POZ

Growing Pains

Having grown up in a culture where HIV is misperceived as manageable and no big deal, four HIV-positive youth reflect on the events that led to their infection—and share their strategies for a bold new generation of activism.

January 1, 2008 By Jessie Torrisi

This past November, Guido Sanchez got a scary phone call—from the hospital. This was in Jersey City, New Jersey (just across the river from Manhattan), where Sanchez is the executive director of Hudson Pride Connections, which serves the local lesbian, gay, bisexual and transgender community (LGBT). “The hospital called to say that they were starting to see young men who have sex with men [MSM] come in for HIV tests—but never return for their results,” says the 26-year-old Sanchez, who is HIV negative.

One young man, tested anonymously, was found to have four CD4 cells; his delay in getting tested caused him to miss out on lifesaving treatment. It also meant he had possibly exposed others to the virus between the time he contracted it and the time he discovered his status. The hospital said the scenario—especially the denial factor—was all too common lately, reminding some of the staff of the epidemic’s earliest days. What, they wondered, could Sanchez do to help?

They called the right man for the job. Sanchez, who is gay and Cuban American, stands strong in the battle against America’s growing youth AIDS crisis. Since taking the helm at Hudson Pride in 2006, he’s overseen the purchase of its office building, which community members helped paint and decorate. It now offers innovative support groups and walk-in services to young people with transmission and treatment concerns. “There’s something about the community [feeling that they] own this building,” Sanchez says. “It’s [about] creating a safe space. As soon as we had a space where people can come ask questions and go to support groups, I see so many more people coming through the door. To all the LGBT people, all the HIV-positive people, this is our house. This is our home.”

They need it. The United States Centers for Disease Control and Prevention (CDC) reports that half of all new American HIV infections occur among people under the age of 25. Among gay youth and young people of color, the numbers are particularly devastating. AIDS is the leading killer of black women ages 25 to 34. And in some metropolitan areas, such as Sanchez’s, half of all young gay African-American men are HIV positive. As many as 75 percent of those men may not know their status.

The causes are many: a feeling of youthful invincibility, which can lead to IV-drug use and unprotected sex; the growing national misperception that AIDS is “manageable” and not to be feared; young women’s feelings of helplessness in confronting partners who won’t use condoms, especially in the African-American community; shifting federal funding priorities; and the national sexual-education quagmire, which ranges from the Feds’ ineffective abstinence-only crusade to an even more common school curriculum: no sex ed whatsoever.

What’s more, AIDS educators have reported that some young gay communities are disconnected from the previous generation’s vigorous AIDS activism and awareness. Any rift between older, often more HIV-savvy gay men and their younger counterparts, who didn’t live through the AIDS horrors of the early ’80s, can measurably affect prevention efforts.

Many young gay men feel no obligation to shoulder what they often consider a depressing legacy that no longer applies to them. Older men, in turn, can resent what they consider a disrespectful nonchalance toward those who have come—and died—before. The divide hampers any sharing of cross-generational experiences and awareness. And in a circular irony, gay young men who do become infected today face intense stigma from HIV-negative young men in their own community. Their negative counterparts often feel that with all of the information about AIDS now available, newly infected young people should have “known better.”

“We no longer feel connected to the fact that this disease is and was responsible for wiping out a whole community of men,” Sanchez says. “How many tens of thousands of writers, of teachers, or creators, of artists, of visionaries did we lose? And it’s still happening….One of the concerns I see is that [within] the LGBT community, our people are not taking responsibility.”

But Sanchez says that the youth AIDS explosion is a symptom of a larger inequity that affects all communities, regardless of race, gender or sexual orientation. “AIDS really pulls back the curtain and shows us so much racism, sexism and classism [in our society]. That’s why a young woman of color, for instance, feels no one is saying this is a disease that affects women.”

The support, prevention and awareness groups Sanchez oversees at Hudson Pride Connections recognize racial and sexual specifics—but aim to bring communities together. He says that “we need to stop trying to target” which particular segment of the population is most affected. “Just because it’s moving into one community doesn’t mean it’s leaving another.” Sanchez cites the recent skirmish over the Ryan White Reauthorization Act, which he believes pits regions of the country against each other in a fight for scarce federal funding. And he’s been frustrated that sometimes the most effective way to get grants is to promise to reach some new niche within the community while ignoring the bigger picture. The answer, Sanchez says, is to have more poster children embody the face of HIV. And to look more critically at some of the faces on HIV med advertisements. “[In] the last 10 years, people have been talking about medication advertisements and what it does to the minds of young people,” Sanchez says. “Seeing people out there living and being healthy—that’s a good message but it does have repercussions.”

