoddard's mouth which he was all but sure was Kaposi's sarcoma.

The only person in his family Stoddard told right away was his brother, John, who is also gay and whom Tom already knew was HIV positive. "I sensed that John was starting to cry on the phone,

and then he said, 'I'm so sorry. I thought my being sick would protect *you.*' It was the sort of magical thinking people fall into, but I was very moved by what he said."

He told only his closest associates at Lambda, and did not inform the board for almost two years. According to his brother John, "He didn't tell the people at Lambda for fear that the board would divest him of power. That sounds like a ridiculous thing, but that's what he really thought, and he knew the board better than I did."

"Certainly he wouldn't have lost his job or his power at Lambda," says Judith Turkel, a co-chair from the period. "I really do think he lost the opportunity to get a lot of love and support from people who really did care about him."

"I had to cope first with myself," says Stoddard. "My friend Sandy Lowe with whom I worked at Lambda put this well, in the context of sexual orientation: 'You never know what time it is in somebody else's life.' By cultural training, I'm a fairly private person. That was one reason for my reluctance. Part of it, too, had to do with the kind of advocacy I did. I didn't want other people to believe that I was an advocate for people with HIV because that was *my* illness.

"And part of it was simply the difficulty of disclosing to people with whom one is not intimate something that is personally difficult. The idea of communicating this essential weakness was hard for me. And so I worked out -- by instinct, really -- a plan to gradually inform more people. I knew there was a certain time when I had to tell my parents, for example. There was a time when I should talk to the gay press about it, and there was a time I should talk to the larger world about it, to the degree that I was able. All those things happened in a sequence that was in the end very satisfying."

Dennis deLeon, the HIV positive former N.Y.C. Commissioner of Human Rights, is an old friend of Stoddard's who asked him for advice on how and whether to go public with his own status, which he ultimately did in a *New York Times* op-ed piece. "I thought Tom missed an opportunity when he was at Lambda to become more public about it. But when you say the words, 'I'm HIV positive,' you in a sense are limiting your own thinking about yourself -- if you're not careful, you know. And I thought that was one of Tom's motivations in not wanting to go down that road until after he left Lambda."

The tension over disclosure and deterioration in his health contributed to an already hellish final year for Stoddard at Lambda. He was brutalized by the controversy over Lambda's use of a performance of *Miss Saigon* as a fundraising event: The musical's producers had been accused of racism for casting Jonathan Pryce, a white actor, as the Eurasian lead character, the Engineer, and of racism *and* sexism based on characterizations in the show. Months of anti-Lambda protests followed.

The strains of the prolonged uproar aggravated long-simmering staff tensions at Lambda which Stoddard clearly failed to manage properly, and which erupted into near mutiny. Disgusted by the acrimony and lacking the stomach to undertake the necessary reorganization, Stoddard resigned at the end of 1991.

Asked about his current health, Stoddard pauses. "July has been a very good month; May was a terrible month. But I experiment with my drugs and my therapies and my day-to-day life, and I still feel full of hope.

“Most recently I was doing AZT and d4T together. But the AZT makes me really sick. I’ve taken it off and on for six years, and after a while when I found myself gagging over some of my meals, I said enough of the AZT, it’s not worth it for me to suffer like this all the time, never being able to eat. So I stopped it -- my doctors permitted me to stop it. And I’m very lucky: I’ve never been in the hospital in six years.”

Describing Stoddard’s full complement of antivirals, prophylactics, steroids and nutritional supplements would occupy pages. Empirical and open-minded, he says that "Medications aren’t enough, but natural therapies aren’t enough, either. So I grab from whatever tradition I can.

"The central issue is hope. If one despairs, believes that one will die, one will die. So you have to believe there is a possibility of a real future, and then you have to work every day to try to achieve that future. It won’t come about by hope alone, but it won’t come about at all without hope.

“Some of it is hope tied to luck. If this were 1985 instead of 1995 I would be dead. I’m not dead. I profit from many medical developments over the last 10 years that allow me to fight both the KS and the HIV and I’m grateful for that. I think it may be valuable for people to know, especially people who’ve been recently diagnosed, that I have had an opportunistic infection for six years, since October 1989 when I had my first Kaposi’s sarcoma lesion. While day-to-day life is not comfortable and not easy, I’m able to run and exercise and do some degree of productive work.”

In February 1993, despite a recent bout of *Pneumocystis carinii* pneumonia, Stoddard dived into public life again when asked to take the helm of the Campaign for Military Service, a hastily conceived effort to support the newly elected Bill Clinton in his pledge to end the ban on gays and lesbians in the military. It was an arduous, six-month effort which showcased Stoddard’s talents at their most inspired. He would go on camera for *Nightline*, upbeat and articulate as ever -- just minutes after completing a pentamidine infusion in his Washington office. And the secrecy of Stoddard’s Lambda days had passed: The Campaign’s staff of young activists and former servicemembers marveled at Stoddard’s ability to juggle his mission and his illness.

The Campaign undoubtedly suffered from its own conceptional and operational flaws, for which Stoddard, as director, bore ultimate responsibility. Yet the overwhelming problem lay elsewhere. As Bernie Nussbaum, the former White House counsel, told me insistently, “There was a quick, hard decision not to lift the ban made in January” of 1993. If Nussbaum is right -- and he was certainly in a position to know -- Clinton’s direct, repeated promises over the following months to lift the ban were bald-faced lies, and the Campaign was doomed before it began. The outcome robbed Stoddard of a flag to plant on the pinnacle of his career. Yet the president’s duplicity rendered Stoddard’s dedication all the more honorable and steadfast by comparison.

These days, Stoddard continues to teach law, serves as vice-chairman of the American Foundation for AIDS Research (AmFAR) and engages in continual, informal consulting with HIV and gay-rights

advocates around the nation.

And he and Rieman have that 30-year mortgage on their new apartment.

"I think it is possible that I can survive the epidemic. I can't be sure. I don't know how much longer I'll be alive. But there's no reason for me not to try. All of these developments are bridges toward the ultimate cure, to use a metaphor others have used. I cross each bridge as it presents itself. I believe it is possible -- at least in theory -- for people like me to survive.

"It's now absolutely clear to me that survival, even now with drugs, requires constant discipline and determination. If one gives up for a week or a month, the illness takes over. I feel that every day. That means that people who are old enough, and experienced enough, and lucky enough, will be able to prolong their lives, but those who are denied the opportunities to move forward will not. I'm alive in part now because I'm 47 years old, I'm a lawyer, I have a lover and a supportive family, I have good health insurance, I have access to wonderful doctors, I have a place in the world. Having a place in the world may be the central question. An 18 year old who is uncertain of himself or the world will have much greater difficulty surviving. I worry about what we do for those who are not so fortunate."

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