HIV in Cuba: Prevention of Mother-to-Child Transmission

By Jorge Pérez, MD, MS

These passages are excerpted from the book *SIDA: Confesiones a un Médico* (AIDS: Confessions to a Doctor) by the physician who more Cuban HIV/AIDS patients call doctor and friend than any other in Cuba. His work as head of the island’s first AIDS sanatorium - where all patients were required to live before Cuba abandoned the policy for ambulatory care in 1993 - and later directing care for AIDS patients at the Pedro Kourí Institute of Tropical Medicine, has brought him in touch with most of the 6,682 who have lived with HIV/AIDS on the island. “I began a diary,” he recalls, “when I first started working with these patients. I finally showed it to some of them, and they encouraged me to go on, write more and eventually it became a book.” The book, edited by Jacqueline Teillagorry Criado, is forthcoming.

“I found they suffered tremendously,” Dr. Pérez told *MEDICC Review*, “and I had studied medicine to relieve suffering. But I had no idea at first the extent of that suffering or how vulnerable they were. The discrimination many suffered out of others’ ignorance, the fact that they had no cure, that their lives were turned upside down - I really knew very little of all the human conflict surrounding their illness. So I started to write for myself really, to educate myself.”

In Cuba, we have detected few HIV-positive children. It was late in 1985 when we detected the first case of HIV in the country, and began to suspect that there were others that had gone undiagnosed until then because they had remained asymptomatic. We thought we might find children among them.

Nevertheless, it wasn’t until 1989 that we discovered the first child in Cuba who was born seropositive - a little girl already three years old. And it was only then that we were able to study both the mother and the child, reinforcing the importance of epidemiological research in these cases, allowing us to adopt the kind of therapeutic actions that eventually saved her life. Yulia is now a young woman, about to celebrate her 19th birthday. While she was infected first, hers was the second case to be detected.

From the start, the national HIV/AIDS program contemplated testing pregnant women, in order to take measures to avoid vertical transmission (from mother to child), perinatal transmission (during delivery), or during the first year of life (through breastfeeding). The screening was how we discovered the second child infected, but the first detected, Daimara.

Daimara’s Story

Beginning in 1986, as new seropositive patients were discovered, we began studying their sexual partners. In the middle of that year, we diagnosed Daniel, a young man from Guantánamo Province who had served in Angola. We then examined his wife, Milagros, who was pregnant at the time. Her first results were negative, but follow-up studies showed her to be HIV-positive. Milagros didn’t believe she could be infected: at the time, there were very few cases in general, and she was the only pregnant woman diagnosed with HIV.

At first, interruption of the pregnancy was an option. But later, this possibility was discarded, since she was quite far along, and also because she wanted to have the baby, and thus had decided against abortion.

Milagros, who had the open and honest approach to life shared by many people from the Cuban countryside, was by then living in anguish and desperation. Difficult as it was for her to accept her own diagnosis, she was terrified at the possibility that her baby could be born with the illness, and at the suffering that would await such a child. She prayed for her baby to be healthy, a baby she had always wanted; she cried herself to sleep; and tried to find...
consolation in everyone around her.

She had never imagined when her husband returned from Africa that such
dangers would envelop her, threaten her family and her desire to be a mother;
that she would spend her days thinking that her daughter would be born with a
disease she had never known of but had learned was terrible, full of suffering.
Physicians in Cuba at the time didn’t have enough experience to give her the
confidence she needed, as she faced the fact that hers could be the first
Cuban baby born with HIV.

In November, 1986, the moment for delivery arrived. Daimara was born at low
birth weight. Since her parents were seropositive, and she was the first
believed to be infected by vertical transmission, her case was carefully
studied. As is well known, even now, detection of the infection in newborns is
difficult, and so periodic follow-up was indicated. The literature notes that
some children develop symptoms sooner than others, and thus their cases are
suspected earlier. But in others, symptoms are not as apparent, and diagnosis
can only be made later. Internationally, definitive diagnosis cannot usually be
made before 18 months of age.

Nevertheless, from the moment of birth, Daimara began to have problems
including anemia and retarded development, both in size and intellectual
capabilities. Thus, she was hospitalized for quite a long time, making her
relationships more difficult, as she began to be raised exclusively among adults
without other children around her. She had learning difficulties, due both to her
state of health and because of respiratory complications caused by continuous
bacterial infections and her anemia.

Psychologists offered her a great deal of support and special care. Yet, her
health deteriorated by the day, and her immune system weakened. Because
she had been hospitalized so often, I remember that she would hold out her
little arms automatically so we could find her vein. She endured that suffering
as if it was something natural, and cooperated with us so that the catheters
would last as long as possible.

She was surrounded by affection - from her parents and from all those who
lived in the sanatorium who were moved by the tragedy of seeing this first child
detected to have HIV/AIDS, and visited her often to cheer her up and just be by
her side.

Blonde and very pretty, despite the pallor from her anemia, Daimara laughed
easily and loved candy. But despite everything, the sanatorium staff and other
patients realized that she wasn’t growing. What followed were four anguish-
ridden years, with respiratory complications coming more frequently, her
anemia becoming more severe, and then a final hospitalization. A few months
before her fourth birthday, Daimara, the first child detected with HIV in Cuba,
died. That was in February, 1990.

