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New York City's only residence exclusively for children with AIDS

Opened in 1989, Incarnation Children's Center (I.C.C.) provides residential and outpatient medical care for HIV-infected children.

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Fax (212) 928-2841
DoctorSWN@aol.com

Paintings by children at I.C.C.

The Marathon Project

Incarnation Children's Center Annual Report

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"Children may be the victims of fate,

But we will not allow them to be victims of neglect."

Mission

Incarnation Children's Center



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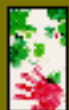
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The Incarnation Children's Center (I.C.C.), New York City's only residence exclusively for children with HIV/AIDS, provides enhanced care in nurturing environment to children with HIV/AIDS. ICC's unique combination of expertise and support provides the child and his family with multidisciplinary services designed to meet the challenges of pediatric HIV/AIDS and minimize its effects on the quality of their life. We are dedicated to serving as advocates for these infants, children, and adolescents in all matters pertaining to their health care and to providing leadership and support for relevant research.

An internationally recognized model of community-based care for pediatric HIV/AIDS, I.C.C. is a joint venture between the Catholic Home Bureau, which is a foster care and adoption agency of the Archdiocese of New York, and the Columbia University Department of Pediatrics.

Every day, 1500 children are being infected with HIV worldwide, and a large proportion are in New York City. I.C.C. is working to provide HIV positive children in New York with high quality medical attention and

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I.C.C. PROVIDES:

Residential transitional care with 24-hour nursing (i.e. "enhanced care") for chronically-ill HIV infected children who do not need hospitalization but require "round-the-clock" medical and nursing care in a nurturing and home-like setting.

Respite care for medically-complex children whose natural or foster parents are temporarily unable to provide care.

Outpatient diagnostic and medical care for HIV-infected children.

Access to clinical trials of new medications to treat HIV-infected children, under the sponsorship of the National Institute of Allergy and Infectious Diseases.

Training and education for pediatricians-in-training, students of medicine, nursing, social work and law, parents and foster parents.

HIV support groups for parents and older children.

RECENT I.C.C. NEWS:

November 11th

The friends of the Incarnation Children's Center invite you to celebrate ***The Sprite of Friendship*** honoring Nancy Addison Altman Lifetime Achievement Award to benefit The Children of ICC.

Our special friend is Rosie O'Donnell. Thursday, November 11, 1999 at the Copacabana. 617 West 57th Street in New York City.

Cocktails start at 6:30pm.

For more information call (212) 928-2590 EXT. 48

Press Releases:

[Her Legacy](#): Manhattan shrine to Princess Diana helps HIV-infected tots

[A Doctor and a Princess Make Wishes Come True](#)

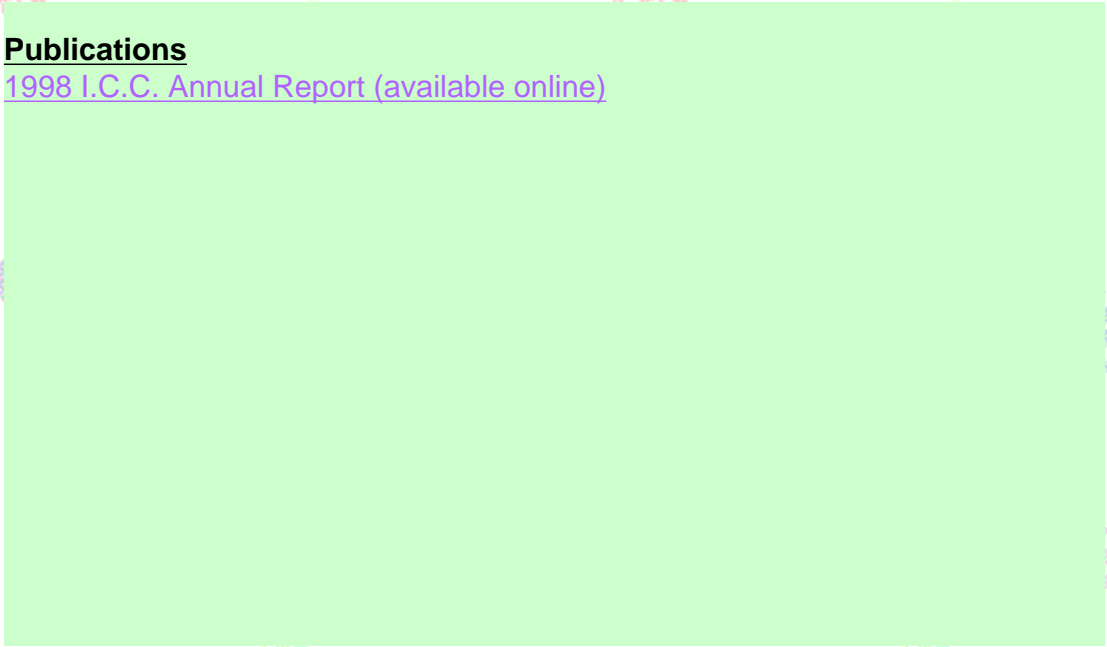
[Stars Shine in the Real World, Too](#): Celebrities Pitch vs. AIDS

[Help the Poor and Afflicted](#): Faith in Action

[Incarnation Children's Center](#)

Publications

[1998 I.C.C. Annual Report \(available online\)](#)



Current Treatment Options

Incarnation Children's Center



The Incarnation Children's Center (I.C.C.) is funded to conduct clinical trials of treatment options for children with HIV/AIDS. Current clinical trials include:

- ACTG 219 (Pediatric Late Outcomes Protocol)
- ACTG 225 (comparison of single vs. two dose measles vaccination)
- ACTG 245 (comparison of didanosine, zidovudine, and nevirapine in children/adolescents with advanced HIV diseases)
- ACTG 254 (atovaquone/azithromycin vs. trimethoprim/ sulfamethoxazole to prevent serious bacterial infections)
- ACTG 265 (effectiveness of varicella vaccine)
- ACTG 292 (effectiveness of pneumococcal vaccine)
- ACTG 299 (use of recombinant interleukin)
- ACTG 338 (effectiveness of combination antiretroviral therapy)
- ACTG 345 (effectiveness of Ritonavir therapy)
- ACTG 366 (combination antiretroviral therapy for children with rapidly progressing HIV/AIDS)
- ACTG 377 (comparison of highly active antiretroviral regimens with protease inhibitors and NNRTIs)
- ACTG 953 (effectiveness of Mycobacterium Avium Complex prophylaxis)
- ACTG 395 (investigates safety, pharmacokinetics and efficacy of Indinavir in combination with stavudine and lamivudine.)

Further information on these clinical trials are available from the [National Institute of Health](#), [National Institute of Allergy and Infectious Disease](#)

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Photo Gallery

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Over the years, I.C.C. has captured the faces of many of our children and staff with the help of photographers Claire Yaffa and Eugene Richards. You may click on any of the photos below to see it enlarged.