Sanchez takes issue with anyone who says it’s solely a matter of young people thinking HIV is not that serious anymore. “I think it’s tied more to the root cause of how we approach the disease.” The challenge: How do educators communicate the dangers of HIV without stigmatizing those who already have it—and without scaring youth into a counterproductive mentality of avoidance and denial?

“As anyone working in this field can tell you, the work never ends,” Sanchez says. “I’ve had moments, I’ve had weeks, where I’ve been fried to a crisp. I’m thankful that I’m young; I probably would be at the end of my rope if I didn’t have so much energy.” Fortunately, Sanchez has support of his own. In its national survey of HIV-positive youth, *POZ* found many who have turned their personal experiences into an activist spark. Here, we introduce three. They hail from the West, the Midwest and the Northeast; they span America’s racial, cultural and sexual identities and communities. Their diverse stories of how they got HIV—and how they help others live with and prevent it—offer a representative group portrait of a growing youth movement.

They live the ideal of one of Sanchez’s mentors—who, he says, “hates it when people say that young people are the future, because young people need to understand that they are the now.”

Cherrell Edwards

“I think I was 19 when I was infected,” says Cherrell Edwards, a 23-year-old African-American woman from Portland, Oregon. “I was 20 when I was finally diagnosed.” Her story touches on many of the issues that young women, especially young women of color, face in preventing or living with HIV: trusting their male partners and a gender power imbalance in demanding that they use condoms. When Edwards was infected, she was in what she thought was a monogamous relationship. “[My boyfriend and I] used condoms most of the time but not all of the time,” she says. “About 2 ½ years into the relationship, I was hospitalized for gonorrhea.”

Other telltale symptoms arrived, but she had no idea they could be related to HIV. She started getting head-splitting migraines—which twice sent her straight from her hospital job to the emergency room. “I had temperatures of 102, 103, 104 degrees. I was in constant pain and didn’t know why.”

Doctors thought she had pelvic inflammatory disease or hepatitis. She got tested for HIV. The results came back negative. Then she developed constant diarrhea. She was diagnosed with colitis and developed ulcers in her colon and rectum.

Furious that she had contracted an STD—and still unaware that she had HIV—she told her boyfriend, “You go back to where you came from. It’s because of you [I have gonorrhea]. It’s because of you I haven’t been able to continue with my life.” She adds today, “He lied to me and there was the opportunity to be honest, to communicate openly.”

Still baffled by her condition, she started looking up symptoms on the Internet. She asked for another HIV test. While awaiting the results, she and a new boyfriend went away for a romantic weekend. They were on their way home when her doctor rang her cell phone. He needed to see her immediately.

Edwards took her diagnosis stoically. “I felt, ‘Thank God. At least now I know what’s wrong with me so I can begin coping with it.’ ”

Coping is something Edwards has been doing all her life. She grew up with a mother who was a drug addict. “I knew my mom shot dope every day, so HIV was real to me.” She worried about her mother using contaminated needles. Her mother passed away from hepatitis C and cirrhosis of the liver when Edwards was 15. But still, HIV remained on the periphery of her life, among people she knew and cared for. “After my mom passed, I didn’t expect to be battling it this way in my own life,” she says. “I take life as a lesson. HIV was just another thing to strap on my back and keep pushing.”

So she started pushing back. Edwards told her father the day she found out. She told the new guy she was dating, too. “I saw that there was a great need for awareness and education.”

She realized the movement was desperate for portraits of young women with the disease. Soon, she was appearing on the *Oprah Winfrey Show* and *Montel* and was featured in an MTV documentary titled *Think HIV: This Is Me*.

“Historically, there hasn’t been research done on African-African women,” Edwards says. “There hasn’t even been [much] research on women. [HIV] hasn’t even been around long enough to study the long-term effects. So I do try to educate myself. It wasn’t long before I started speaking publicly.”

Today, Edwards speaks all over Oregon and visits other states, too. She has also just taken part in a national stigma-fighting campaign called “HIV Stops With Me,” sponsored by Gay Men’s Health Crisis. Her face is plastered on bus-stop booths throughout New York City.

