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Teen Voices of AIDS

As the Epidemic Continues, Some Young Victims Begin to Speak Up



"Too many young people are frightened to talk about their own HIV," says Adam Tenner, executive director of Metro TeenAIDS. Here, Lydia Robinson, a former Metro TeenAIDS peer educator, lights a candle at a vigil protesting cuts in funding for local groups serving adolescents. (Metro TeenAids)

By [Susan Levine](#)

Washington Post Staff Writer

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"The other swans laugh and call me names for I have HIV"--Travis

For nearly a quarter-century they have come to the first floor of Children's Hospital: teenagers infected through circumstances, always tragic, or through choices, admittedly bad ones. More than 30 new cases in 2007 alone, as the epidemic that is HIV and AIDS extended its reach through a second generation of adolescents.

Fears of ostracism have kept them largely silent elsewhere. As patients, however, they've been urged to talk. Not just about their pasts, but about living and dying and coping with the possibilities of both.

Encouragement was all they needed.

"Before I told anyone, I felt like I was in a box," one teen says. "I couldn't sleep. I was like, 'Who can I tell?' "

"I went to school and no one wanted to learn anything," a girl recounts. "It was, 'She's got AIDS, don't touch her.' "

"I believe that I am going to live a long life," another allows. "I believe I have a purpose, and the purpose is to help youth do something."

These are the voices that psychologist Maureen Lyon and physician Lawrence D'Angelo have woven into "Teenagers, HIV, and AIDS," perhaps the first text on the subject to place young people, in prose and even poetry, alongside the experts. It is a true collaboration, one that gets and gives plain-talk advice.

Most of all, says [Adam Tenner](#), executive director of the local advocacy group Metro TeenAIDS, it is a book that helps "bear witness."

"Too many young people are frightened to talk about their own HIV, or the HIV of their friends," Tenner says. "One of our biggest obstacles to healing our communities is getting rid of the stigma."

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Lyon and D'Angelo explained their rationale in the book's dedication, a tribute to the more than 400 HIV-positive patients for whom they and others on the Children's staff have cared.

"They have served as teachers to us all," the longtime clinicians wrote.

With new infections occurring with increasing frequency among 13- to 19-year-olds, thousands of adolescents across the country are receiving diagnoses every year. The shattering results must be followed by compassion and very tailored conversation, according to the book, for every aspect of HIV can be different in these cases, from the virus's progress in the body to the services available to a suffering teenager.

"Managing a life-threatening and socially stigmatized illness is emotionally difficult and challenging for adults," one of the contributing authors noted. "It is even more difficult for adolescents, who are more vulnerable and less prepared to deal with a health crisis of this magnitude, much less deal with it alone."

The book, available online and in stores, addresses the host of medical, treatment, disclosure and support issues. Beyond teens, it's aimed at health-care providers, who often don't listen well to adolescents; at school leaders, who in many systems still provide minimal education on sexually transmitted diseases; and, of course, at parents. Over the years, both Lyon and D'Angelo have comforted teens who've been kicked out of their homes after telling their families.

"Sometimes," Lyon said recently, remembering past heartaches, "HIV is not the biggest problem in their lives at the time we see them."

"These patients have defined for me what it means to be a good provider," D'Angelo said.

She has been at Children's since 1985, he since 1982. As Washington became an epicenter of the virus during that decade, their hospital became a major nexus for HIV and AIDS care. Its Burgess Clinic, founded by D'Angelo and named for an internist who was among the first local doctors to tend to infected youth, is where they are seen today. With around 160 cases, divided mainly between the District and [Maryland](#) suburbs, the clinic is one of the largest such programs nationally.

Each still thinks about early cases and draws on lessons learned in caring for them. For Lyon, there was the girl whose mother had been prostituting her on the streets. For D'Angelo, there was the boy who'd received a contaminated blood transfusion during surgery. They were insightful, courageous -- the boy until he died of AIDS and the girl even now. She is a rarity from those years, married and with three children of her own. None is infected.

The arc of the disease is reflected in Children's current patients. Three-fifths were born to infected mothers, a proportion that is waning because of the availability of medications to block any viral transmission during and after delivery. The remainder, both male and female, put themselves at risk through sexual behavior. And the makeup of that group is shifting: Girls have gotten smarter, and safer, whereas HIV among gay males is rising dramatically.

"There's a whole new cohort that has to be educated," Lyon acknowledged.

For Carl, a slim college sophomore from [Prince George's County](#), it's too late. He told his own story one evening last month for the same reason Lyon and D'Angelo published the others. He'd already read the book; the teens' comments were his favorite part. "Teens should know that HIV is real," he said, and he believes hearing from those who know firsthand is the best way, maybe the only way, the message can have real impact.

Like many adolescents who are positive, he never thought it would happen to him. Carl wasn't that knowledgeable about the virus, but he admits to knowing that his sexual hookups could be dangerous. He put off an HIV test for a couple of years. His ignorance kept him sane, kept his fears at bay. Then he got sick during his senior year of high school and no longer could avoid them. He was 17.

He was at Children's when the doctor gave him and his mother the news. It was Jan. 13, 2006 -- Friday the 13th, he said with a small laugh, "what a horrible day to find out." What made it worse: "My mom was just as ignorant on the subject as I was. So when we got home, it was a circus. . . . She made me eat off of paper plates,

eat from paper products." For several months, she ordered him to bleach the tub after he bathed. His clothes were washed separately from his brothers' and sisters'.

It took Carl more than a year to come to terms with his status: "I used to have pity parties for myself. You know, that was the hardest part. I would have a weekly pity party, where I would go and I would sob and it would be sob, play the blame game, feel sorry for myself."

Finally, he asked himself, " 'Am I gonna let HIV define who I am as a person?' And I said to myself, 'No, no, I'm not.' " He's been helped by generally good health and the support of a sibling and a few close friends. "I've really become one with who I am," Carl said. "I've embraced being HIV-positive."

His words linger. As do those of the young people speaking from the pages of the book. D'Angelo and Lyon quoted them anonymously to protect their privacy, though the poets among them -- former pediatric HIV patients at the [National Institutes of Health](#) -- have names attached.

One of the verses was written with singsong attitude nearly a dozen years ago. Lindsay is still alive today, still hopeful.

*Chimi, chimi cocoa puffs, chimi chimi rye
Chimi, chimi cocoa puffs, chimi chimi rye
Lindsay, Lindsay is sick in bed.
She called the doctor and the doctor said
I've got the HIV virus (ding dong)
I've got the HIV virus (stamp your feet)
I've got to take a lot of medicine (ding dong)
I've got to take a lot of pills (stamp your feet)
I've got to take a lot of nasty stuff (clap)
Let's get the rhythm of the virus
Let's get the rhythm of the virus.
Put it all together and what do you got
Pills, medicine, virus, infection
Ding dong, clap, stamp, high dong
HIV gone, stamp, HIV gone. ÿ*

Comments: levines@washpost.com.