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Further information on other organizations with efforts devoted to HIV/AIDS and children can be located below:

NATIONAL/INTERNATIONAL:

Centers for Disease Control:

[National AIDS Clearinghouse](#)

National Institutes of Health:

[National Institute of Allergy and Infectious Diseases](#)

Pediatric AIDS Foundation

National Pediatric and Family HIV Resource Center

Children Affected by AIDS Foundation

Ryan White Foundation

Children's Hope Foundation

National Library of Medicine's AIDS-Related Databases

Pediatric AIDS Clinical Trials Group Overview

World Health Organization

Clinical Care Options for HIV

NEW YORK:

New York State Department of Health: AIDS Institute

New York HIV/AIDS Information Outreach Program

Columbia University

Harlem Hospital (212) 939-4012

Babies and Children's Hospital of New York

Archdiocese of New York

Northern Lights Alternatives

Tamarand Foundation

New York City Administration for Children's Services (718) 226-7125

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**For further information on the activities of the Incarnation
Children's Center and how you can help, please contact:**

Stephen W. Nicholas, M.D., Director

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The **Friends of ICC** is a non-profit organization created to provide publicity and raise money to support ICC's programs. Its creation was prompted by recent cuts in governmental funding that threaten ICC's survival and by new financial needs that will result from ICC's state-mandated relicensure from a social services to a health-related facility.

Directors include:

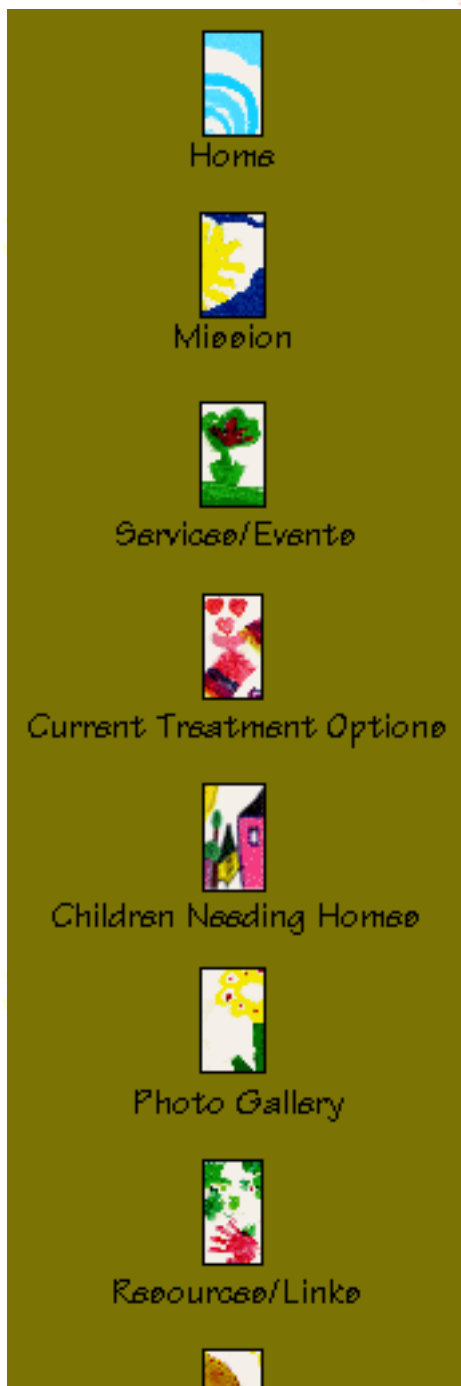
- CEO and Chairman: John M. Leonard (Vice President, Chase Manhattan Bank)
- Executive Director: Dr. Stephen W. Nicholas (I.C.C. Director)
- Secretary: Daniel J. McNamara (Senior Vice President, Hughes, Hubbard and Reed)
- Treasurer: Carrol A. Muccia, Jr. (Partner, First Manhattan Co.)
- Claire Yaffa (Photographer for the New York Times)
- Msgr. Thomas Leonard (Pastor, Church of the Holy Trinity)
- Frank Kelly (President, Kelly Pioneer Group)
- M. Katherine Dwyer (President, Revlon Cosmetics USA)
- Robert J. Hoy
- Nancy Addison Altman (President, Nancy Addison Collectibles
Actress, Television & Stage)

Advisory board members include:

- Jack Rudin (Rudin Management)
- Sr. Una McCormack (Executive Director, Catholic Home Bureau)
- Dr. Margaret Heagarty (Director of Pediatrics, Harlem Hospital Center)
- Dr. John Driscoll (Chairman, Columbia University Department of Pediatrics)
- David Pincus (CEO of Pincus Brothers-Maxwell, which produces Bill Blass clothing and other fine apparel)
- Sr. Bridget Kiniry, former director of ICC, serves as the organization's publicist and fundraiser.

If you are interested in helping support the children with HIV/AIDS at Incarnation Children's Center, please contact:

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Paintings by children at I.C.C





Photo by Claire Yaffa

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Children Needing Homes

Incarnation Children Center

We Need Your Help:

Children grow better in families and HIV+ children, like all children, need love, affection and guidance. We need homes for infants, toddlers, young children, and teenagers who are living with HIV virus.

If you are at least 25 years of age, live in the NYC or surrounding areas, are able to provide a safe and healthy home and have enough living space for one or more children, please contact us today!

Catholic Home Bureau provides a comprehensive training program and supports you with our professional staff consisting of Social Workers, Mental Health Clinical Staff, Educational, Medical and Religious consultants and a stipend to help with the foster child's expenses.

For more information on how to become a foster parent, call Catholic Home Bureau today:

CATHOLIC HOME BUREAU HOMEFINDING DEPARTMENT

1011 First Avenue
New York, New York 10022
(212) 371-1000
Ext. 2245 or 2246

[Click here to meet one of the
ICC residents that needs a home.](#)



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Stars Shine in the real world, too: Celebrities pitch vs. AIDS

Daily News
October 14, 1997
By Jim Dwyer

The Copacabana nightclub crawled with celebrities and nuns, all buzzing like a thousand bees in the ears of Steve Nicholas, who would have to make a speech into the din. Every time he glanced at his notes, someone else hollered a star sighting to him.

Look—there was Geraldo Rivera. Kate Mulgrew, the "Star Trek" actress. Rosie O'Donnell.

Then people started telling Nicholas not to worry about his talk. Yes, it was a benefit for kids with AIDS, but the guests already had written their checks. The stars had turned up and done their bits.

So what more could anyone expect?

"Keep it short," urged Nicholas' wife, Ellen Sargent.

"People never listen to speeches," said a very self-assured friend.

"I do have to mention a few things," Nicholas said.

"Just a few," the friend proclaimed. "No one listens at these things."

Nicholas shrugged. He had a story to tell, and at least he'd get some of it out that night. Maybe the celebrities would hear him.

Steve Nicholas is a big, tall doctor who grew up in Wyoming and now runs a place on Audubon Ave. in Washington Heights called Incarnation Children's Center. You may not have heard of it. Across the world,

"Incarnation" is famous as a center for children who are HIV-infected and have AIDS.

