

Many in Cohort Surviving HIV-Infected Heritage

BY ERIK GOLDMAN
Contributing Writer

OLD GREENWICH, CONN. — A small cohort of young people who were born infected with HIV is alive and well, and struggling to come to grips with an adulthood no one ever thought they'd live to reach.

"We first saw some of these kids when they were 4 or 5 years old, and it is so heartening to see them now as young adults. We never expected them to live this long," said Dr. Katlyne Lubin of the Albert Einstein College of Medicine's Rose F. Kennedy Center for Excellence in Developmental Disabilities, Bronx, N.Y. Since the early 1990s, the Kennedy Center has had a special program to help young children born with HIV, many of whom have significant HIV-related neurologic and developmental problems.

At a meeting of the Eastern Society for Pediatric Research, Dr. Lubin reported preliminary qualitative data gathered from the first-ever U.S. follow-up study of young adults born HIV positive. Her findings provide a window into the inspiring yet heartbreaking world of a unique generation.

"There was nobody like these kids before they were born, and because here in the United States we've been so successful in preventing maternal-fetal HIV transmission, there are hardly any others coming up behind them." Many of the survivors of the original Albert Einstein cohort are doing surprisingly well given the daunting difficulties posed by a chronic and life-threatening disease and cognitive impairment, all against a backdrop of inner city poverty.

Today, these young people face entirely new challenges as they enter an adulthood for which neither they nor the health care system are prepared.

Dr. Lubin's study is a follow-up to work originally begun by P. Papola, M. Alvarez, and H. J. Cohen at Einstein in 1994. The team assessed the neurocognitive status of 90 children, ranging in age from 5 to 14, who were born infected with HIV. All were residents of the Bronx, and nearly all were from poor African American or Hispanic/Caribbean communities (*Pediatrics* 1994;94:914-8).

The original study showed that 44% of these young people were below average in intelligence for their ages, and 56% were at borderline intelligence. Half had significant language impairments, and 74% re-

quired special education services.

As the youths have aged, nearly all of them have ceased coming to the Kennedy center, and have been essentially lost to follow-up.

"We began to wonder what had happened to all of these kids, so about 2 years ago we decided to try and do a follow-up study, and track down as many of them as we could. If you know anything about doing research in inner-city communities like we have in the Bronx, you'll know this was a Herculean task," Dr. Lubin said at the meeting, cosponsored by the Children's Hospital of Philadelphia.

Her team was able to find leads to 44 of the original 90 young people, who now range in age from 16 to 24 years, with a mean age of 19. Twenty of these were confirmed deceased, but the researchers were able to make contact with 24 of the former patients, some of whom they'd not seen in over a decade. "We sent them letters and called them asking if they would come in and fill out follow-up questionnaires."

Nine were living with adoptive families, and six were still living with a biologic parent, some of whom were HIV positive themselves. Three were living independently, and others were living with grandparents, siblings, or other relatives. Unfortunately, a significant number were in prison or detention centers.

The cognitive and neurologic problems present during their early childhoods have persisted to some degree into young adulthood. The mean total intelligence quotient in the group was 87, which is slightly lower than average (90-110). However, 17 of the young people were within the average range, and only 3 showed evidence of mild retardation. Fourteen still had language impairments, and 9 had learning disabilities.

Many of them were working very hard to overcome their disabilities. Nine of them were currently in school, four had already graduated from high school, two had obtained a general equivalency diploma, and two had actually graduated from college. "Given all the factors against them, these are major accomplishments," said Dr. Lubin.

Dr. Lubin attributed their survival in part to improvements in antiretroviral

therapy over the last decade. She noted that 14 of the 24 patients reported taking their anti-HIV drugs every day; 9 reported poor compliance. One patient reported taking the drugs on at least 5 of every 7 days. The investigators observed an age-related trend toward noncompliance; the patients who were over 21 tended to be less compliant than those under 21.

Compliance also seemed to correlate with education; the youths who dropped out of high school were less likely to take their medications consistently. But Dr. Lubin cautioned that the sample size was not large enough to determine if these are truly meaningful observations.

Some of the young people were very actively engaged in self-management; 8 knew their T-cell counts, and 10 knew their current viral loads. Those who were most compliant with their medication regimens were less likely to abuse alcohol or street drugs, and less likely to have run afoul of the law than those who were non-compliant.

