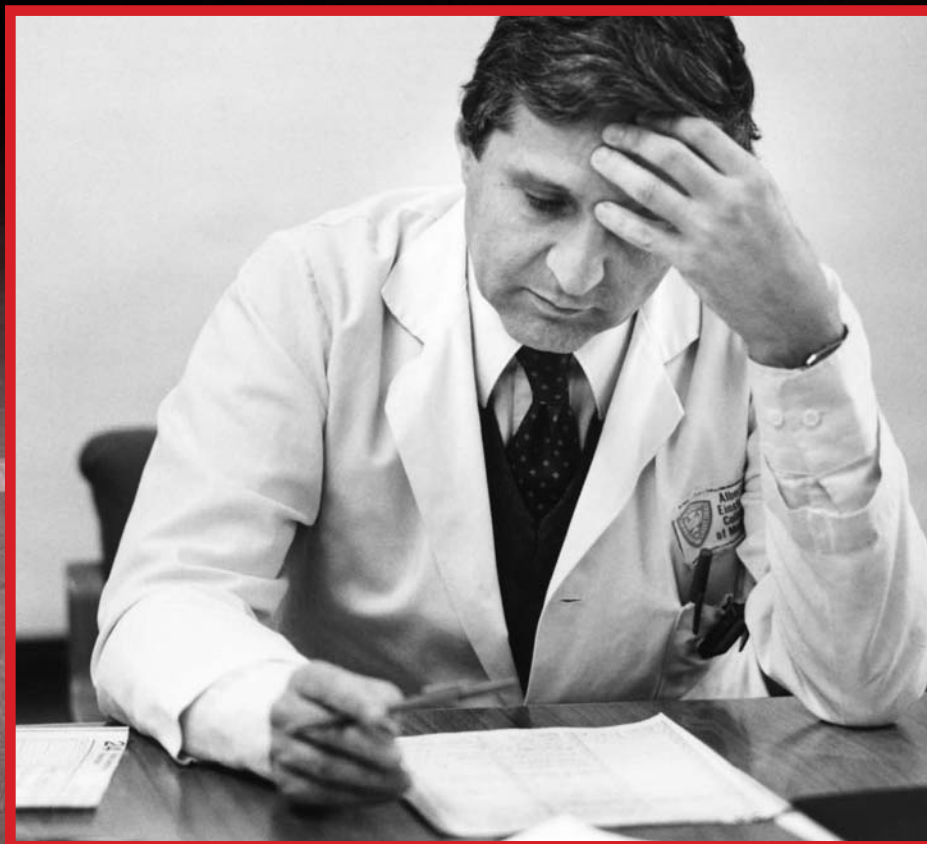


Children WITH AIDS

THE REMARKABLE STORY OF AN AMERICAN EPIDEMIC PREVENTED



Dr. Arye Rubinstein during the early days of the pediatric AIDS crisis.



Twenty-five years into the AIDS epidemic, these worldwide statistics stand above the rest: 65 million infected, 25 million dead, 0 cured. They are a sobering reminder of the suffering that continues and the challenges that remain, especially in the developing world.

But there is a different—and happier—story to be told about pediatric AIDS in America. In 1992, the Centers for Disease Control and Prevention reported 942 new cases of pediatric AIDS (defined as children under 13) in the United States. Tens of thousands of additional cases were expected in the years ahead, threatening to overwhelm hospitals and social service agencies. Thankfully, this doomsday scenario for children never materialized. In fact, pediatric AIDS has almost disappeared in this country, dwindling to a total of only 48 new cases in 2004.

A significant portion of the credit for this remarkable turnaround belongs to one institution, Albert Einstein College of Medicine, and to one physician, Arye Rubinstein, M.D., Professor of Pediatrics and Microbiology and Immunology.

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Einstein Firsts:

First to discover AIDS in children | First use of gamma globulin therapy in children | First finding of *in utero* transmission from mother to child

“... although Rubinstein was an eminent immunologist, he could not get anyone else to believe his unlikely analysis ... word quietly circulated that the Israeli-born researcher had gone a little batty.”

