Don’t Mess With These Girls

Many transgendereds face the double whammy of HIV and a hostile health-care system. But watch out docs--they’re finally fighting back.

August 1, 2004 By Rebecca Minnich

It’s hard to imagine anyone pushing around HIVer Chloe Dzubilo. A tall, striking 43-year-old male-to-female (MTF) transgendered (TG) with a long, elegant face and nut-brown eyes set against pale skin and platinum hair, she rivets a listener with her unwavering stare. Pearly pink lipstick and black mascara complete the ultraglam persona of this downtown New Yorker who rubs shoulders with avant-garde artists and high-profile celebs. Ask how long she has identified as a woman and she brushes you off, preferring to remain outside what she calls “the binary gender construct” of male/female. Like many TGs, she identifies simply as “trans.”

On this balmy April day in the East Village, she’s not here to drop boldfaced names but to share her all-too-firsthand experience of the ignorance and discrimination she says the medical establishment reserves for TGs—especially HIV positive TGs, since an HIV diagnosis will often compel them to seek care they might otherwise avoid.

In the summer of 2003, Dzubilo suffered increasing hip pain. Diagnosed with HIV in 1987, she had saved an April 2002 *POZ* article (“Hip to the Future”) that explained avascular necrosis (AVN), which afflicts a growing number of HIVers on HAART. The condition cuts off blood flow to the bone, causing joint breakdown and often requiring a new hip. She brought the article to her main doctor at nearby St. Vincent’s hospital, which has long treated HIVers. He found her X-rays inconclusive—and then, Dzubilo claims, never called back with a referral, though “I nagged him for three weeks.”

Fed up, she made her own appointment uptown at St. Luke’s-Roosevelt Hospital with a surgeon who had done several AVN-related hip replacements on HIVers. “He seemed to know what he was doing and was open to discussing surgery,” says Dzubilo. On her second visit, she believes, he detected her TG status, though he never said anything directly. “You can tell when doctors figure it out,” she says. “I’ve seen it over and over. The voice and the look in their eyes changes. They become evasive.” (Asked why she didn’t disclose her TG status up-front, she says with a shrug, “My insurance says female—and what does being trans have to do with needing a new hip?”) After that visit, she says, her calls weren’t returned. “When you’re trans and trying to access health care, you may as well be in the Twilight Zone,” she recounts. “I was falling through the cracks.”

The surgery was finally scheduled. But during the three-month wait, she says, she faced more

humiliation at St. Vincent's, where she'd been referred for pain management. Dzubilo says the neurologist there "yelled at me: 'You screw up your body with all these hormones and then you want me to figure it out?'" (She adds that when she offered to hook him up with TG sensitivity training, he laughed.) Meanwhile, Dzubilo claims, a St. Vincent's nurse "made a comment about my breasts having large nipples" while she was hospitalized for pain and depression. And a psychiatric intern asked about her menstrual cycle: "I told him I'm trans, that I don't have one. *Helloo?* He said, 'You're *what?*' and asked me again. He totally didn't get it. I threw him out of the room."

In the end, Dzubilo got her surgery. But she believes that if she hadn't fought for it until the last minute, she wouldn't be able to walk. An avid equestrian, Dzubilo is savvy and tenacious enough to have launched Equi-Aids, a charity that puts inner-city kids on horseback. So imagine: If she braved this medical ordeal in New York City, what must less plucky HIV positive TGs endure in less trans-friendly locales?

Transgendered status and HIV are deeply, sometimes lethally, linked. In April 1999, *POZ*'s first major story on HIV positive transgendereds ("Love Me Gender") reported HIV rates among African-American MTF trannies in San Francisco at 63 percent, compared to 31 percent for the city's gay men and 12 percent for its injection-drug users.

Today, national stats are elusive. "One problem is [that] the Centers for Disease Control lumps MTF trans in with HIV prevalence data for MSMs [men who have sex with men]," says Kelly McGowan, a New York City consultant for programs serving populations at risk for HIV. "It's not only inaccurate—it's insulting." Still, Jessica Xavier, an MTF and board member of the national group Gender Education and Advocacy, says she has collected data putting HIV rates among MTFs at 20 percent in New York, Chicago and Los Angeles and more than 30 percent in San Francisco and DC. (As for female-to-male [FTM] trans, one 2001 San Francisco study showed HIV rates of 2 percent.) Since so many TGs—outcast from families, jobs, housing and medical care—veer into sex work, homelessness and drug use, says Xavier, it's no surprise that their HIV rates in large U.S. cities meet or exceed those of sub-Saharan Africa.