But she acknowledges there’s a lot more to the fight than TV appearances and posters. “Our funding needs to be reevaluated,” Edwards says. “It’s based on stigmatizing factors,” she adds. Too often, she says, the prevention messaging suggests that all young women with AIDS are, say, heroin users or sex workers. “[Those messages] feed into the idea that everyone else is safe.” Edwards thinks the movement needs to go further to give all people—including women, African Americans, heterosexual people—an accurate assessment of their risk factors.

Her viral load was 110,000 when she was diagnosed, nearly four years ago. Now it’s 40,000. Edwards remembers going to clinics as a teenager and being told since she was in a monogamous relationship she wasn’t really at risk. She says society will not be able to stop new infections until it embraces new tactics.

“There has to be a broad approach,” she says, one designed by young people. “The disease may not be the No. 1 factor in their lives—kids under 18. And 80 percent are sexually active,” she says.

“So there’s a lot to deal with: men and women being powerless in sexual relationships, limited access to health care.”

She partners with faith-based organizations and local business leaders to try to mobilize her home community from as many directions as possible. “Kids are getting their information from their friends and what they see on TV. There’s this stigma that no one is breaking down.” It’s not uncommon, Edwards adds, for a young woman to go to a clinic asking about an abortion and only then ask for information on sex or get tested for sexually transmitted diseases.

Edwards says that when she was small, God was all she had to turn to. She says she has used her faith to get through lean and lonely times. So she doesn’t understand how others use Christianity as a justification to silence AIDS educators from trying to teach others how to prevent infections. “Ungodly to talk about sex?” Edwards asks. “I would laugh at anyone who says that to my face. The only person who can be held accountable is the person who prevents information from getting out there. It’s giving people options.”

Ionel and Loredana Belfiore

Ionel Belfiore, 19, and his adopted sister Loredana Belfiore, 18, were infected with HIV as infants in Romania. At the age of 3, they were adopted—along with three other HIV-positive Romanian children, all unrelated by birth—by an American couple from Princeton, New Jersey. The affluent Ivy League college town is worlds away from Guido Sanchez’s Jersey City.

Ionel and Loredana have been sharing their story since they were very young, speaking publicly and serving as thriving examples of how treatment advances have revolutionized the lives of those infected as infants or perinatally (in the womb). They and their siblings also advocate for lessening the stigma that can surround adopting positive kids.

“My first speech was when I was 10 years old,” says Ionel, a freshman at Catholic University in Washington, DC, where he’s studying politics. “It was in Chicago. I spoke to a couple hundred people on my life and HIV. Naturally, I was nervous. But it wasn’t the scariest one, not by a long shot,” he said. That was speaking to his high school. “It was kind of quiet after I gave the speech,” he recalls. “Uneasy.” The next day, spring vacation began. “I spent quite a bit of time wondering how people would see me when I got back.” But when classes resumed, he found that his classmates treated him no differently.

Loredana recently spoke to her high school, where she’s a senior. “I got in front of the whole school. My [family] nurse came and she helped me do the speech. After, everyone was very accepting and gave me hugs.”

Back in Romania, the hugs were few. In the ’80s, when Ionel and Loredana were infants there, public health officials reused needles to vaccinate against childhood illnesses, prompting an HIV outbreak. “At the time, Romania was very poor,” Ionel says. “Ceausescu had just come to power. Things were kind of in a state of chaos. They reused needles because they didn’t have money.

Shortly after the government realized there was an outbreak, they came to my door to take me to get tested. When I came up positive, they took me away from my family and put me in an orphanage."

It was there that Ionel and Loredana met their adoptive mother, Susan, and their soon-to-be siblings. A volunteer at the orphanage, Susan had no children of her own; soon, she was determined to have five. At the time, Loredana weighed only 8 pounds. She was so weak she couldn't get out of her crib by herself.

Bringing HIV-positive children into the United States wasn't easy. One lawyer told Susan she'd never win in court, but he suggested she write the judge a personal letter. "A lot of people wouldn't understand," she wrote, why someone would want to adopt children with HIV. She added that she found their presence in her life "a gift from God." The adoptions went through.

Ionel and Loredana shock people when they tell them that in many ways, they are thankful for getting HIV. "I have a great life, possibly a better one than I would've had [if I hadn't had HIV and been adopted]," he says. "I've always looked at HIV as one of my blessings."

