Work 2000

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January 1, 2000

As the first and only openly HIV positive member of the New York state legislature, Sen. Thomas K. Duane is an outsider on the inside. But his HIV status is no mere accessory to his legislative life—it's the motor that runs it. Long before making it to Albany, Duane, 45, had distinguished himself as a champion of people with HIV. He'd defended PWA rights as a New York City Democratic district leader in Chelsea, the city's gay epicenter, and as a member of the New York City Council he went hand to hand with Mayor Rudolph Giuliani (R) to save the city's Division of AIDS Services from the budget ax. He'd used direct action as a member of ACT UP, blocking traffic in the street during demos with the disarming mien of an altar boy. In his long career as a public servant, Duane has combined the bureaucrat's suit and the activist's bullhorn with singular results.

This double role grew twice as tricky the moment Duane left New York City, with its dozens of AIDS organizations and heightened AIDS awareness, for the comparatively small town of Albany. Players in New York's capital haven't shown much neighborliness to AIDS since 1997, when the press—and politicians—discovered Nushawn Williams, the HIV positive city kid who allegedly infected dozens of young women in upstate New York. According to Duane, the frenzy over Williams gave legislators "permission to be racist, homophobic and sexist in their rhetoric around issues of HIV." Duane descended on Albany in January 1999, after the nastiest bile had been vented, but he says he still often feels like the lone voice of reason for people with HIV.

And community support has rarely been unanimous. Once Duane entered the state senate, some colleagues began to suggest that his activist stance was ill-suited for the compromise-heavy world of electoral politics. A candidate for Duane's vacated City Council seat spoke during a televised debate about Duane's "horrible relationship with the mayor, which hurt us in getting services." Liberal politico Marty Algaze, former president of the Stonewall Democratic Club, told *POZ* that Duane "tries to hoard AIDS" and has let relationships with other gay elected officials sour. Operatives on the right sent a postcard to a dozen Republican legislators last March that asked "Is Sen. Tom Duane HIV positive?" and charged him with using AIDS for personal gain. The cards, though unsigned, prompted a local tabloid to call Duane's doctor to confirm his HIV status.

Duane was a subject of speculation and spin even before his arrival in Albany. Colleagues were

already alert to this relentless politician who voted his conscience more often than the party line. When he won a City Council seat in 1991, Duane became somewhat of a national celebrity as the first openly HIV positive elected official in the country. Then there was the matter of his multiple arrests with ACT UP. “They expected me to be an activist and not a City Council member. But I’m different from what they thought,” Duane says. “They see I’m a regular guy.” While Duane won’t name names, he says certain legislators have even approached him for help in supporting HIV positive friends and family members in their efforts to secure appropriate health care. “It is a whole new dynamic for us to have a senator who can go peer-to-peer about our issues,” says gay advocate Matt Foreman, director of the Empire State Pride Agenda.

“I’m lucky—not many people can say that they love their job,” Duane says. But pressure is what fuels politics. Gripe number one is the lack of time senators have to investigate an issue before voting—background briefing and behind-the-scenes lobbying are crucial when Duane has to challenge a bill that would further erode the civil rights or health care of HIVers. This past year, he says, the battles came with frustrating frequency, including famously failed attempts to oppose laws requiring HIV names reporting, partner notification and contact tracing, all authored by fellow senator Nettie Mayersohn.

Mayersohn, though a New York City Democrat, has harnessed upstate Republicans to a paranoid agenda of protecting “people” from people with AIDS. Caught between a Republican majority in the Senate—“no Republicans have ever voted with me on public health issues”—and liberal Democrats who rarely stick their necks out on AIDS, Duane feels he has no true allies in Albany. “There’s very little collegiality here,” he says.

The constant conflicts have forced a change in Duane’s signature low-key delivery. The altar boy has had to become, at times, a firebrand. “On the floor, I’ve raised my voice; I’ve had to show my anger,” he says. “It’s not a regular part of my persona.”

Duane seroconverted more than 10 years ago, and he enjoys stable health without any antiretrovirals. But the thought of one day making therapy decisions weighs heavily. Senate duties keep Duane on the run—could he even deal with a protease inhibitor regimen? “Once you start [on meds], it’s forever,” Duane says soberly.

“My schedule would make it hard to be compliant.”

Putting aside free time for himself and partner Louis Weber “is an issue I’m working on,” Duane admits sheepishly. Currently, they get away for only a week in the winter and one in the summer. Well aware of the toll that stress can take on CD4 cells, Duane promises more exercise and downtime in 2000. But that’s a promise he’s made before.

His commitment to a political agenda for the new year is far more certain. Duane vows to fight against the laws on names reporting and partner notification, in an effort to prevent them from “driving people [who need services] underground.” He also pledges to lobby for money for more

explicit prevention programs. Perhaps Duane's role as the only activist in the Albany wilderness will shift in the coming year; changing state demographics could herald more Democrats in the Senate. "If there are more Democrats," Duane says hopefully, "we won't be fighting so many horrible [anti-HIV] bills." While a new Senate majority would not signal an end to legislative battles, Duane says, it might at least help reduce the stress: "I'd rather be fighting with friends than fighting with people who can do damage."

—Jay Blotcher

Tom Duane
New York state senator, 45; diagnosed '88

"In 1992 when I was running for the New York City Council my fellow AIDS activists Larry Kramer and Rodger MacFarlane urged me—let's say strongly—to come out. My issue was whether it would become an edifying piece in the Times or an exploitative story in the Post. I wanted it to be empowering, I wanted it on my own terms and, yes, I wanted to win the race. So the battle really was not whether I wanted to disclose, but how it would happen. I was told before I went up to Albany last year to begin my term as state senator what it would be like. People I love were concerned about the stress. But that stress isn't a detrimental factor for me. The pressure I'm under is self-imposed. Much more stressful for me than my job is very good friends dying. It's been difficult to replace them. And I find I keep having to do it—over and over again."

