

Jamel's a champ in battle to live



Laura Bruno

ABOUT STATEN ISLAND

In the corner of a filthy Staten Island crack house, a woman lay bleeding with her one-pound son beside her, still connected by the umbilical cord.

Two years — and only about eight pounds — later, Jamel stirred peacefully yesterday in the arms of one of his nurses.

As a result of being born with AIDS, Jamel looks and functions as if he were 2 months old, instead of 2 years.

He is the sickest, and possibly the most lovingly spoiled, of the eight AIDS children living in the Herbert G. Birch Children's Center in Brooklyn.

"He's our miracle baby," said Ruth Mullen, manager of the home that was dedicated yesterday. He already has lived past the average age for a baby born as sick as he was.

In the five months Jamel has lived in the Birch home, he has been hospitalized six times, brushing death on nearly every occasion. Until January, he was kept alive in St. Vincent's Medical Center, where police rushed him from his dangerous birth.

No one expected him to reach his second birthday on Memorial Day, and no one wants to limit the odds on how much longer the little fighter will survive.

"He has a will unlike any we have seen," said Phyllis Susser, executive director of the not-for-profit Herbert G. Birch Community Service agency that runs the home.

But if Jamel's second birthday is his last, the Birch staff and a Staten Islander who visits Jamel regularly made sure the day was filled with as much celebration as the day of his birth was filled with desolation.

He cooed happily yesterday, rocking in the arms of Carol Rehrauer, one of three nurses on staff at the Birch home.

A good day for Jamel means "he eats and sleeps," Ms. Mullen said. "We're real happy when he does that. We let him lie in his little swing in a room with other

AIDS research funding matches that for cancer — Story on Page A 15

children, and he looks around. You need to think of him as two months old."

Jamel's eyes cross and wander like those of a normal 2-month-old might. Besides his size, there are few visible signs of the disease that is stealing his life. His tiny hands are wizened and there is a little patch of discolored skin above his lip.

"That's a scar from a herpes infection," Ms. Rehrauer said.

"We watched that infection spread across his face in the course of an hour," Ms. Mullen said. "It could have been fatal."

Fortunately, Dr. A. Izzet Berkel, who is the Birch home's pediatrician, was right there.

"He drove Jamel right to the emergency room," Ms. Mullen said.

Berkel, professor of pediatrics at the Children's Medical Center of Brooklyn of the State University of New York at Brooklyn, was honored yesterday at the dedication, along with Dr. Arye Rubinstein, professor of pediatrics, microbiology and immunology at Albert Einstein College of Medicine.

Berkel said Jamel is not in pain now, but the disease has attacked his brain, leaving him with irreparable damage.

Despite Jamel's severe developmental disabilities, he "absolutely" has developed a personality, Ms. Mullen said. Berkel insists the child has "a sixth sense."

After each hospitalization, "he comes home really irritable, but he calms right down," Ms. Mullen

said. "He responds to care."

"And he has the ability to tune us out when he wants," Miss Rehrauer said.

Though she's become attached to all the children at Birch, she's tied most closely to Jamel.

The Birch staff has had limited contact with Jamel's father, a Staten Islander who told the staff to do as they pleased with his son. A Staten Island woman, whom the Birch staff would not identify, has become Jamel's mom, Ms. Mullen said.

The staff knows nothing of the child's biological mother, except that she passed AIDS along to Jamel.

"The vast majority" of children with AIDS "are born to mothers who are infected with AIDS as a result of drug abuse," Ms. Susser said at the dedication.