It began 10 years ago, when the wards of city hospitals were crowded with babies no one wanted to take home. The parents stayed around long enough to give their children a virus, but usually not a name. The virus was called HIV. The kids were called boarder babies. They were stuck in the hospital because they had nowhere to go.

One afternoon 10 years ago, a children's doctor from Harlem Hospital, Margaret Heagarty, drove up to 175th St. and rang the bell at the parish house for the church of the Incarnation. Behind her was Michael Katz, who ran the pediatrics department for Columbia University, Jack Rudin, who is in the real estate business, and Brook Trent, who works in child welfare for the city.

They went into the parlor and sat down with Tom Leonard, the pastor. "Msgr. Leonard served us cream cheese, and Nova, and ice-cold bagels," Rudin said.

Leonard knew about an abandoned convent down the street. They could put the kids in there. Rudin threw in the first of what would be \$1.5 million. They needed doctors and nurses.

Heagarty, who has trained a core of doctors now working all over the city, grabbed Nicholas. "He was another one of these smart young doctors who was going to do health care policy down in Washington, for God's sake," Heagarty said. "I said, do health care. Someone else will get the policy."

In the next 10 years, the people at Incarnation took care of 600 kids with AIDS, one at a time. Many kids who looked like they were about to die turned around when they were fed, medicated and cuddled. All those years, the neighborhood street corners were run by drug dealers who murdered hundreds of people. At the center of all that gunfire was the old brick convent, where the people inside fought like happy tigers for life.

"The drug dealers left us alone," said the retired administrator, Sister Bridget Kiniry, a woman of manners and presence.

"The kids are living longer," said Pam Clark, a nurse who was at Incarnation from the beginning. "Now we need to have a place for the teenagers."

So on Thursday night, Nicholas took the podium at the Copacabana. They had never had a benefit on this scale.

He told the crowd the history and ended up explaining what the money

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would pay for.

"We are going to be relicensed this year by the state, and that will cost about a million dollars," Nicholas said, "and one day, our dream is to get another building in the neighborhood."

There was applause and no sign whatsoever that he had spoken too long.

A minute later, Geraldo Rivera was on the stage.

"This city has been very good to me and my family, and we've talked about this, and Cece [Rivera's wife] and I have decided that we would like to pay for half of the new building," Rivera said.

At his table, Nicholas looked up. "I almost dropped that form the speech," he said because that was a six-figure fantasy.

Now Rosie O'Donnell was on stage, talking about her admiration for the double earring worn by Nancy Addison, an actress who had organized the benefit. Then O'Donnell paused. And she mentioned a foundation she had put some money into a while back.

"I guess the legal way to say this," O'Donnell began, "is that, after Geraldo spoke, I called the foundation board and the board had a meeting, and they agreed to pay for the other half of the building."

It took a moment before people in the room began yelling. It took that long because they were all shivering, just those few seconds, when they felt a finger run down their spines. The world can still do the necessary.

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Many residents at Incarnation Children's Center are in need of foster or adoptive homes. I want to take this opportunity to tell you about one child who is now freed for adoption and needs a permanent, loving home.

"M." is a 4 year old boy who lives at Incarnation Children's Center. He is a charming, funny, energetic child who has a spirit that lights up the room. He attends a full day preschool program which he loves and he is talking up a storm. M. has many medical complications and is on almost 20 medications daily. He needs a family in which there is someone home to care for him full time. Because M.'s medical needs are so great, a family with a medical background is preferred but not necessarily required. The family must also live in close proximity to NYC and be able to maintain his outpatient medical care at a Manhattan hospital.

If you think you may be able to provide a permanent loving home for M. and want more information about the adoption process, please call me, Mindy Wacks, Social Worker at Incarnation Children's Center at (212) 928-2590 x27.

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Photo by Claire Yaffa

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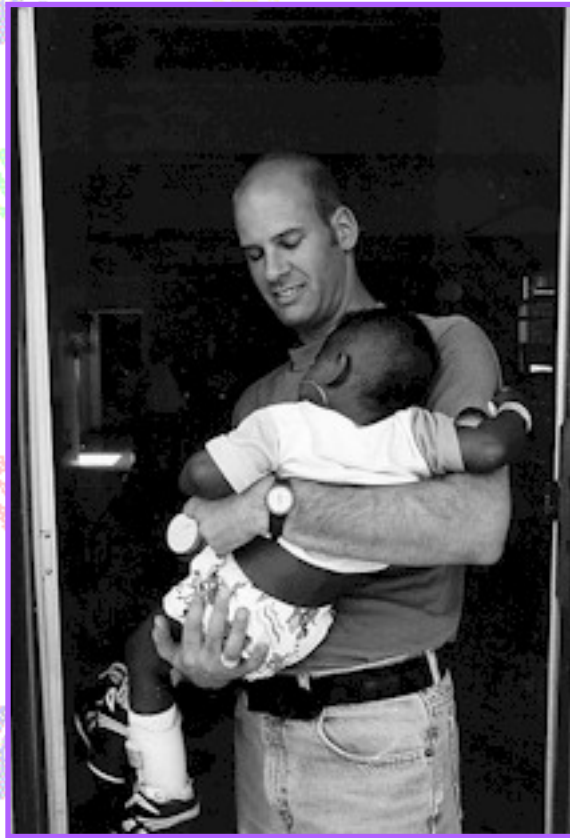


Photo by Claire Yaffa

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Photo by Eugene Richards

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**Photo by Eugene
Richards**

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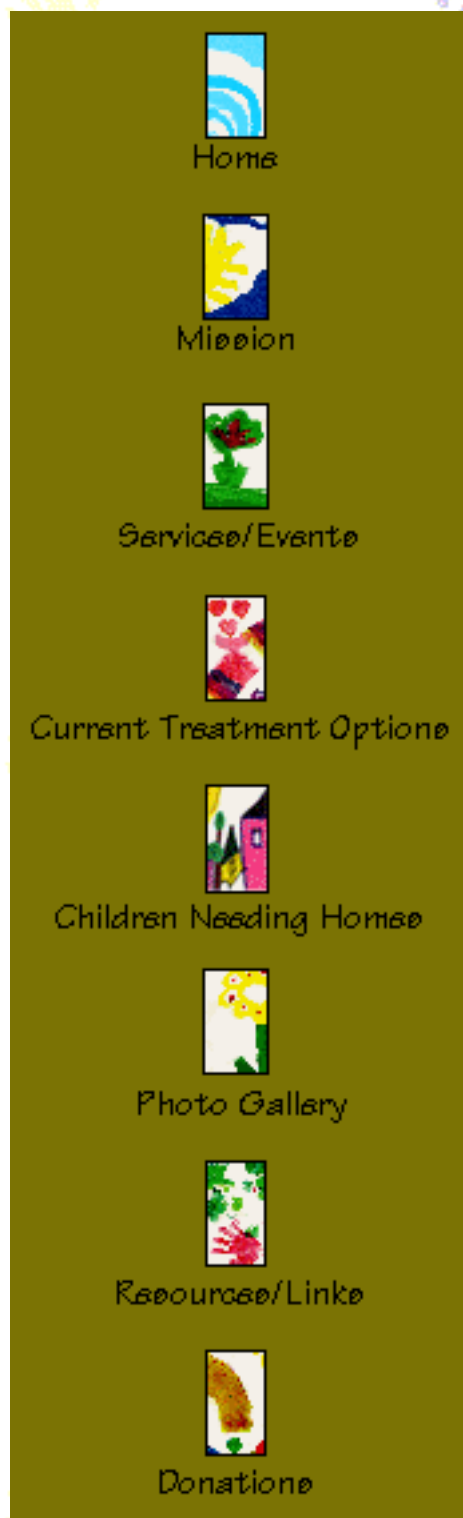
**Photo by Eugene
Richards**