Evan Ruderman
Electrician, 40; diagnosed '89

"Work is a way to pay your bills. I was an apprentice at 20, and my skill gave me stability, a sense that I could take care of myself and be part of something bigger—building things. I was a founding member of United Tradeswomen. I saw myself as an example for other women. After my diagnosis, I kept working, but I was careful who I told. There are a lot of accidents in construction, things people would be nervous about. I had to work 50 to 80 hours a week, so it became way too much. I was in the hospital, and then back at work. We didn't have sick days. I was always taking herbs and special health stuff, and guys would make fun of me. Finally I had to take disability. When I retired, it was depressing—I thought, "Who am I if I'm not this woman electrician?" But I didn't have the luxury of choosing otherwise. I just had to let it go. Now I'm doing better. But when I think of going back, I get worried about how physically demanding electrical work is. The dirt and the chemicals would be hard on my system. I couldn't work outdoors. This country has a rigid work ethic. Most people don't want you part time. It's all or nothing, and I'm not ready for the 'all' yet. Now the only thing I want to do with my life is something that will fulfill my heart and soul. When you face death, long-term dreams aren't there, but you search for why you're here, what the cycle of life and death is all about. All the little things you thought were fixed—they become more dimensional."

Frank Holliday
Artist, 42; diagnosed '90

"An audience finds out you're an 'artist with AIDS' and two things happen: First they get condescending and give you that pitiful 'you're gonna die' look. Then they just write you off as no longer a contender. I make art about my life. The works are brutal. I mean, it ain't purty. I'm a gay person with AIDS trying to

share my emotions. And let me tell you, people don't always want them—it's kind of Pottery Barn–ish in the art world I found out I had HIV when I had 38 T cells and pneumonia. I already knew, but I'm Southern, I was like Blanche DuBois—'I want magic, ya hear?' My health is better now, so a lot of my paintings are about that conflict of not having been cured but trying to move forward. Since we're not dropping like flies anymore, people don't want to hear about AIDS. But we keep reminding them that we're human beings going through this. For us, AIDS is not just an idea. I've always known that I wanted to be an artist. When I was 4 years old, I marched up to my father and said, 'Daddy I'm gonna be a famous artist someday.' I'm still trying."

Keith Carter
Clinical trials administrator, 36; diagnosed '87

"I never thought I would work for a drug company. My father was in the business at Johnson & Johnson, and I figured I would do something different. I started out at Bristol-Myers Squibb as a temp in the copy department, with no ambition, but then I got promoted. It's good to be active and working. For a long time it was OK just to exist, but now I want more. Sometimes having HIV and working for a pharmaceutical puts me in an awkward position. I've thought about quitting, but I can't afford to lose my health insurance. And more important, I help the people in this office by teaching them what my life as a black, openly gay man with HIV is like. After I was in a clinical trial and had problems with hydroxyurea, I helped develop a strategy for treating people who failed with the trial regimen. In my job now, I mostly do marketing studies and work as a liaison with the AIDS Clinical Trial Group, making sure they get the drugs needed for trials. If it was only about the money, I don't think I could do it. I get to work with people who are helping to extend and enhance life—including mine. If I have to go to an appointment or need a doctor here on a conference call with my doctor, that's OK. I don't have to take personal time, even for my work on the board of a Philadelphia ASO. My company would rather see me healthy. Then there are times when it gets so stressful that I just go into my boss' office and cry, and that's OK, too."

Cesar Carrasco
Psychotherapist, 45; diagnosed '86

"I was coordinator for HIV patient education at Montefiore Hospital when I went back to school for my master's of social work. Around the time I finished my degree, I started being in pain, and I stopped working. Then, in 1996, I lost my long-term disability because they said my HIV status was 'not threatening.' Now I work with London Terrace Psychotherapy Services and run a private practice out of my home. I work 25 hours a week, and with the problems I have with my HIV, I don't feel like I could go to a full-time job. I see a lot of different clients with different issues—men and women, gay and heterosexual, couples. I tell some clients about my status, especially those who are HIV positive. Some already know who I am. It's not like I'm famous, but I was in ACT UP and on television and all that. I went on disability when I had problems with my meds, but I dreaded that image of a pathetic retired person, at home all day watching television. In Santiago, Chile, where I grew up, people work their asses off. I was raised to never depend on the government. I wasn't humiliated, exactly, but it was just so…undesirable. If I'd had nothing to do, I would have killed myself. I'm not being dramatic—it would have been intolerable to feel so useless. There are still days that I feel rotten. I wonder, will my life ever be back to normal? I don't know."

Janis Thomas
Substance Abuse Counselor, 50; diagnosed '96

“I work at the Samaritan Village Facility in the Bronx, but I live in Brooklyn. The drive takes 40 minutes. I blast soul and R&B the whole way up. In the office we listen to the oldies station. My coworkers are very supportive; HIV in the substance-abuse field is not rare. As far as clients go, I don’t disclose unless I need to. You know, to get through to somebody. Before I took this job, I was using drugs. I used for 35 years. I see myself now in the clients, especially the women—remembering that time helps me stay clean. The best advice I can give to people who want to stop using is to stop for themselves. Not for a husband or child—it doesn’t work then. Somewhere in that darkness there is a will to live and you just need to find it. I work with a lot of clients who are mandated and not really here because they want to be. But when they find their motivation, you see a glow. I think, ‘My God, he’s got it.’ It’s like a flower that blooms. Me? I’m blooming until I die. I’m a work of art—that’s when the piece is finished.”

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