There have been hurtful moments, though. Another Belfiore sibling, Ramona, now 20, once offered a classmate a pencil, and he refused to touch it because he didn't want to get HIV. But Ionel and Loredana's parents have taught them not to take incidents personally, and to fight back with facts. "Obviously, you have to try to stay open and educate people," Ionel said.

Loredana says her mother also helped them feel comfortable fielding the questions most people ask. "Sometimes, people ask if I'm gonna die," Loredana says. Last year, she spoke at an event in California organized by the Elizabeth Glaser Pediatric AIDS Foundation. Last December, Ionel traveled to Toronto for the 16th International AIDS Conference, where he spoke before 100 journalists, including one who had traveled all the way from his hometown in Romania.

A politician in the making, he loves giving speeches (see "Pass the Mike"). Awareness, he says, is the key to stopping HIV. "A lot of people are afraid to say the word *HIV*. This only makes it easier for the virus to spread."

Tyler TerMeer

Tyler TerMeer, 24, is a gay man living with HIV. He always thought he'd land a theater job when he finally left small-town Ohio. But his life unfolded on a different stage after his diagnosis, at 21, in 2004. Today, he works at the Ohio AIDS Coalition, where he tries to help other young people break through the walls he faced growing up.

"I grew up in Dublin, Ohio," says TerMeer. "Dublin is famous for being the headquarters of Wendy's." When TerMeer, whose father is Caucasian and mother is African American, was 19, he had finally come out as gay to his mother and found his niche at college. His first love, he says, cheated on him.

“It really crushed me ’cause it was the first time I had a relationship where I was myself,” TerMeer says. “I swore off men. I swore off dating.” Two weeks later, his ex phoned. “He was calling to tell me he had just found out he had gonorrhea.” TerMeer went to the doctor and said, “Test me for everything under the sun.”

He tested negative. “I really thought I’d dodged a bullet. I started dating someone else.” A few months later, his ex called again. “He said, ‘Listen, you should know that I just tested HIV positive.’”

TerMeer’s mind raced through all the reasons he couldn’t have the virus. “I grew up in a nice community. I have this supportive family. I always use condoms,” he told himself. “And then I remembered one night the condom broke and we made the decision to keep going.”

He called his new boyfriend. “That was the hardest because here’s someone I could’ve infected,” he said. At first, they broke up. Neither knew how to handle HIV. “Then we realized we had a lot to learn,” TerMeer recalls. They’ve been together for four years and recently got engaged. “It definitely has its ups and downs. Our life has never been the same since that day I was [diagnosed].”

TerMeer became obsessed with the idea of finding someone else with HIV, someone like him. “I went to AIDS support groups, anything I could try to think of to find someone who looked like me.”

TerMeer says that he knew they were out there; he’d seen the statistics. “I know people in New York and Los Angeles who are out and comfortable with it. But being HIV positive in Ohio is a whole different world.” His search eventually took him from county to county in Ohio trying to organize a Positive Leadership Summit. Finally, he found eight people—“eight people who were courageous enough and strong enough to walk through the door,” he said.

“There’s a huge generational gap that has developed in the epidemic,” TerMeer says. “It’s a direct result,” he says, “of the silence in communities.”

For TerMeer, developing leaders means preparing people to tell their story. “Sharing your story about HIV is sort of like a social vaccine,” he says. At the Leadership Summit, TerMeer got everyone to record their story into a tape recorder. For most of them, it was the first time they’d ever spoken the words of what happened to them aloud. TerMeer edited the piece into a powerful five-minute audio clip. The themes are simple, he says: “I want the world to know that I’m still me. I’m still a part of this world. I still date. [I’m] still here.”

TerMeer says that hearing one HIV-positive person’s story firsthand is worth a hundred health classes. He continues to recruit new leaders and organize retreats for young people with HIV. “We live in a time where young people are not afraid of HIV, not the way they should be,” he says. “How do you not make it about fear but still get people to take HIV seriously?”

“Each time I see a jaw drop, I realize the power of my voice. I see the start of a new activist era.

Our faces, our stories, are now becoming the new wave of activism.”

He pauses.

“I’m looked at by some in the older generation as someone who should’ve known better. My answer to them is ‘How?’ I grew up in a community that teaches abstinence only, that doesn’t talk about sex or being gay. So how was I supposed to know better?”