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Photo by Claire Yaffa

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Her Legacy:

Manhattan Shrine to Princess Diana helps HIV-infected tots

September 25, 1997

By Stephen Steele

The legacy of Princess Diana brought joy to the lives of some little New Yorkers last week. Stuffed animals, toys and flowers that mourners left at the British Consulate in Manhattan were presented to two pediatric AIDS centers, Incarnation Children's Center in Washington Heights and Harlem Hospital

The late princess, who during the latter part of her public life was an advocate for the world's children, visited Harlem Hospital's pediatric AIDS wing twice, in 1989 and 1995.

Dr. Stephen W. Nicholas, Incarnation's director and a staff physician at Harlem Hospital, said the photographs of a smiling, radiant Diana holding babies infected with the AIDS virus legitimized pediatric AIDS care. He was present for both visits.

He called her visits the "most important event that happened in terms of treating HIV children in New York City."

Before Princess Diana's visit, Harlem Hospital experienced great difficulty in finding foster parents to care for AIDS children, Dr. Nicholas said, but within two years of her visit the number of caretakers rose from "near zero to an actual surplus."

"Before Princess Diana came, no one wanted to be near kids with HIV," he told CNY. "Most people didn't even want to be in the same room as

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them. Certainly no public figures were involved."

Incarnation Children's Center opened its doors in the former parish convent in March 1989, one month after Diana's visit to Harlem Hospital.

"Because so many foster parents came forward, 160 children were placed in loving foster homes," he said.

"We quickly became the Ellis Island of homes for children with AIDS. That wouldn't have happened without Diana's help. There's no doubt about that," he said.

Dr. Nicholas recalled shaking hands and exchanging brief words with the princess.

"What I remember most was the way she looked at you—right into your eyes. I could feel her looking right into my soul," he said. "It was very profound."

On Sept. 18, Gerry McCrudden, British deputy consul general, and Dewi Williams, press officer at the consulate, received a special welcome from about a dozen children at the Incarnation center, some of whom sang and performed a brief dance for their guests. One child presented them with a huge greeting card signed by some of the residents.

"The children can get very excited when we have visitors," said Sister Bridget Kiniry, O.P., Incarnation's director.

Shortly after Diana's death in a Paris car crash early Aug. 31, Sister Bridget called the British Consulate expressing condolences and promising prayers. About a week later, a consulate representative called about donating to Incarnation toys and flowers left as a shrine to the princess.

As he presented Sister Bridget with the stuffed animals, McCrudden said the British Consulate believed that the "best thing to do was give the toys to organizations like Incarnation because this was what the princess would have liked."

"This was a topic the princess was keenly interested in," he said. "We'll try to continue our relationship with Incarnation as a way to honor her legacy."

The British representatives also presented Incarnation with a framed official portrait of Princess Diana, which is displayed outside its Chapel.

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A Doctor and a Princess Make Wishes Come True

The College of Physicians and Surgeons of Columbia University
Winter 1998
By Kristen Watson

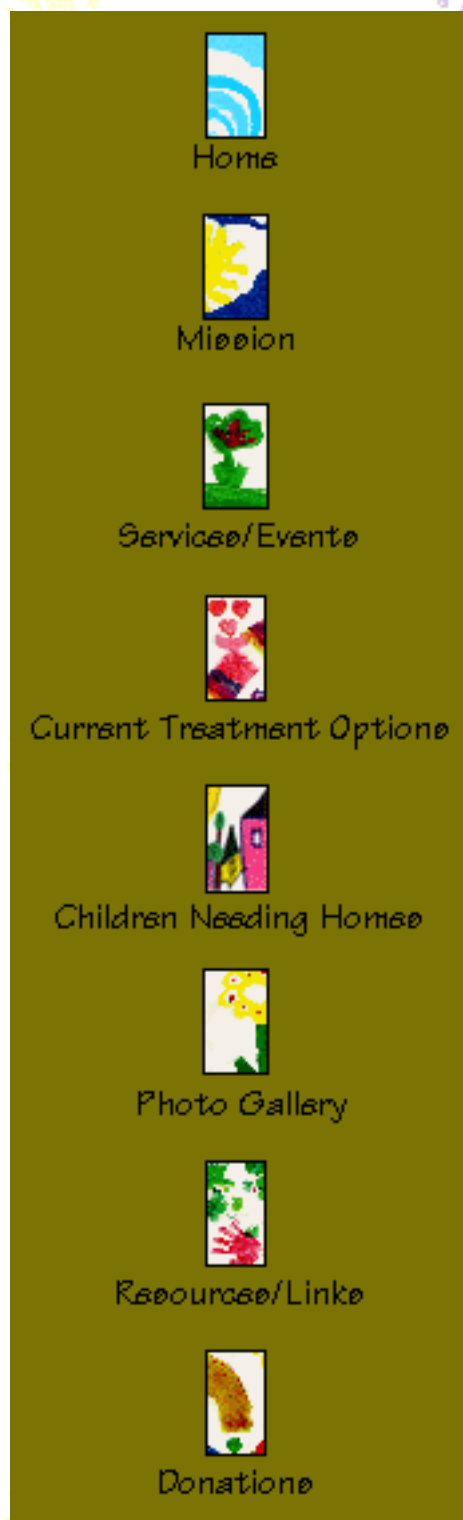
In the mid-1980s more than 60,000 children needed foster care, a social problem brought on by the rise of poverty, AIDS, crack and the abuse and neglect of children. A large number of these children also had HIV and became "trapped on the wards" in the city's hospitals. Some of their parents were too sick with AIDS to care for their children or had died from the disease, some were homeless, and others were junkies. At the time, HIV was still the big mystery; potential foster families worried about catching the disease from the children and a stigma was attached to the disease that most people thought only homosexual men, drug addicts and prostitutes could get. Many of these children were left in hospital pediatric wards for lengthy stays, while doctors and nurses acted as surrogate parents.

Dr. Margaret Heagarty, director of pediatrics at Harlem Hospital Center, proposed small community-based homes for children with HIV. With the help of the Archdiocese of New York, Columbia University, philanthropist Jack Rudin, and others, ICC opened its doors in March 1989 in a former convent for the Incarnation Church in Washington Heights. The collective wish at ICC was that through education about HIV, potential foster parents would overcome their fears of the disease and the children would be taken into homes instead of spending years at the group home. Fortunately, something serendipitous happened one month before ICC opened: Princess Diana visited the Harlem Hospital pediatric AIDS unit and pictures of her cuddling a sick child were published throughout the world. The rate of recruitment of foster homes for children with HIV went from almost zero to a surplus of interested families. ICC placed 160 children—approximately two-thirds of the homeless HIV-infected children in New York City—in foster homes in its first two years.