Not surprisingly, given the age range of the subjects, use of alcohol and cannabis was common, with 18 reporting use of the former, and 13 reporting use of the latter. Only 4 of the 24 reported using "hard" drugs such as heroin or cocaine.

Although most were doing fairly well, seven had major problems with the law (arrests, detention or prison), and six had already done jail time.

For Dr. Lubin and her colleagues, as well as for the patients themselves, the reunions were extremely moving and often bittersweet.

"It was so amazing to see them as big kids. We knew them as little children and now here they were, fully grown. Many of them looked absolutely wonderful. They have a sense that they're doing well, and that they're going to be around for a while. But at the same time, it is very sad because their futures are very uncertain. And they're reaching an age where they are becoming sexually active and having relationships. And no matter how open-minded you are, HIV carries a huge stigma. They're struggling with the question of to whom they should disclose their status."

Eleven of the former patients reported disclosing their HIV status to close friends, but an equal number had not disclosed it

to anyone. Sixteen of the youths were sexually active, but only 7 reported that they always disclosed their serostatus to sexual partners. Another seven said they'd never disclosed to a sexual partner, and two said their willingness to disclose was variable. Ten of the 16 said they used condoms all the time, and 4 said they used them on most occasions. Two said they had never used condoms.

Some of the youths, particularly the older ones, expressed the desire to become parents themselves but they feared having an HIV-positive child. Dr. Lubin noted that two of the girls in the cohort had already had their first babies, both of whom were HIV negative.

These youths were also struggling with the larger question of what to do with their lives—adult lives no one expected them to have.

As a group, they have a lower educational level than the average, which limits their employment prospects. "A lot of them are really pretty lost. They're having difficulty transitioning to independence. They do not know how to deal with money or pay rent or anything like that. We've identified the need for programs that help them deal with basic life skills, and teach them how to deal with the various medical and social services for which they qualify."

Dr. Lubin acknowledged that this qualitative study had major limitations such as a small sample size, reliance on self-assessment, and selection bias. Naturally, it raises as many questions as it answers. Since these youths are no longer patients of the Einstein programs, the researchers were unable to do any medical testing. Dr. Lubin is hoping to be able to set up a study of their medical status in the near future.

Limitations aside, the study does represent the first comprehensive look at how people with congenital HIV infection are faring as they emerge into adulthood. What is clear is that these young people have unique medical, psychological, social and practical needs that are not currently being met by any existing agencies. She said that her team is actively trying to link this cohort with other, smaller groups of people born HIV positive, as well as with other HIV/AIDS service organizations.

The latter can be tricky, since these young people may not readily identify with other HIV-positive subgroups such as gay men, lesbians, IV drug users, or immigrants from countries where HIV is widely prevalent. "They really are a distinct and unique group," Dr. Lubin said. ■

Utah Flu Hospitalization Data From 2004 to 2005 Show Ethnic Disparities

ATLANTA — Blacks, Asians, and Hispanics were significantly more likely to be hospitalized for influenza during the 2004-2005 flu season in Utah, compared with non-Hispanic whites, Lisa Wyman reported in a poster presented at the International Conference on Emerging Infectious Diseases.

Overall, the hospitalization rate per 100,000 person-years was 22.2 cases among blacks, 22.6 cases among Asians/Pacific Islanders, and 19.0 cases among Hispanics, compared with 7.2 cases among non-Hispanic whites.

Children younger than 5 years had the highest hospi-

talization rates of any age group, and these rates were significantly higher among minority children, compared with non-Hispanic whites.

Ms. Wyman and her colleagues at the Utah Department of Health reviewed all cases of laboratory-confirmed cases of influenza reported in Utah during the 2004-2005 season. A total of 253 hospitalizations were reported, and complete race and ethnicity data were available for 209 cases. The type of influenza virus was determined for 224 hospitalized cases; 136 were associated with the influenza A virus, and 88 were associated with

the influenza B virus. Hispanics and Asians/Pacific Islanders were significantly more likely to have the influenza B virus (46% and 69%, respectively), compared with non-Hispanic whites. In addition, Hispanics aged 25 years and older were more likely to have the influenza B virus, compared with non-Hispanic whites.

Although the study was limited by relatively small numbers, a preliminary review of data from the 2005-2006 flu season showed similar trends with regard to ethnic disparities in hospitalization rates, the investigators noted.

—Heidi Splete