

# NYUPHYSICIAN

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## Building Social Support for Teens with HIV

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In 1995, NYU PEDIATRICIAN Sulachni Chandwani, MD evaluated an emaciated seven-year-old girl who had arrived at Bellevue Hospital with an unusually severe case of chickenpox. "Her immune system was so ravaged, we decided to test for HIV," she says. The test led to a positive diagnosis for the girl, a younger sister, and their immigrant mother, who, until then, never knew that she had the virus and had passed it on to two of her three children at birth. That very ill little girl became a regular patient. Today, she works part-time and is herself the mother of a healthy, uninfected two-year-old.

The Bellevue clinic for children with HIV/AIDS began almost at the start of the epidemic in the early 1980s. "We actually saw our first patient in 1981," says William Borkowsky, MD, professor of pediatrics and director of infectious pediatric diseases. "By 1983, we started seeing a number of infants we thought were infected." Many of those babies—most of them poor black or Hispanic—died in the first few months of life from opportunistic respiratory infections. Of those who survived infancy, about half were dead by age two.

But with the advent of effective antiretroviral drug therapy in 1996, maternal testing and treatment have meant that babies are rarely infected at birth anymore, and those that are account for less than 1 percent of the 1 million or so Americans now living with HIV and AIDS. Older teens, who acquire the infection through sexual behavior, account for about 5 percent of the total, or 56,500, according to the Centers for Disease Control and Prevention. The most recent data from the New York City Department of Health and Mental Hygiene show that of

the 100,000 New Yorkers now living with HIV and AIDS, 591 are children and 1,584 are teens.

As effective drugs have turned HIV/AIDS from a fatal disease to a chronic illness, Bellevue's pediatric infectious disease patients are now reaching adolescence and young adulthood, with all the issues affecting that age group-and then some.

Many have watched a parent die. Some are in group homes or foster care. Even in stable homes, parents or caregivers are generally overprotective and want to hide their children's illness, "just because of the isolating nature of HIV, and that can be fraught with mental health issues," says researcher Susan Abramowitz, PhD, assistant professor in the Division of Pediatric Infectious Diseases and Immunology and co-director of NYU School of Medicine's Lower New York Consortium, a provider network in lower Manhattan and Staten Island that provides a continuum of care for people living with HIV and AIDS.

Dr. Abramowitz and her colleagues reported on the social isolation of HIV-infected teens in the May 2009 issue of *AIDS Patient Care and STDs*. As a result of this study, the two sets of HIV-infected teenagers--those infected at birth and those who acquired the disease later--have been brought together by clinic staff to help each other deal with issues like managing feelings, understanding their illness, taking care of themselves, and developing goals for the future.

"The younger kids like listening to the older kids, who are much more fluent

about sex-related issues. The older kids are more unsteady about their diagnosis, something the younger kids have been living with for a long time," Abramowitz says. Talking with peers confronted by the same issues appears to help make them more aware of their options with the goal of improved decision-making.

"One of the problems with teens who have chronic diseases is adherence to their medication," she says.

"Adolescents don't want to be reminded that they're sick." For older teens, their lives may be too chaotic to start or stay on regular treatment. That becomes a problem with HIV medications, which require strict adherence to avoid drug resistance. For those who have been taking medicine since childhood, there's a fatigue factor. There are side effects, too, including headaches, nausea, and cognitive impairment.

Teens infected later in life tend to have more friends who know their status, but this rarely translates into more emotional, psychological, or even practical support. They also tend to take a different stance toward their diagnoses. "When you ask them directly, 50 percent will identify other issues as more important than HIV, from losing a parent to witnessing someone shot on the street," says Bret Rudy, MD, associate professor and vice chair of the Department of Pediatrics, who works extensively with HIV-infected youth and conducts national clinical trials. He joined the Medical Center in early 2009. "There's a lot of loss, a lot of trauma."

"The challenge is how to address low adherence and risky sexual behavior, because both affect their health," observes Abramowitz. "Taking care of

adolescents is a challenge.

The real goal is to try to figure out how to help them stay healthy. Improving the social support available to infected youth may be one way to help."