Now ICC functions more like a nursing home, housing only children who

are too ill for foster home placement. The child care workers at ICC are mostly Dominican women from the Washington Heights neighborhood. "These women are all about love and nurturing children," says Dr. Stephen Nicholas, associate professor of clinical pediatrics and director of ICC. "They give the children quality care." But Dr. Nicholas stresses that ICC is not primarily a hospice: "It's a place where children live until they are well enough to be placed in a home setting."

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Help the Poor and Afflicted: Faith in Action

The New York Times
January 24, 1998
By David Gonzalez

Child-sized wheelchairs sat empty in the corridor, an odd sight alongside the playful murals of elephants peeking through the jungle bush. Colorful, too, were the red and yellow syrups and pills by the nurse's station with notations for AZT or Dilantin. In a crib tucked into one corner, a 3-year-old rested, his chest rising and falling with every rasp of breath.

Thomas Cahill walked into the room and glanced at the youngsters living at the Incarnation children's Center, a residence for H.I.V.-positive children in Washington Heights. He was there to read bedtime stories, a simple act filled with the singsong cadences of tales about giants, princesses and animals. Yet in reading to these fragile children, Mr. Cahill and his friends hoped to find strength for themselves.

Mr. Cahill, the author of the surprise best seller, "How the Irish Saved Civilization," has for the last two years led a small prayer group in midtown called the Friends of St. Giles. It is affiliated with the Community of Sant'Egidio, a large ecumenical group that was established by Roman teen-agers in 1968 to pray, read the Gospels and lead lives of friendship with the poor. City dwellers may be too caught up with getting ahead that they have no time to make friends with their neighbors, much less the poor, but Mr. Cahill insists it is neither impossible nor foolish to think that small acts of charity can make a difference.

"We're just a bunch of middle-class people," he said. "None of this is earth-shaking or monumental. It seems extremely minor, but everything is minor in a way. You know the famous response of Mother Teresa when someone asked her how she did it? 'One by one.' I think that is always the response."

One by one is how the Friends of St. Giles formed in 1996 when Mr.

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Cahill was leading a discussion group at St. Malachy's Roman Catholic Church on West 49th Street. There, he met others who shared his aspiration to emulate what he had seen in the Sant'Egidio community in Rome.

The Italian group, born of the social protest and religious renewal of the late 1960's, grew to a point at which it fed thousands of people, educated children and sheltered the homeless. It was, Mr. Cahill said, a powerful reflection of what faith could accomplish. He calls it "nonprofessional" Christianity, lay people who pray together, read the Gospel and try to act on those words.

"The Gospel is like a treasure hidden inside a beautiful building that no one goes into," he said. "That's been contorted out of shape by uptight church people who put up a smoke screen between the Gospel and ordinary human beings."

Since last year, he and his friends have been reading to the children at Incarnation, talking with hospitalized AIDS patients and compiling a list of soup kitchens that need volunteers. On Monday at St. Malachy's he begins a series of talks on "Encountering God" in the hope of attracting more people to the prayer group. Then, he hopes to work with imprisoned youths, a group Mr. Cahill feels is overwhelmed by hopelessness.

The idea of connecting with the poor can engender its own hopelessness, familiar to anyone who ever avoided the gaze of a beggar while wondering if he was denying someone a meal.

"Being confronted with that is a conscience tickler," said Peggy Pugh, a newcomer to the prayer group. "You give something and you hope it's to someone who really needs it and not adding it up for drugs. It's a huge problem, unless you turn off your heart when you walk the street."

Linda Dickey, one of the group's original members, said her visits to former addicts suffering from AIDS has given her insights into her city and herself. She has seen how people's lives disintegrate in a flash, something that she thinks strikes fear and denial in others.

"Why do people fear the poor?" she said. "Because we have so much privilege, we think it's so terrible. But we're fooled by our possessions."

What she clings to now are the moments she spends running errands for the sick, writing letters for them, or just listening.

"I've gotten to meet people I wouldn't otherwise ever met, except maybe as a victim," she said. "They taught me you can have a painful life and yet be a loving person."

"Friends even."

"Until you try, you might think it's scary," she said. "For New Yorkers like me, middle class and educated, it could be hard. But I feel different now about the other people I see on the subway. They're *my* people."

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1996

Stephen Nicholas, M.D., Director

The Department of Pediatrics has played a significant role in the creation and support of Incarnation Children's Center (ICC), New York City's only residence for HIV-infected children. Located on Audubon Avenue at 172nd Street in a 4-story red brick former convent, ICC's residential and outpatient programs have provided care for over 600 HIV-positive children since opening its doors in 1989.

In the mid-1980's, children with HIV infection and AIDS were often homeless and foster parents were in very short supply. As a result, hundreds of AIDS boarder babies languished for months to years on hospital wards because they had nowhere else to live.

In 1987, Dr. John Nicholson, Professor and Attending of Pediatrics, after finishing a month as ward attending at Harlem Hospital, which had the greatest number of AIDS boarder babies in the city, had an idea to use Incarnation Convent, which was empty, as a home for AIDS babies. At his prompting, a collaborative group formed: Monsignor Thomas Leonard, then a rector of Incarnation Church; Sister Una McCormack, executive director of Catholic Home Bureau, a foster care and adoption agency of the Archdiocese of New York; Dr. Michael Katz, then chairman of the Department of Pediatrics; Dr. Margaret C. Heagarty, Director of Pediatrics at Harlem Hospital; Jack Rudin of the Samuel and May Rudin Foundation; Brooke Trent, then Deputy Commissioner of the Child Welfare Administration.

This collaborative group envisioned a sanctuary of love, a home-like nurturing residence where HIV-positive children would receive the best possible nursing and medical care while awaiting placement into foster homes.

Dr. Stephen Nicholas was recruited to become the founding medical

director. With his assistance and together with cofounders Sister Bridget Kiniry, M.Ed., Sr. Constance Gaynor, M.S.W., and Pamela Clark, R.N., M.P.H., the program was created.

During its first two years, ICC became the Ellis Island for homeless children with AIDS. One hundred and sixty children were admitted to ICC from all five city boroughs. During this period, ICC worked with the Child Welfare Administration and a large number of foster care agencies to encourage foster parents to accept HIV-positive children. As a result, foster parent recruitment increased at an astonishing rate. After three years, a surplus of foster parents existed for all but the sickest children. New York City's AIDS boarder baby crisis had ended. ICC had played a pivotal role in this success story. Having accomplished its goal, ICC would have happily closed its doors had it not been for an unexpected discovery.

Pediatric AIDS was first recognized in 1982-83. Early in the epidemic, HIV disease of childhood was considered to be down-hill course leading to death. But in the late 1980's, before AZT was available, many very ill children admitted to ICC got dramatically better with proper nurturing and high-quality medical and nursing care. As the importance of convalescent care became clear, many of the sickest HIV-infected children in the city began to be referred to ICC for temporary care.