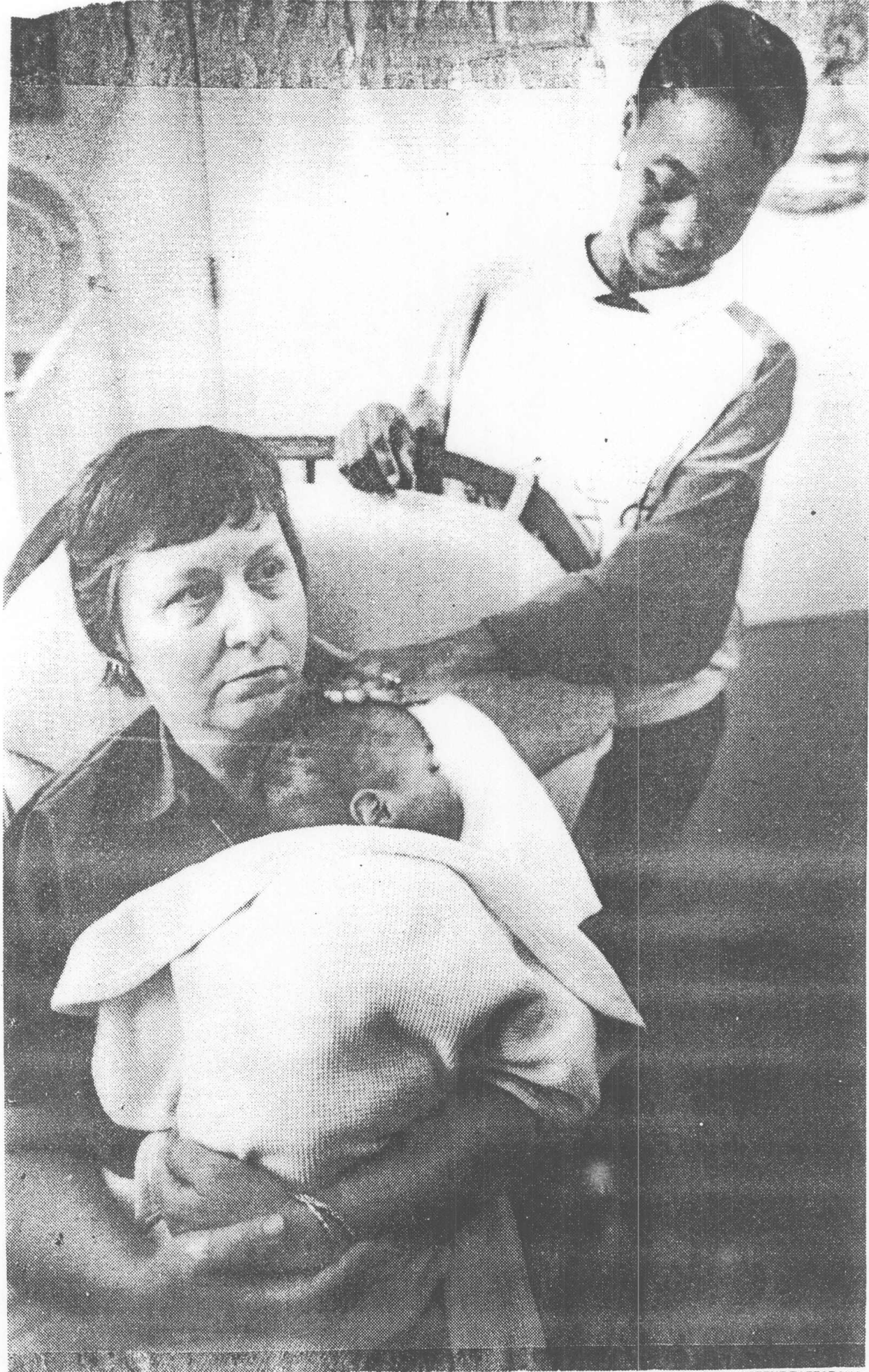
Jamel's case is among about 400 pediatric AIDS cases in the city, and projections say the national total could reach 20,000 by 1991, she said. Ninety percent of all children with AIDS are between the age of 1 and 4.

In five years, AIDS will be the single largest cause of mental retardation, she said.

"We have HIV-infected babies because we have HIV-infected women," said Dr. Beny Primm, who serves on the Presidential Commission on the Human Immunodeficiency Virus Epidemic. As keynote speaker yesterday, he urged that AIDS education be geared toward women, and that congregate-care facilities for patients be funded.