Her death was a terrible blow to Milagros and Daniel, and for all of us who
knew her and lived with her - doctors, psychologists, other staff and patients.
With her passing, the Santiago de las Vegas sanatorium lived through one of
its saddest days.

Yunia’s Story

In April 1989, a patient is diagnosed who says that she had sexual contact with
a truck driver whose route took him all over the island. That same month, in
Santiago de Cuba, another female patient is interviewed and refers to a similar
relationship with a truck driver.

In May 1989, in Ciego de Ávila Province, a pregnant woman is screened and
diagnosed seropositive. When her husband is tested, he is HIV-positive as
well. When he is interviewed, he says that he has a three-year-old child from
his first marriage in Guantánamo Province, and in all, he mentions nine
unprotected sexual contacts, of which five resulted HIV-positive and four
negative. Jorge was a truck driver, and he had served in Africa, returning to
Cuba in 1982. His ex-wife Nereida and his little girl Yunia were tested, and
both resulted positive. Thus, Yunia was in reality the first child to be born
infected by HIV.

Yunia had been born in Guantánamo on August 14, 1986, and was diagnosed in 1989. She lived in the same province until 1990, when she began having health problems and was transferred to Havana for hospitalization at the Juan Manuel Marquéz Pediatric Hospital for anemia, retarded growth and respiratory disorders.

Since she had to remain near the hospital for treatment, when she arrived at the sanatorium, I was asked to accept her there on a permanent basis with her mother - where she has lived all these years. From the beginning, she captured our hearts. She was very thin, dark-haired, small and congenial, eager to play with anyone around. She grew up on the sanatorium grounds, went to grade school, junior high school and graduated as a technician from a nearby technical school.

In 1996, the Cuban government bought the first antiretroviral medications. Yunia was one of the first children to have access to the therapy, and improved considerably with treatment. We've watched her grow up, go to school, and develop healthy relations with other youngsters at her schools. I remember they would visit her at the sanatorium to study or play. We celebrated her 15th birthday with her school friends, her own family and her sanatorium family. She's now the longest surviving child born with HIV, and soon will be 19.

On New Year’s Eve, 1995, I was visiting patients hospitalized at the Pedro Kourí Institute of Tropical Medicine (IPK), and had a bedside conversation with Yunia’s father, who was very sick at the time.

He told me that he felt he wouldn’t be alive much longer. ‘I feel death creeping up on me,’ he said. And he began to talk about the other daughter he lost from AIDS when she was only two.

Jorge was referring to his daughter born in 1989 to his wife in Ciego de Ávila Province. She was unfortunately born with HIV despite all the measures taken during pregnancy and delivery. At the time, there was no possibility of prophylaxis medications, and the delivery in Havana was by caesarean. Mother and child were transferred to Ciego de Ávila, where they lived, but the infant developed severe anemia from the start, as well as respiratory infections.

She was hospitalized in the province several times, and finally referred back to Havana where she was received already suffering from many infectious complications. A few days later, on August 30, 1991, she died at the age of two years. Jorge became severely depressed at the news, lost weight and began to suffer from his own complications, a prelude to his progressive immunological deterioration.

AIDS-related complications - opportunistic infections - ended Jorge’s life on April 21, 1996. This young man who had served overseas had been unaware of his diagnosis, and thus infected five women and in turn, two little girls, his only children. Perhaps this is why on that New Year’s Eve in 1995, he asked me to take care of his remaining daughter.

His eyes were dry. ‘Do whatever it takes to help her live,’ he said. ‘It’s too sad, too painful for me, to think that I’ve brought these children into the world without knowing I was sick. I would give my life so they could live.’ He begged me to do all I could to keep Yunia alive.

His words stay with me to this day. I would go often to visit Yunia and her mother Nereida at their house in the sanatorium; I took other visitors there; I would show up with any little gift and keep track of Yunia’s grades in school.

Now Yunia is 18, a teenager who shows the signs of her illness in her height - she’s a bit smaller than her peers. But her social development is quite normal; she’s well integrated in her group of friends and classmates; she visits Guantánamo to keep in touch with her mother’s side of the family; and chooses to continue living in the Santiago de las Vegas sanatorium.
It is important to recognize that Yunia has grown up and developed without her father in an environment that, although never without warmth and affection or the attention of her mother, has been an aggressive one. Her activities as a child and young woman have been limited by her sickness, by its occasional complications, and by the multitude of medications she still has to take. Nevertheless, you don’t see her depressed. She’s learned to live with her illness, and done a good job of overcoming all the adversities that have touched her life.

Yunia has plans for the future, she has fun, she goes to parties, and has had protected sexual relations, infecting no one. She has a great degree of sexual responsibility. She dreams of the day when a cure will be discovered for AIDS and no more children will have to go through what she has.

She dreams of living.

In 2013, only two children in Cuba were born with HIV and five with syphilis, the statement said. ScienceDirect reports that it was brought about by relatively simple strategies: better testing and treatment of expectant parents, and providing HIV- and syphilis-positive mothers with options to protect their babies, such as bottle-feeding and C-sections. One of the barriers South Africa faces is that pregnant women may not seek PMTCT (prevention of mother-to-child transmission) services because they fear stigma if they are found to be HIV-positive following an HIV test. The WHO reports that although the burden of HIV infection in South Africa had been large for many years, the country did not implement a PMTCT programme until 2002.