In 1992, an outpatient clinic for HIV-positive children was established; the same year, with funding from the National Institute of Allergy and Infectious Diseases, the clinic became a sub unit of the Columbia University Pediatric AIDS Clinical Trials Unit, directed by Dr. Anne Gershon, Professor of Pediatrics. In addition, ICC from its earliest days has worked in close collaboration with the Harlem Hospital Pediatric AIDS Program, directed by Dr. Elaine Abrahms, Associate Professor of Clinical Pediatrics.

Today ICC is an internationally-recognized model of community-based care for children with HIV/AIDS. It's 1996-97 operating budget is \$2.0 million for the residential program and \$756,899 for the clinic program (\$286,087 of which is for clinical trials). A staff of 70 provide a full array of medical, nursing, child care, social, nutritional and developmental services. Approximately 70 volunteers supplement staff activities. The Friends of Incarnation Children's Center, a newly-organized non-profit organization for publicity and fund-raising, raised \$334,818 in 1996, of which \$100,000 was donated by The May and Samuel Rudin Family Foundation for the support of Columbia University medical staff salaries.

ICC medical personnel include three pediatricians, two research nurses, two-field nurses, one senior clerk and one part-time psychologist.

During 1996, ICC's average residential census was 88.6%, with 42

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children admitted for an average length of stay of 82 days.

During clinic sessions each week, 1438 evaluations were given in the past year to 133 HIV-positive children, 118 children were referred for HIV testing. Under the direction of Dr. Nicholas, 34 children are currently participating in 7 clinical trials, including ACTG 219 (Pediatric Late Protocol); ACTG 240 (zidovudine vs. D4T); ACTG 245 (comparison of didanosine, zidovudine and nevirapine in children/adolescents with advanced HIV diseases); ACTG 254 (atovaquone/azithromycin vs. trimethoprim/sulfamethoxazole to prevent serious bacterial infections); ACTG 300 (zidovudine/3TC vs. didanosine/zidovudine/didanosine); ACTG 327 (a continuation of ACTG 240), and a Roche-sponsored trial of DDC monotherapy.

ACTG 338 (zidovudine/3TC vs. D4T/ritonavir vs. zidovudine/3TC/ritonavir), the first phase II pediatric trial of a protease inhibitor, will start in early 1997. The ICC clinical trials subunit was awarded funding from NIAID for an additional three years (1197-2000).

Dr. Nicholas was promoted in 1996 to Associate Professor of Clinical Pediatrics and Associate Attending. He was listed among The Best Doctors in New York in New York Magazine, and in the 1996-97 edition of The Best Doctors in America.

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Annual Report

Incarnation Children's Center

Annual Report 1998 Incarnation Children's Center

Incarnation Children's Center [ICC] has an 18 bed residential chronic care unit and an outpatient medical program for children with HIV/AIDS. Patients come to ICC from all five boroughs as well as Westchester and Dutchess counties. The Center provides education and training for Pediatric residents and students of medicine, nursing and social work. It is also a site for clinical research, including NIH sponsored clinical trials of investigation drugs

Optimistic Trends in New York's Maternal-Infant HIV Epidemic: Current Status

Maternal-infant, or prenatal, transmission, which accounts for virtually all new HIV infection in children, decreased significantly during the past 4 years because of increased HIV testing during pregnancy and prophylactic AZT therapy for pregnant HIV-infected women and their babies. Children born with HIV infection now live longer, often into adolescence, and pediatric HIV infection is evolving into a chronic disease of childhood. This good news is partially offset by the reminder that many HIV-infected women are newly infected, their disease remains undiagnosed, and they do not receive or accept anti-retroviral prophylaxis during pregnancy. Many children with HIV infection still die. With new multiple drug treatment regimens, state-of-the-art medical care for pregnant women and children has become exceedingly complex and highly specialized, and the cost of outpatient care, with longer life, has likewise increased significance. As infected children grow older and treatment becomes more complex, issues of adherence and disclosure take on new importance. Because many children have suffered recurrent loss (death or parents, siblings, change of foster homes, etc.,) behavioral, emotional and mental health issues have pushed to the forefront. All these issues are further complicated by the process of adolescence.

Residential Chronic Care Program

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Forty eight HIV-infected children received residential care during 1998. They received an array of medical, nursing, social, developmental, rehabilitative, nutritional and educational services. Mental health services were provided by Ilene Rabinowitz, MD, Sheila Ryan, MSW, and Warren Ng, MD, of the Department of Child Psychiatry's Special Needs Clinic which is directed by Jennifer Havens, MD. Margaret Fisher, R.N., joined our staff this year as Director of Nursing. Medical care was provided by Catherine Painter, MD, and Joseph Richter, MD.

Outpatient Clinic

Ninety four children, in addition to the children in residence, were given HIV-specialized and/or comprehensive primary care in the clinic during the past year. Children came from the Bronx (59%), Manhattan (15%), Brooklyn (11%) and elsewhere (4%). Pediatric care is provided by Drs. Stephen Nicholas, Adrienne Rogers, Catherine Painter and Joseph Richter. Though funding from the Robin Hood Foundation, the Gertrude E. Skelly Charitable Foundation, and the United Hospital Fund, and adherence and disclosure team, consisting of a social worker, nurse educator and community liaison worker, was established to assist families with these difficult issues. Emergency funds for families were made available from grants from the Children's Hope Foundation and the Eliabeth Glaser Pediatric AIDS Foundation.

Snoopy's Place: A New Outpatient Clinic

With funding from the *Friends of Incarnation Children's Center*, an adjacent row-house has been purchased and will be renovated and turned into a new outpatient clinic. Charles Schulz, the creator of *Peanuts*, has given permission to name the new clinic *Snoopy's Place*. This clinic will have expanded mental health services for HIV-infected and -affected children, adolescents and adults. It will also house a new program for HIV-infected adolescents.

Field Nurses Program

Under the supervision of ICC, Mara Juntado, RN, and Anne Spitalney-Bacon, RN, provided community-based nursing care for 78 HIV-infected or -exposed foster children in placement with Catholic Home Bureau.

ICC Pediatric AIDS Clinical Trials Subunit

Under the direction of Dr. Nicholas and with the coordination of Leslie Nielsen, RN, clinical trials research nurse, 19 children

participated in treatment trials and 28 participated in ACTG 219 (Pediatric Late Outcomes Protocol). Treatment trials included ACTG 254 (Phase II/III, double blind, two-armed study of micronized atovoquone and azithromycin as compared to trimethoprim sulfamethoxazole in the prevention of serious bacterial infections when used in children aged 3 months to 19 years with HIV infection); ACTG 338 (Phase II rolling arm master protocol of novel antiretroviral therapy in stable experienced HIV infected children); ACTG 366 (Phase I/II master protocol of novel antiretroviral combination therapies in antiretroviral experienced children with rapidly progressing or advanced HIV disease); ACTG 377 (Phase I/II randomized, multicenter protocol comparing four antiretroviral regimens containing combinations of protease inhibitors, nucleoside reverse transcriptase inhibitors and a non-nucleoside reverse transcriptase inhibitor); ACTG 395 (A multicenter, open labeled 48 week study to investigate the safety, pharmacokinetics and efficacy of indinavir in combination with stavudine and lamivudine in pediatric patients with HIV infection).