What's more, HIV positive TGs often face appalling mistreatment from the medical community, including providers otherwise experienced with HIVers. "Chloe's story is not unusual at all," says FTM trans Dean Spade, an attorney who heads New York City's TG-serving Sylvia Rivera Law Project, which he says has a growing list of clients pressing health-care–discrimination charges. "Trans are turned away daily from treatment in this country," he says, and are often "just outright ignored while waiting in the ER." If TGs do get seen, he adds, "providers think it's their right to ask invasive questions"—say, about an MTF's enhanced breasts when she's being seen for a broken wrist. Many trans have a different gender on their Medicaid card than the gender they present. "The nurse calls for Richard Smith, a woman gets up, then it's all snickers and nasty remarks," says FTM trans Samuel Lurie, who founded the Vermont-based Transgender Training and Advocacy.

Consider Josephine, a New York City trans HIVer who withheld her last name. "I was raped four

years ago," she says. Police took her to a Harlem hospital, where, she remembers, a laughing doctor asked, 'Are you sure you weren't prostituting?'" Or take San Francisco trans HIVer Cecilia Chung, whom two men assaulted and stabbed in 1995. "The police and ambulance came, and the cops arrested the guys," she recalls. "I begged the EMT workers not to reveal my gender identity, but they told the cops, who told my attackers." She was terrified that if the assailants ever caught up with her, she would meet the same fate as FTM Brandon Teena, whose 1993 murder at the hands of men enraged by his gender "deception" was dramatized in the film *Boys Don't Cry.*

Then, says Moshay Moses, transgender advocate with New York City's Positive Health Project (PHP), there's the trans who walked out of a hospital after hearing "one staff member ask another, "What is it, a man or a woman?" Such humiliation keeps trans HIVers from seeking health care until they're in dire straits. "I had a client in bed for a week with PCP who nearly died before she let a friend call an ambulance," says Moses' colleague Michele Sosa. And many TGs are all too familiar with the name Tyra Hunter, who died after a car accident in Washington, DC, in 1995 when firefighters at the scene stopped giving her emergency care after noting she had male genitalia.

But making it past the prejudice of medical gatekeepers doesn't necessarily mean the hard part is over. In 1979, the Harry Benjamin International Gender Dysphoria Association (HBIGDA) developed standards of care for TGs, including hormone treatment and gender-reassignment procedures, which it updates regularly. But HBIGDA is controversial among TGs for supporting the term "gender-identity disorder," listed in the DSM IV book of psychiatric disorders. Sadly, such a diagnosis may be the only way to get health plans or Medicaid to pay for hormone treatments procured in a safe medical setting rather than off the street, where they can be pricey, tainted or of poor quality.

In fact, perhaps the stickiest medical issues for trans HIVers involve hormone therapy, the primary medical intervention for "transitioning" from one gender identity to another. Gender-reassignment surgery—on the genitals, breasts or other body parts, such as the face, to create the look and feel of the opposite sex—is costly, usually not covered by insurance or Medicaid and hence a rarity.

MTFs take estrogen to grow breasts, lose body and facial hair, transfer fat from the gut to the hips and soften skin; FTMs take testosterone to increase body hair, deepen their voices and develop more muscle mass. But both hormone therapy and HIV meds can mess with the liver, heart and blood, so trans HIVers on HAART and hormones face potential interactions that need expert monitoring. "Trans patients on estrogen and HAART, especially protease inhibitors, should be getting liver-enzyme profiles, prolactyn and lipid profiles," says San Francisco's Lori Kholer, MD, who has treated hundreds of trans HIVers, often in prison.

Yet only a handful of docs are skilled in treating positive TGs. "My comfort level administering hormones isn't quite where I want it," says Houston's Shannon Schrader, MD, whose HIV practice includes a few TGs. "I can't guarantee I fully understand the dosages or how to prescribe for the best outcomes." HBIGDA's hormone guidelines still don't address interactions with HIV meds. And the HIV-care establishment has only just begun to embrace trans care: Last year, the American

Academy of HIV Medicine included in its self-study guide a TG chapter. It's a whopping two pages.

You'd think the dearth of guidelines would inspire HIV-treating doctors to work closely with trans patients. "HIV doctors have an incredible role to play," says Lurie. "Providing both hormone therapy and HAART is an incentive for HIV positive TGs to get regular health care." But treating trans HIVers can also be daunting, according to Eric Bates, MD, who sees many of them at Housing Works' health-care center in New York City. Facing reduced Medicaid funding for hormone therapy, he says, he spends "hours on the phone—on hold, mostly," fighting rejected claims so that patients, often homeless sex workers, won't have to pay out of pocket.

Indeed, Dzubilo thinks trans needs are so complex that they could scare away even the most dedicated caregivers. Because she may pursue legal action against hers, Dzubilo wouldn't allow *POZ* to name them, nor would she sign releases allowing them to discuss her case with *POZ*. Yet she insists that her primary doc, well-known in New York's HIV-care circles, "left me to fend for myself" by failing to refer her to a specialist. Unable to comment directly on Dzubilo's case, that doctor dismisses the suggestion that he may be trans-phobic: "While I haven't had any specific transgender medical or sensitivity training, I've read many books." What of Dzubilo's claims that other St. Vincent's staffers made inappropriate comments? "We would certainly reprimand any employee that made [such] remarks," says Matthew Baney, administrative director of the hospital's HIV-care department. He says that the hospital's annual cultural sensitivity trainings included a trans component that wasn't mandatory but "encouraged."

