A positive blood test was a death sentence.

Welcome to SBH Bronx Health Talk, produced by SBH Health System and broadcast from the beautiful studios at St. Barnabas Hospital in the Bronx. I'm Steven Clark.

From the early 1980s, when it was first identified, through the mid-1990s, the prognosis was dire: Almost uniformly, it was fatal. And, very likely, the end was not kind. Those afflicted with the disease literally wasted away. Lesions often grew on their brain, causing dementia. Thrush, a painful fungal infection, ravaged their mouths, tongues and throats, impairing their ability to eat or drink. A virus destroyed their retinas and their eyesight. Spots appeared on their skin, painless, but marking them as lepers of this insidious and stigmatizing condition.

Hospitals in New York City were overwhelmed. Doctors, nurses and funeral homes often kept their distance for fear of contagion. Government shied away from funding research for better treatments.

Today, nearly four decades later, HIV/AIDS is a chronic and often manageable disease. Patients who are compliant with their meds can expect to live long and normal lives.

Today's episode of SBH Bronx Health Talk departs from our regular format where we interview a featured clinician. Instead, we will examine the evolution of the HIV/AIDS crisis in New York City, based on interviews held recently with medical experts at SBH Health System who have witnessed the journey up close. This included a roundtable discussion with five infectious disease specialists who started their medical training at the beginning of the epidemic and an interview with the hospital's Director of HIV who has been on the front lines for nearly 30 years.

Dr. Ed Telzak, chair of the Department of Medicine at SBH and an infectious disease specialist, remembers being a young physician at a Manhattan cancer center with a very large HIV population. At first, the symptoms left doctors bewildered and isolated. Eventually, the city's major health institutions introduced weekly intercity calls to discuss this puzzling illness. This helped them identify new risk groups and the importance of such things as donor screenings prior to blood transfusions.

One of the very strong memories I had when I was at Memorial was a lot of people died from cancer and a lot of people died from HIV. The people who died from cancer, their rooms were filled with family at the end. The people who died from HIV, they were alone. Sometimes they had a partner, sometimes a crying mother from Nebraska would come. People died alone. I think the staff felt an obligation to sort of be involved in their death because no one else was there.

Dr. Telzak treated his first AIDS patient when he was an intern training in Boston in 1981. The patient was a young gay man about his age who had been transferred from a hospital in Cape Cod. The more experienced infectious disease doctors, he recalls, didn't know what to make of the patient's symptoms. A lung biopsy showed the patient had pneumocystis (NEW-MO-CYSTIS), a serious fungal infection of the lung, and was placed on a ventilator. Doctors treated him with a daily injection of Pentamidine (PENT-A-MY-DINE), a medication so rare it needed to be flown in by the CDC and picked up at the airport.

I remember giving him this daily injection in the ICU because he had failed Bactrim and Bactrim was a known treatment for pneumocystis based on all the leukemia population in children who developed pneumocystis. Bactrim was a proven therapy but he was getting worse. I gave him these daily IM injections…in his thigh, in his right and then in his left. He probably over the course of 10 days wound up dying and that was the beginning of a series of patients, all young gay men, who came in. Many had pneumocystis, but also a range of bizarre infections that most very experienced ID doctors had not seen.

Within several years, local hospitals in New York City, as well as in cities like San Francisco and Los Angeles, became inundated with HIV positive patients. Even more heartbreaking, the doctors as medical students and residents would see during their rotations in pediatric units a large number of children with AIDS. Dr. Judy Berger, Director of Infectious Diseases at SBH, was a medical student at Mount Sinai and resident and fellow at hospitals in Brooklyn.

I was in medical school from 1976 – 80 and didn't know there was HIV, but we began to see IV drug users by 1978 see IV drug users come in with swollen glands and we would send them for biopsies and there were all.

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It was a disease, says Dr. Berger, initially focused around the 4H's: homosexuals, Haitians, hemophiliacs, and heroin.

Dr. Jonathan Samuels first saw patients dying of AIDS when he came to New York City at around this time to train.

I remember there was one Christmas. **They were just so many of them and they were so sick and then weren't going to get better. It was so sad. Then AZT came out and they would get better for a little while. Their hair would grow back and they would gain weight and they would start to feel better and then after a year or two they would peter out and they would get really sick and die**. **And then they would be dead.**

Recent research shows that the AIDS virus actually first landed in America a decade earlier, around 1971. It's now believed that the time between acquiring the infection and the onset of symptoms, on average, runs about 10 years. This contradicted a once accepted premise that an Air Canada male attendant was "patient zero," spreading the disease through sexual partners along his route. The disease, it's since been determined, started in the Congo. It then spread as the result of a roaring sex trade, rapid population growth and unsterilized needles by rail and river after the Congo gained its independence in 1960.

Patients typically came to hospitals for care in the later stages of the disease. It was part stigma and part denial – after all, there was no rush to begin treatment. Once diagnosed as HIV positive, little could be done, remembers Dr. Telzak.