Other Research

Pediatric Spectrum of HIV Disease Study. ICC continues to be one of several New York City sites for this nation-wide natural history study, funded by the Center for Disease Control and Prevention. FACTS Electronic Charting System. Funded by the New York State Department of Health's AIDS Institute, ICC is one of two pilot sites for this study which is evaluating a new computerized charting system for children, adolescents and families with HIV. Determinants of Adherence to Complex Medical Regimens. Directed by Dr. Claude Mellins of the Psychiatric Institute's HIV Center, this pilot study will provide the basis for a larger, prospective interventional study that is being planned.

Fundraising, Honors and other News

Sarah Ferguson, Duchess of York, was the honoree of the *Friends of ICC's* second black-tie fundraiser at the Copacabana Club in October, which was underwritten by Revlon Cosmetics USA and raised \$350,000. Dr. Nicholas was the recipient of the Claire Lucille Pace Humanitarian Award in November. ICC is planning to establish a new residential program for HIV-infected children with mental health problems. ICC has also established formal collaborative relationships with four pediatric AIDS programs: St. Clare's House in Newark, New Jersey; Nyumbani House in Nairobi, Kenya; CAIO in Santos, Brazil; and Centro Urbano in La

Romana, Dominican Republic.

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The Marathon Project

The Incarnation Children's Center is a home built around strength and love. Living day to day against unthinkable odds these children are role models for all of us. The Marathon Project is an opportunity to show that they are not forgotten.

The goal of the Marathon Project is a simple one, to make a difference! Through sponsoring my run you can make a difference in the lives of children who weren't born with the same opportunities as you and I. It is the perfect vehicle to take action in support of an issue that although may not affect your life directly, touches our soul and consciousness as human beings.

ICC was brought into the public spotlight back in the early 90's when the late Princess Diana made a visit that sent this issue to the forefront of everyone's mind. Unfortunately, there are so many tragic issues plaguing our society that the smallest of us are the easiest to be forgotten-these children cannot afford to be forgotten.

Sponsorship of the run can be done in one of two ways. First, sponsorship per mile, i.e. \$10/mile. Second, one lump sum donation, i.e. \$250, any and all denominations are greatly appreciated. Checks should be made payable to The Incarnation Children's Center, credit card contributions are also accepted. ALL contributions are fully tax deductible. Contact info. Is as follows:

Scott Callahan: scallahan@theglobe.com

(914) 722-2612

I.C.C.-Sr. Bridgett Kiniry (212) 928-2590

All donations should be sent to:

The Marathon Project
C/O Scott Callahan

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This page will be updated as the New York City Marathon approaches so be sure to check in on recent progress and announcements. I thank you all in advance for getting involved and making a difference!

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AIDS Care:

Dedicated To Improving The Quality Of Life Of All People Living
With HIV



Suffer the Children

A portfolio of photographs

by Claire Yaffa

When Incarnation Children's Center, a pediatric AIDS facility that serves one of New York City's most blighted neighborhoods, Washington Heights, opened in 1989, photographer Claire Yaffa was there. "She simply appeared on my doorstep," says Dr. Stephen W. Nicholas, the executive director of I.C.C., "and she never left." During the ensuing decade Ms. Yaffa documented the heroic efforts of Dr. Nicholas and his dedicated staff to provide comfort, compassion, social and emotional context, and comprehensive care for some of the poorest, sickest, and most marginalized children in America. For all too many of these children, the doctors and social workers, nurses and nuns of Incarnation were more than care providers -- they were family, to infants and toddlers whose own families had been sundered, scattered, or swept away by AIDS.



HIV-positive neonate, New
York City, 1990



When Anthony was well enough, he sought out one or more of the only playmates available to him -- other pediatric patients at Incarnation. When he was overcome by infection, fatigue, or sadness, he often retreated to a nest of pillows in one of the facility's sitting rooms.

In the days before multidrug antiretroviral therapy altered the outlook for children with HIV, many of Incarnation's patients lived the whole of their brief, pain-filled, illness-ridden lives in the center. They took their first steps there. They celebrated their first birthdays there. They cut their first teeth there. And along the way, they won the hearts of the staff -- few more completely than Anthony, the Little Prince of I.C.C. A bright and delightful child at all times, Anthony was especially ebullient and outgoing on his "good" days -- but even on those days he was obliged to endure the plastic tube that had been slipped down his right nostril (below), so that life-sustaining medications could be run directly into his esophagus at fixed intervals throughout the day.



After Anthony's mother died of AIDS, he came to live at Incarnation -- New York State's only residence for children with advanced HIV infection. At the time, I.C.C. was home to two-thirds of the city's so-called AIDS boarder babies, infants whose families were, for various reasons, unable to provide them with the kind of care they required. Anthony's dream was to live with his older brother and their father -- who shared this dream. But because of family problems that Anthony was too young to understand, that dream went unfulfilled -- another pain to bear in a life that had far more than its share of pain.



Anthony learned his alphabet from one of the volunteer teachers who augment the physicians, nurses, and social workers who attend to the physical, emotional, and social needs of I.C.C. patients -- in this case providing Anthony with the tools that he would need in order to learn to read, assuming he lived long enough to acquire that basic skill.



As Flannery O'Connor, who suffered from chronic disseminated lupus all her adult life and died of its effects at the age of 39, once declared, "I have never been anywhere but sick." The same can be said of Anthony -- especially at the end. Bedridden, frail, incontinent, and miserable, he was tended round the clock by a team of I.C. C. nurses, led by Sister Constance Gaynor (above).

First the hair loses its sheen, then its texture and color. First the skin grows sallow, then it becomes gray and almost translucent. Subepidermal fat is consumed, exposing the skull beneath the skin, the viscera under the sheath of the belly. You can actually see blood coursing through surface veins; you can see the heart beat against the fallen ribcage. The foe is implacable; the downward spiral, inexorable. There are no longer any "good" days, but there are still a few passable days, when it is possible to get the patient out of bed for a few hours (opposite). And then