The St. Vincent's neurosurgeon that Dzubilo claims said she had "screwed up" her body tells *POZ* he can't recall her visit. But he adds: "I would never have said anything like that about the hormones. I see several transgender patients, and my concern is always with the person, not their gender." But he acknowledges, "Sure—it can be awkward."

To Dzubilo, if doctors will admit that awkwardness *on* the record, she can only imagine what they say about TGs among themselves. Not to mention what they privately think and feel the moment they realize a new patient is TG. That's why, she contends, "trans have a history of dying at home—because of the stigma."

In the 1980s, fed up with being left to die on gurneys, PWAs banded together to demand—and ultimately win—health-care rights. "One big reason you don't hear about transgendereds" doing the same, says PHP's Sosa, "is that so many are just fighting to survive. They have enough on their plates without one more struggle."

But transgendereds are starting to join lesbians and gays on the equal-rights radar. In 2002, New York City became one of more than 40 towns, counties, cities and states to extend human-rights protections to transgendereds, whom a *New York Times* op-ed called "some of society's most vulnerable citizens." Meanwhile, HIV positive TGs are fighting back—and teaching caregivers how to serve their population. Take Chung, whose EMT workers exposed her gender identity to her attackers. The incident so infuriated her that "I got more involved in my Asian-Pacific Islander HIV support group," she says. "I learned how to do simple things to defend myself in medical

situations, like look doctors and nurses in the eye and tell them calmly but firmly to call me by my female name. I learned that the only person who can speak up for me is me." She has since been appointed to San Francisco's HIV Health Services Planning Council, where she advocates for trans HIVers.

She's not the only trans HIVer who's taking charge. "I'm out and proud as a trans," says New York City's Sunny Shiroma, 47, diagnosed with HIV in 1990. "I always tell [caregivers] up-front that I'm trans," she says, and she encourages the TGs she counsels at the Asian-Pacific Islander Coalition on HIVAIDS to do the same. "Honesty always works."

So believes New York TG Arlene Hoffman, 37, a Housing Works social worker diagnosed with HIV in 1988. "At first my doctor wasn't sure whether he should give me hormones along with my HIV meds, and I told him, 'I've been on them all my life, and I'm not going to stop now just because I'm positive,'" she says. "So he put me on a hormone patch, which delivers a continuous dose that's smaller than injections. I feel like I'm getting what I need without burning out my liver and kidneys."

Not all TGs are as empowered, but a growing network of advocacy groups can help them speak up (see "TransHelp"). "We will accompany clients to the doctor if they're being mistreated," says PHP's Moses. "Getting an advocate on your side can help you make sure you're not isolated." Trans HIVer Earline Budd's Transgender Health Empowerment group, in DC, seeks out TGs on the streets where they live and work. "We hold a lot of events like lasagna dinners where we discuss safer sex and how to get your rights respected," says Budd.

As for Dzubilo, now that she has fought for her own rights, she's stepping up for other girls like her. Last year, she was appointed to New York City's HIV Planning Council, where she's pushing to change how the city collects its HIV data among TGs. "Once they know how many of us are infected, we can get some programs that work," she says, adding that since P*POZ* spoke to her primary-care doc, "he's much more willing to be open," even telling her of a new book he had just read on TG medical care.

It's all about education, insists Hoffman. "People really have to understand who we are," she says, in order for the ignorance and discrimination to stop. "They think they have the right to treat us that way," she adds, a trace of rage in her otherwise carefully modulated social worker's voice. "But they don't."

TransHelp

Resources for TG HIVers…and their docs

GLBT Health Access Project
130 Boylston St.
Boston, MA 02116
617.988.2605 x201
www.glbthealth.org

International Foundation for Gender Education [IFGE]
P.O. Box 540229
Waltham, MA 02454
781.899.2212
www.ifge.org

The Sylvia Rivera Law Project
322 Eighth Ave., 3rd Fl.
New York, NY 10001
212.337.8550
www.srlp.org

Transgender Awareness Training and Advocacy
802.453.5370
www.tgtrain.org

also:
www.gender.org
www.hbigda.org

TransAction

Hey, trans HIVers! To get the care you deserve…

BLOW THE WHISTLE If you've been verbally abused, denied care or ignored in a health-care setting, report it to a TG advocate in your city.

JOIN FORCES Try to find—or start!—a trans HIV support group to share tips, friendship and strength.

ASK FOR BACK UP Get a loved one, friend or professional advocate to accompany you on doctor's visits.

SPEAK UP! Tell medical staff how you want to be addressed and treated.

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