— Randy Shilts
And the Band Played On, 1987

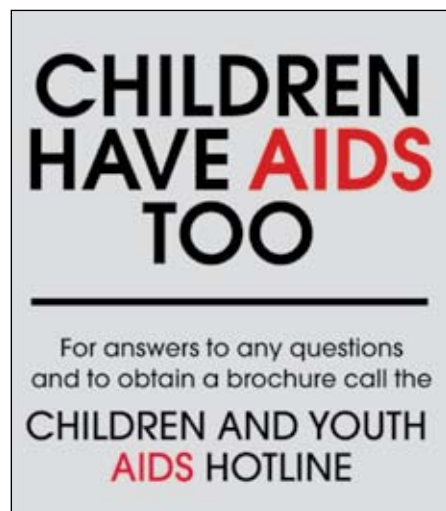
THE FIRST CASE

The story of pediatric AIDS begins in 1979, when an anxious mother brought her three-month-old to Dr. Rubinstein’s office. From all indications—enlarged lymph nodes and a bevy of infections—the infant was suffering from an immune deficiency. But the blood tests were confounding. The child’s immune system was clearly abnormal, yet the irregularities did not fit any known pattern.

Over the next two years, similar cases trickled into his office. At first, Dr. Rubinstein suspected that they were suffering from a new or rare congenital immune system defect. His thinking changed in late 1981, when he saw an infant with an immune deficiency whose mother was also immunocompromised. It made no sense. Parents of children with congenital immune deficiencies were never immunocompromised themselves. When more immunodeficient mother-baby pairs began to appear, Dr. Rubinstein was convinced that an infectious agent was to blame, and that somehow it was being transmitted from parent to child.

He also believed that the new disease, even though its presentation was a bit different, was related to GRID, or Gay-Related Immunodeficiency Disease (as AIDS was then known), the mysterious syndrome coursing through homosexual communities in New York City and other urban centers.

Dr. Rubinstein sounded the alarm through the usual channels, in meetings with colleagues and in scientific



papers. But, with a few exceptions, other infectious disease specialists wouldn’t listen, and medical journals, including the *New England Journal of Medicine*, wouldn’t publish his findings, despite his reputation as a leading immunologist.

Indeed, as Randy Shilts wrote in *And the Band Played On*, his landmark book about the early years of the AIDS epidemic, “... although Rubinstein was an eminent immunologist, he could not get anyone else to believe his unlikely analysis ... word quietly circulated that the Israeli-born researcher had gone a little batty.”

Given the projections of new AIDS cases, it was clear that many more such babies would be born to infected mothers. Many of these mothers would die. Who would take care of their babies? How would society cope with supporting a population that seemed born to die of such a horrible disease? Yet, pondering

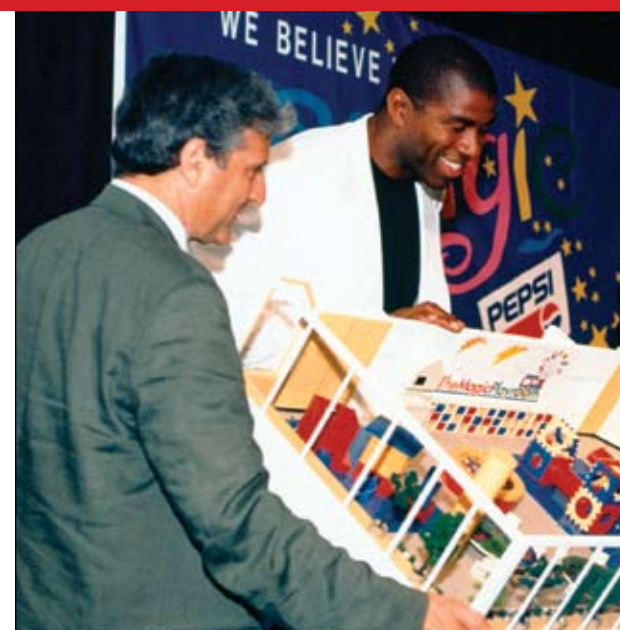
such solutions would happen only after Dr. Rubinstein had convinced somebody important that there was a problem, that these babies even existed.

FEAR AND LOATHING

Dr. Rubinstein kept at his seemingly quixotic quest. A scientist as well as a clinician, he knew that if he compiled enough data to support his theses, the medical establishment would have to respond. A big break came in 1982, when he was awarded the first National Institutes of Health (NIH) grant to study AIDS in women and children, focusing on the epidemiology, immunology, and pathogenesis of the disease.

