

WOMEN ON THE VERGE OF A MAJOR BREAKTHROUGH

At the city's first—and only—research and treatment center for women and children with AIDS, fundamental questions about the disease may at last be answered

"ALL FALL DOWN," THE CHILDREN SAY, giggling as they collapse on the waiting-room floor. Against a background of loud and constant chatter, a girl shows her dad how she ties her shoes, a grandmother shares cookies, and Joan Lunden babbles away on *Healthlink* on TV. At the other end of the room, women come and go through a swinging door. The children—mostly African American, with a few Hispanics and whites—are wild and cheerful; the harried nurses laugh along with them.

Nobody stumbling on this room would guess how sick some of these children are. But this is the Pediatrics Clinic of the Women and Infants Transmission Study (WITS) at the University of Illinois at Chicago Hospital. It's the city of Chicago's first and only research project, combined with a treatment and referral center, for women and children infected with the HIV virus, which is believed to cause AIDS.

In Chicago, AIDS is on the rise. The number of reported cases in men increased 39 percent last year. But the incidence among women almost doubled. And the number of cases involving children under the age of 13 rose more than 100 percent.

"We are calling this the third wave of the disease," says Tom Schafer, spokesman for the Illinois Department of Public Health. "AIDS began with homosexual/bisexual men; the next wave was the injecting drug users; and the third

wave is heterosexual contact, which infects women more than it does men." It's ten times easier for a man to infect a woman than vice versa. As a consequence, AIDS last year became the fifth-largest killer of reproductive-age women across the United States. In New York and New Jersey, the disease actually

en and 50 children with the HIV virus in Chicago. (WITS projects are also under way in New York, Boston, and San Juan, Puerto Rico.)

The program's primary purpose is to discover how the HIV virus is transmitted to fetuses, a process that remains mysterious. Why do only 15 to 30 percent



■ **Gerri Alexander** is project coordinator for the clinic, which has treated and studied more than 150 mothers and children.

of infants born to infected mothers become infected? When does the infection occur—in the womb? during birth? Are there ways to prevent transmission altogether? These are the sorts of questions WITS hopes to answer. "This project will be the largest study of perinatal AIDS in the world and certainly one

of the best controlled," says Dr. Kenneth Rich, the Chicago study's principal investigator and head of pediatric immunology and rheumatology at the University of Illinois at Chicago.

WITS also represents one of the few opportunities Chicago has had to lead—or at least remain on a par with—other major cities in the race to understand AIDS in

ranked number one.

But little research has been done anywhere in the country into how the disease affects women or their children, which makes WITS one of the more important (though little-publicized) AIDS studies under way. An \$8-million initiative funded by the National Institutes of Health, it has already involved more than 100 wom-

women and children. "Out of 47 AIDS clinical trial sites, Chicago was funded again to continue," says Bob Hultz of the not-for-profit Test Positive Aware Network. "Numerous other cities were not. A number of sites were cut back dramatically. The fact that Chicago was renewed is your best indication of optimism."

An African-American woman in her mid-20s sits in the waiting room and watches as her 15-month-old son runs from corner to corner, hiding behind desks, playing peek a boo with the staff. He's in constant motion. Both he and his mother are infected with the HIV virus.

"When I was pregnant with my daughter, three years ago, they asked me if I wanted to be tested," the woman says. "I said OK. I was sure I didn't have it. A week later, a telegram came, and it was urgent." She had tested positive.

Her daughter was born free of the virus, but when she became pregnant with her son a year later, the woman enrolled in WITS. Although any HIV-infected woman in the Chicago area between the ages of 15 and 44 is eligible to do the same, few do. "It's always difficult to find the women," says Gerri Alexander, the fiercely dedicated Chicago project coordinator for WITS. The main obstacle is obscurity: The study is not well known, so getting the word out to the health-care community is one of Alexander's top priorities. "We participate in community network organizations, send out pamphlets, speak at public gatherings, go to hospitals," says Alexander, who is a registered nurse.