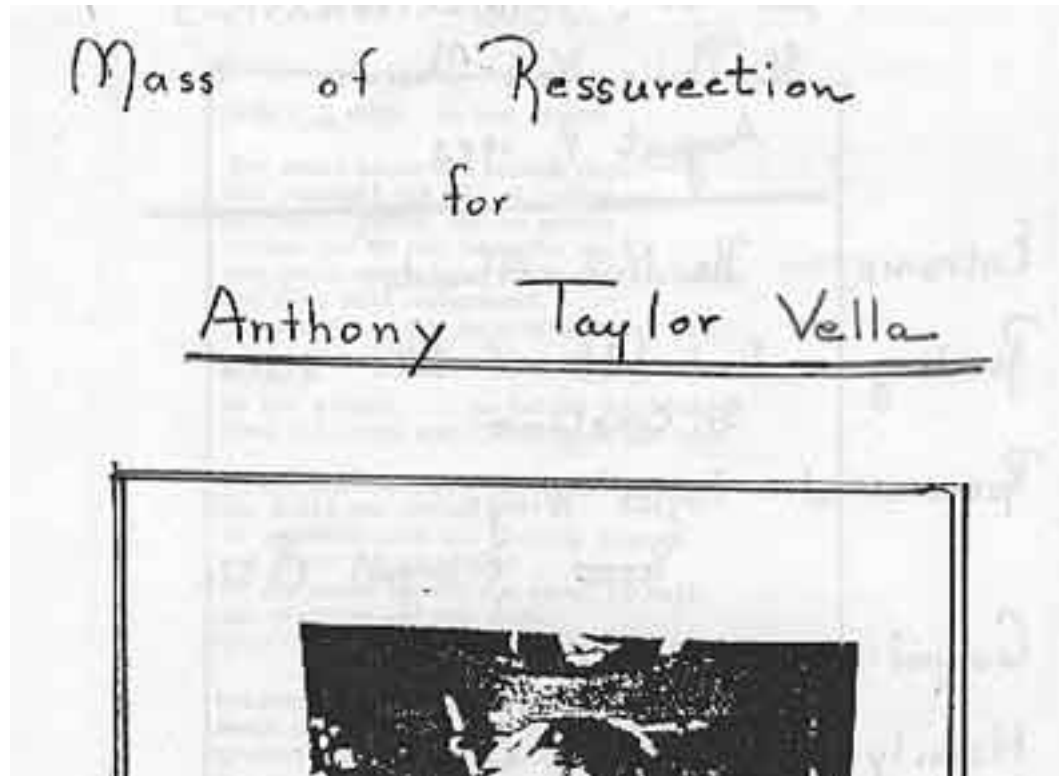


there are no good days, only bad ones and terrible ones. In the end, the anti-HIV medicines that once helped have nothing to offer but their adverse effects -- and when that time comes there is only palliative care, the essential elements of which are a comforting hand and a soothing voice.





When Anthony died, Sister Connie was with him. She had been his faithful and loving companion throughout his final illness, and it was she who held him close at the end of his life's journey.





Incarnation's Little Prince turned seven a few days before he died, in late July of 1992. There was no birthday party for Anthony that year; he was too sick. But there was a Mass of Resurrection held for him a few days later. The program was designed, and the service was attended, by members of Anthony's grieving family -- all of them from Incarnation, the only home he had ever known. As Claire Yaffa was to discover, the bodies of indigent infants who die of AIDS are transported to New York's Welfare Island, where they are interred in a mass grave with the corpses of other children whose families haven't the means to bury them properly. Not the



children who died at Incarnation, however. Most of them are buried in the Guardian Angel plot of Gate of Heaven Cemetery, under a granite headstone, provided by the Archdiocese of New York, on which each child's name is inscribed. The list is headed by infants who did not live long enough to receive names: Baby Boy Hernandez, Baby Girl Thomas. Anthony's name is midway down the third column. There is room for other names, but they are being added more slowly these days.



When Devonne came to Incarnation, he was less than a year old, he was very sick, and he was too young to take his daily medications by mouth, so they were administered through a nasal tube and by syringe (left). Like his two sisters before him and a brother who would follow, Devonne was placed in foster care shortly after his birth, because his mother was incapacitated by drug addiction. She was an erratic and infrequent visitor to I.C. C., but she was present for her son's second birthday party (at left, in the photograph below). After studying

Claire Yaffa's pictures of the event, she told her that they would be nice for Devonne to have after she died: "If he wonders if I loved him, he will see in your pictures that I really did," she said. And then she added, "Tell him that I couldn't control the drugs, so I couldn't control who I was."



The rituals of life are always important, and they take on heightened importance in a place like Incarnation -- where much is made of each birthday that each patient celebrates, because their number is likely to be cruelly limited.



Devonne with his new parents, Angelo and Rose Ruiz, and his younger step-sister, Nyla. Adopted a year after Devonne, she too is HIV-positive, and like him she remains clinically stable on antiretroviral therapy.

Two things have transformed the lives of pediatric HIV patients in recent years: protease inhibitors and publicity. The former have made it possible to suppress viral replication in seropositive children as fully, and as durably, as it is suppressed in adults who respond well to multidrug antiretroviral therapy. The latter has made the public aware of the plight of AIDS boarder babies like Devonne -- and this, in turn, has made it possible for institutions like Incarnation Children's Center to find homes for all but the very sickest of their charges. Devonne, who spent three of the first four years of his life at I.C.C., now lives with his adoptive family on Long Island. He returns to Incarnation for routine check-ups (below), but he

remains asymptomatic and clinically stable five years after his discharge.





At nine, Devonne is competent to take his own medications by mouth -- under the watchful eye of his new mother (left). In all other respects, he is typical of boys his age: he rides a bike, he rides the bus to school; he does his share of the household chores, he gets his share of affectionate nuzzling from the family dog (below). The respect in which Devonne's young life differs from that of his classmates and playmates is that his day is structured around the dosing schedule imposed by his triple-drug antiretroviral regimen. Because these

medications have been a part of Devonne's life from his earliest days, because they antedate his first memories, he is remarkably accepting of taking his medications -- and thanks to the ever-vigilant Mrs. Ruiz, he is fully compliant with his assigned regimen.



Children who are living with HIV need to take their prescribed medications -- in the doses assigned, at the times assigned. But they also need to take time for the other things that matter in a young life, like letting the family dog get a little "sugar" every now and then.



Proud owner of an entire fleet of dump trucks, hook-and-ladders, and police cruisers, Devonne is just another mischievous nine-year-old boy. Except that he isn't, of course: he is an AIDS orphan who is living with HIV. It is important to remember those facts, given how hale and rambunctious Devonne seems. Dr. Stephen Nicholas and his colleagues at Incarnation Children's Center can do more for the Devonnes of today than they could for the Anthonys of six or seven years ago, but they cannot stem the epidemic of HIV that is sweeping impoverished, drug-ridden communities like New York City's Washington Heights -- and that unchecked plague is producing new cases of pediatric HIV faster than Dr. Nicholas can discharge stabilized patients to foster families.

Readers who wish to make a contribution to support the work done at Incarnation Children's Center can

do so by contacting Dr. Nicholas, at (212) 928-2590. Readers who wish to introduce their coworkers and communities to Anthony, Devonne, and others like them through the remarkable work of Claire Yaffa can do so by contacting her, at (914) 698-8060. A travelling exhibition of 25 framed photographs -- selected from the hundreds that Ms. Yaffa has taken at Incarnation Children's Center over the last decade -- has been used by the Albert Einstein College of Medicine, the Cleveland Museum of Health and Science, and other institutions to tell the story behind the statistics on pediatric HIV infection. This exhibition can be made available to interested individuals and institutions at a nominal charge.

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