From this work flowed a wave of findings, including evidence of links among the various immune disorders affecting infants, mothers, and homosexuals. One piece of evidence, found in the blood of patients from all three groups, was a common antibody that reacted with T cells, a type of immune cell, the presumed target of the infection. Ominously, Dr. Rubinstein found the same antibody in hemophiliacs who had come down with a mysterious immune disorder. The implication was that the blood supply was tainted. Again, no one in the United States wanted to hear of it, although his data did convince Japan to start screening its blood stores, using his antibodies. (In America, blood screening didn’t start until a few years later, in 1985, after the discovery of HIV, the virus that causes AIDS.)

In other studies, Dr. Rubinstein and his colleagues in the Division of Allergy and Immunology were the first to clarify the epidemiology of the disease, identifying the major routes of transmission: from mother to fetus, through sexual activity, and through blood products. “We also suspected transmission through sharing needles



Dr. Rubinstein pictured with Magic Johnson at the dedication of the Magic Johnson Playroom for children with AIDS.

because many of the mothers we identified as infected were substance abusers,” he says.

Nonetheless, scientific debate over transmission continued. “In fact, there was an editorial in the *Journal of the American Medical Association* in ’83 or ’84 in which some prominent epidemiologists thought there might be casual transmission,” he recalls.

It was exactly the wrong message the public needed to hear. Communities across the nation had begun to panic, barring HIV-positive kids like Ryan White, a young hemophiliac from Indiana, from attending school or participating in group activities.

“I was almost assaulted after testifying in court in Brooklyn,” says Dr. Rubinstein. “The parents in one school wanted to remove children who were infected, but I testified that HIV was not transmitted through casual contact. The parents got very upset, to the point where I had to be hauled out of the courtroom through a back door.”

The fear spread right to Dr. Rubinstein’s front steps. When he applied for a permit for a modest addition to his home in a New York suburb, hundreds of neighbors protested, accusing him of planning

a day-care center for AIDS babies, among other things. The permit was granted after a seven-year wait.

Sadly, some of his colleagues did not behave any better. As Dr. Rubinstein recounted in *AIDS Doctors: Voices from the Epidemic*, by Ronald Bayer and Gerald M. Oppenheimer, “In the beginning, everyone threw their patients at us because they were afraid of them.”

Ironically, those closest to the epidemic—the doctors and nurses in the trenches—didn’t fret much about catching the disease, knowing from experience that it was hard to get infected if you avoided risky behaviors such as unsafe sex and needle sharing. “We were not so worried because we had been, what should I say, extremely negligent in the beginning,” says Dr. Rubinstein. “We drew bloods from patients without gloves. We came into contact with the babies’ saliva. There were no precautions taken whatsoever, and none of us got infected.”

As time went on, Dr. Rubinstein published numerous papers documenting that casual transmission did not occur.

By the end of the decade, Albert Einstein College of Medicine had cemented its reputation as a leader in pediatric AIDS. When the NIH got around to establishing a national network of Centers for AIDS Research, one of the first seven grants naturally went to Einstein. Dr. Rubinstein was appointed director.

A GROWING EPIDEMIC

Meanwhile, the cases continued to mount. What started as a trickle soon became a flood. The largest number of pediatric HIV infections in the nation appeared in the Bronx, where a terrible mix of poverty, drugs, and promiscuity proved to be the ideal incubator of the disease. Most of those children eventually found their

way to Dr. Rubinstein and his team at Einstein.

Dr. Rubinstein responded to the growing epidemic by opening a service for children with HIV at the Einstein-affiliated hospital across the street, Jacobi Medical Center. It was the first, largest, and most comprehensive service of its kind, and a model for hospitals around the nation. By 1985, its second year, the service was caring for 60 children and almost 200 family members.

The following year, after realizing that many of these kids had never learned how to play or to socialize, he created a day-care center for children with AIDS.

Over at Einstein’s University Hospital, Montefiore Medical Center, Karen Hein, M.D., Clinical Professor of Pediatrics, launched a program for adolescents with HIV, another first.