At present, 100 women—about ten of whom are pregnant—and 53 children locally are enrolled in WITS. Most of the women were identified while in their pregnancies—which in itself is a major advance in AIDS research in Chicago. "In 1990, over 50 percent of women with AIDS were identified either at the time of their deaths or shortly before, precluding any possibility of altering the course of their illness," says Dr. Pat Garcia, high-risk obstetrician at both Northwestern University and WITS.

"It wasn't until the last half of 1991 [when heightened awareness of heterosexual transmission led more doctors in Chicago to implement routine testing for pregnant women] that we began to see that ten percent of the cases of AIDS in Chicago are women."

Treatment was another problem. Before 1989, when WITS began, the only clinic for HIV-infected women in the Chicago area was at Cook County Hospital. What WITS could offer that Cook County couldn't was care specifically tailored to pregnant women with HIV. They get medical exams and prenatal care, along with individualized support from social workers who are on call 24 hours a day. After they give birth, they see a doctor every six months, receiving \$20 per visit to cover expenses. Mothers' and children's appointments are scheduled for the same time. "Women have always been much better at attending to the health-care needs of their families, to the exclusion of themselves," says Dr. Garcia.

Christine, 35, a suburban white woman and former drug addict, concurs. "If I didn't have my baby, I probably would never get to the doctor. I go in there mainly to keep him healthy. And now my attitude is: I want to keep myself healthy, because I want to keep him healthy."

The research side of WITS proceeds unobtrusively; few of the women seem to care that they're part of a major clinical study. Nurses take samples of blood, urine, and placentas; monitor T-cell counts (a type of white blood cell that helps protect the body against infections); and note changes in body weight and condition. "Our goal," Alexander says, "is to prove that many of

RESULTS FROM THIS STUDY WILL PROFOUNDLY AFFECT WOMEN FAR BEYOND THE CONFINES OF THE UNIVERSITY OF ILLINOIS HOSPITAL, ONE DOCTOR SAYS.

the women who have been described as tough to keep in a research project actually can be reached, helped, and will stay if you organize it appropriately and give them the right kinds of services."

The WITS staff includes pediatricians, obstetricians, an infectious-disease specialist, a neurologist, a developmental psychologist, as well as phlebotomists, nurses, social workers, a nutritionist, data-management specialists, and support staff—in all, 25 full- and part-time members, plus volunteers. Together, they are gaining insight into some fundamental questions about women and AIDS, such as why women who know they're infected with HIV choose to be-

come pregnant or to give birth. "For women from [poverty-stricken] high-risk environments, 70- to 85-percent odds of a healthy baby don't sound bad," explains Joan Palmer, coordinator of social work.

Then there are the children, and WITS devotes considerable effort to studying their development. "We are already learning some things that are surprising," says Dr. Lucy Park, a WITS pediatrics immunologist at the University of Illinois at Chicago. "The incidence of transmission from mother to fetus is less than what we used to think, and the babies seem to stay well for a longer time than we previously thought." Which leads to some psychological issues: "AIDS is a disease, but this disease is now also a stressor in a kid's life," says Scott Azuma, of the National Association for Perinatal Addiction Research and Education, who is developmental psychologist for the WITS program. "So even if a kid doesn't develop [as] HIV positive, they're still living with someone who has a chronic, fatal, terrible disease. The effect of that alone on a kid is mind-boggling."

WITS hopes to present its findings on these and other issues in July at the Eighth International Conference on AIDS, to be held in Amsterdam. "Since this program involves such large numbers, clearly any information that comes out of this project will hold more statistical significance than projects that are following smaller numbers," says Alexander. "We're following women over a long period of time, and we're following different populations in different parts of the country."

The implications, Dr. Rich says, are considerable. "One of the things that's important about the WITS program, in terms of its research component," he explains, "is that a lot of studies can be incorporated, making use of the huge amount of correlative data we have."

Which means WITS and its findings will affect women far beyond the University of Illinois Hospital. "It's quite profound," says Dr. Garcia. "I think about it all the time, that amidst the great tragedy, there's such huge potential to contribute to something so important."

Joan Palmer sees both sides of that contribution. "I feel very much indebted to the women [in the study]," she says. "The sheer magnitude of the difficulties some of them go through is unbelievable. And I'm amazed and in awe of their ability to keep going, to enjoy life, and to have hope." ~