The Birch residence, which opened in January, serves children up to 6 who are developmentally disabled and diagnosed with acquired immune deficiency syn-

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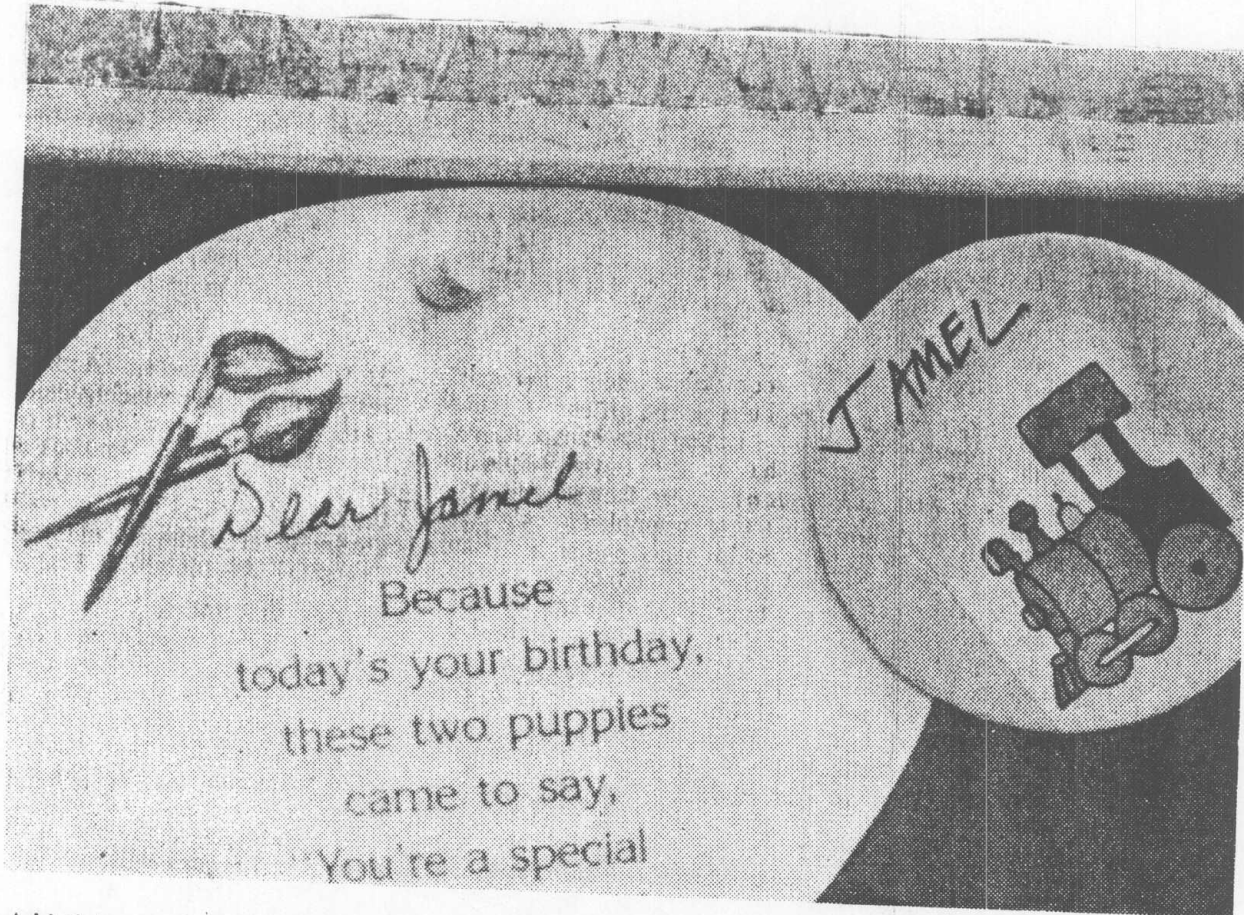


ADVANCE PHOTO/STEVE ZAFFARANO

Two-year-old Jamel snoozes comfortably in the arms of nurse Carol Rehauer as nurse Yvette Stephenson pats his head.

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Jamel



A birthday card and a button reflect the love shown to Jamel at the children's center.

ADVANCE PHOTO/STEVE ZAFFARANO

drome or are infected with the HIV virus that causes AIDS.

It is the first and only such residence in the state, but it is hoped to serve as a model for more, said Arthur Webb, commissioner of the state Office of Mental Retardation/Developmental

Disabilities. OMRDD contracts with the Birch agency to run the home that provides round-the-clock medical care and huge amounts of love.

For Jamel, that means "if he wants to be held, he will be held," Ms. Mullen said.

For the children less advanced in the disease, that means helping

them thrive, Ms. Susser said during the outdoor dedication.

"Whether or when the children live or die — and even more importantly, how they live or die — is the reason that this house came to be," she said from the podium in the Birch home's yard.

Inside, one of her toughest little fighters slept.