Later, Dr. Rubinstein started a summer camp in the Catskills for the children and their families. The name and location of the camp had to be kept secret, so as not to stir up fears and protests in surrounding communities. Dr. Rubinstein himself attended, bringing along his twin girls and a variety of staff members.

And, he was also a principal force behind a therapeutic playroom for children with HIV, funded by the Magic Johnson Foundation, which opened at Jacobi in 1992. “We’re here today to forcefully declare that these children should get the very best care we can give them—medically, socially, and emotionally—for as long as we have them,” he said at the dedication ceremony.

“I never thought I would do so much work in social services,” says Dr. Rubinstein. “But the reality of AIDS pushed us into it.” He further elaborates in *AIDS Doctors*:

“I realized I was dealing with a totally different population. You cannot just see these patients for an

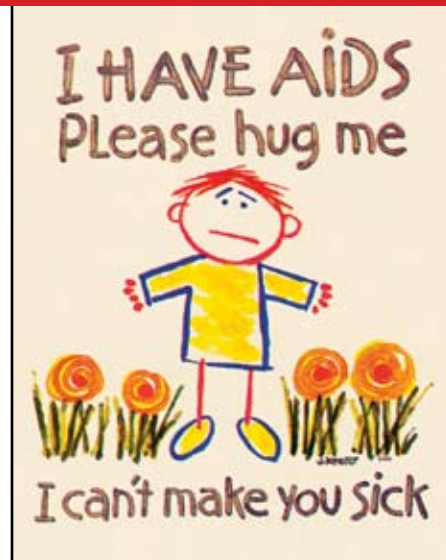
hour in your own clinic and say good-bye and assume that ... there will be compliance ... It was clear from the beginning that you have to go much more into the socioeconomic situation of those families ... And that's why I started this social medicine program here very quickly. At this point, we have social workers. We have outreach workers that go to the houses. You cannot treat these children without having this kind of outreach. It's a futile exercise."

OVERWHELMED

The first of those social workers was Dr. Anita Septimus, who started at Einstein in 1985. Relatively new to social work and admittedly naïve about HIV/AIDS, Dr. Septimus was overwhelmed. "In the first month, we lost four babies. I told Dr. Rubinstein, 'I didn't come here to bury children. I can't handle it,'" she says. The work was infinitely heartbreaking, especially for a mother with four children of her own at home, including a two-year-old. Family and friends thought she was "nuts" to take the job in the first place.

At Dr. Rubinstein's urging, she agreed to stay a while longer. Twenty-two years later, she's still working with children and families with HIV. "Once I was involved in that work, I couldn't turn back," she says. "It was very intense, very difficult. But there were also beautiful lessons of love and care, coming especially from foster mothers who found out after the fact that their foster children were infected but would not give them back."

Dr. Septimus started with 30 families, a normal caseload. Within months, her caseload doubled, and doubled again. She hired one assistant, and then two more. The staff leapt from crisis to crisis, managing as best they could to make sure the children and families received the care,



support, and education they needed. Early on, Dr. Septimus initiated a family-centered model for AIDS case management, a program that is still operational today. Still, many families disintegrated. "Boarder babies"—newborns abandoned by their mothers, many infected with HIV themselves—began to fill the pediatrics wards of local hospitals. "It was so difficult to deal with it," Dr. Septimus says, "and I always wondered why these babies were being born to suffer."

But Dr. Septimus would come to learn, as Dr. Rubinstein had learned before her, that there were extenuating circumstances. Early in the epidemic, he made home visits in the South Bronx, which had come to resemble Dresden after the war. As he told the authors of *AIDS Doctors*, "I had no idea what poverty was. So when you go into such an apartment, and you see a kid on the bare floor, with just a television set, a kid who's living with rats, has never seen the ocean or a nice tree ... At that time, in '84 and '85, we had volunteers who took kids to the zoo, to the beach. And one of the kids, I'll never forget it, when this kid saw the ocean, he thought it wasn't real ..."

At Einstein, Dr. Rubinstein knew what the rest of the country was just beginning to figure out: that AIDS was no longer a problem limited to gays. It was also spreading among IV drug abusers, heterosexuals, women, and children, hitting poor minority neighborhoods the hardest. He feared

that HIV would soon make the leap from drug abusers to teens, and then it would proliferate among sexually active high schoolers. Accordingly, he lobbied for aggressive education in schools, but his pleas were dismissed by critics as alarmist. Once again, he was tilting at windmills.

"If you look at the projections, the numbers are grim," he told the *New York Daily News* in 1985. "I don't think there'll come a time when AIDS will have passed into history. There are a few million carriers, some may develop the disease in 10 or 20 years."

In a perfect world, such projections would have translated into even more support for AIDS-related health care. But Einstein's Division of Allergy and Immunology consistently had to struggle to keep its clinics afloat and to mute neighborhood opposition to expanded AIDS services. In 1991, the Division lost almost one million dollars in state and private grants for its clinics, which had served 1,200 patients the previous year.

TURNING POINTS

Despite all the gloom and doom, Einstein's infectious disease specialists were making headway. Early in the epidemic, they found that intravenous gamma globulin—a blood product rich in antibodies—helped prevent bacterial infections and T-cell attrition in children with AIDS, significantly improving survival rates. "Without gamma globulin, most of these patients would have died within a few years," says Dr. Rubinstein. "It gave us time to tide over many patients until HAART (highly active antiretroviral therapy) came into play" in the mid-nineties.

The group's educational efforts—ranging from one-on-one sessions to community forums to public health campaigns—also made a difference, persuading countless women to get tested for HIV, to take precau-

tions against the virus, and to avoid becoming pregnant if they were already infected.

The most significant advance in pediatric AIDS was Zidovudine, better known as AZT, the first of many antiretroviral medications to come. AZT was approved for use in adults in 1987, though it didn't become a staple for preventing mother-to-infant transmission until trials were completed in 1994. Again, Dr. Rubinstein played a role in this treatment milestone. His studies were the first to show that, in some pregnant women with HIV, transmission of the virus occurs at the cusp of the first and second trimesters, not only at delivery or through breast feeding. This finding figured in the development of Protocol 076, the guideline for administering AZT to pregnant women infected with HIV.

Within a few years, new cases of pediatric AIDS began to plummet. The worst of the epidemic was over.

"It's very unusual now," says Dr. Rubinstein. "Last year, I think we had two new patients."

LINGERING EFFECTS

The pediatric AIDS epidemic in the United States may have subsided, but its effects linger. Thanks to Dr. Rubinstein and colleagues, many of the first children with HIV are still with us, moving through adolescence into adulthood, presenting a whole new challenge to health-care workers.

"Now we are struggling with medical compliance," explains Dr. Septimus, whose staff follows some two dozen of these patients. "They're angry. They don't want to be different. They don't want to take medications or use protection or tell their partners. They are typical teenagers who do not listen."

Many of these teens have no parents or have left their foster homes, struggling to survive on the street.

... the real work in pediatric AIDS is just getting started at the global level.

Some disappear for months at a time, calling the social workers only when they are in crisis, with dismally low T-cell counts and high viral loads. "We have to constantly run after them," she says. "We have a few encouraging cases, who are in college or in stable relationships. But for the most part, it's a huge challenge."


Unfortunately, many healthy teens are just as complacent about HIV, a source of great worry in the AIDS health-care community. "No matter how strong the message—get tested, use precautions, consider everybody as a potentially HIV-infected person—it's not getting across," says Dr. Septimus. "They grew up in a different time. It is almost like they have to relearn what we learned the hard way, and that is very scary."

JUST GETTING STARTED

With pediatric AIDS on the wane, Dr. Rubinstein has shifted his clinical focus back to patients with primary, or congenital, immune deficiencies, one of

his specialties before the epidemic struck.

His AIDS research continues, however. "I am very pleased to see fewer HIV-infected women and children," he says. "But there is a lot of work that has to be done in developing countries." In one research project, he is developing an anti-HIV contraceptive gel based on urea, a natural component of urine. He also hopes to resurrect his long-standing AIDS vaccine studies, which have been sidelined for lack of funding.

Despite all these accomplishments in the United States, the real work in pediatric AIDS is just getting started at the global level. At the most recent International AIDS Conference, experts noted that 2.5 million children under age 15 worldwide are infected with HIV. 

Dr. Arye Rubinstein and Dr. Anita Septimus, still working together more than 25 years after pediatric AIDS was first identified at Einstein.