People were not motivated to be tested. Many of the patients we saw throughout the '80s already had AIDS by the time they were first tested. The median lifespan was 12 to 18 months. - As time went on, treatments became better there was much more motivation to be tested earlier. People started out at a much healthier position. The trick was to keep the patients alive until something better came around to treat them.

The drug AZT gave patients and providers hope but, in retrospect, Dr. Telzak calls it no better than a C minus drug. Dr. Michelle Dahdouh, an infectious disease expert at SBH, remembers some of the drug's drawbacks when she trained in the Bronx.

I remember with AZT it was very difficult for them to tolerate things, to have to take it every four hours, but it would keep them alive longer. The medication was so difficult for them to tolerate that it was almost equivalent to the disease.

There were concerns before, during and after the deaths of these patients. In some cases, healthcare professionals didn't want to take care of them. Surgeons didn't want to operate on them. Funeral homes didn't want to bury them.

Dr. Telzak says he began to feel as if he were a palliative care doctor. Dr. Berger, who started working at St. Barnabas Hospital in the early 1980s, remembers the precautions that were taken by staff.

We started wearing gloves. When it was first suggested we wear gloves, it wasn't accepted readily. They felt that the patient would feel stigmatized. It was really an issue of educating people that you would wear them on everybody. As long as you wore them for everybody, it wasn't a matter of being stigmatized.

There became more clarity among physicians when The New England Journal of Medicine published an article on June 7th, 1981. A month later, on July 3rd, The New York Times ran its first article with the headline "Ran Cancer Seen in 41 Homosexuals." By the end of 1981, the disease better known then as GRID (for gay-related immunodeficiency) had affected at least 335 people and killed 136.

In the mid-80s the NIH developed a consortium of clinical trials at several major New York City institutions. This led to incremental improvements in care with the arrival of individual drugs. Doctors did whatever it took to keep their AIDS patients alive. Dr. Carol Epstein, then a fellow in infectious diseases at a hospital in lower Manhattan, remembers counterintuitively using steroids on patients during acute episodes of pneumocystis (NEUMO-CYSTIS) pneumonia. The steroids saved their lives by calming the inflammation. Yet they did nothing to restore their immune systems. Many patients lived a little longer. It was putting a band aid on a hemorrhaging wound.

Occasionally, a patient survived. It was like hitting the AIDS lottery. These "elite suppressors" or "long-term non-progressors," as they were called, were blessed with robust immune systems that withstood the infections. Dr. Epstein has treated one patient now for nearly 30 years.

One of the patients in my private office I've seen since 1992. He's a super in a building Yonkers.

Over the next few years, organizations like Act Up rang the bell in search of answers. Dr. Telzak, who at this time was also spending time at the New York City Department of Health, believes Act Up helped save patients through their efforts.

It was the beginning of very intense patient advocacy and group advocacy. I think Act Up, in retrospect they were a pain in the ass and no one could do their work. They came in. They took over the commissioner's office. Ultimately they had a dramatic effect on the amount of the investment the federal government made. I mean Reagan and Bush were not interested. It was like God's message. This was a marginalized population. I think their mission was to get funding for treatment at earlier stages. The hell with three years of randomized control trials. You have a hint of a benefit then you give the drugs out. In fact, they sped up the FDA process.

In the summer of 1996, hope surfaced. Scientists presented startling data at the International AIDS Conference in Vancouver. Revealed was the extraordinary power of new antiretroviral drugs. Called protease inhibitors (PRO-TEASE), when used together they formed what became known as combination therapy (or HAART – highly active antiretroviral therapy). Although not a cure, the drugs overnight altered the course of the epidemic. Doctors were better able to treat their patients' opportunistic infections.

We all felt if we could get patients to take their medications, something better would come along.

There was a good deal of skepticism about the drugs at first – and the taste of the medication was nothing less than foul. Dr. Berger remembers how patients coated the inside of their mouths with peanut butter to soften the taste. The drug companies gave out water bottles with the pills because patients had to drink eight ounces three or four times a day. But these patients, who had been wasting away, started to gain weight and their T cell levels improved dramatically. To Dr. Berger and the others doctors, this was a parting of the seas, manna suddenly delivered from heaven.

The world changed. Our attitudes towards taking care of HIV patients. Why? Because we had something to offer. It wasn't just seeing patients and treating their opportunistic infections and trying to be positive. We all of a sudden had something to offer them.

Patients who were HIV positive and facing death found themselves planning for the future. Ralph Belloise, director of HIV at the SBH Health System, has been on the front lines in treating HIV positive patients for 29 years. He's seen what it was like then, and how it is today. The rates of infection in New York State, where treatment is paid for and social support is robust, continue to fall annually. Testing goals are continually surpassed. Those in the Bronx who get engaged in care in a timely fashion is at an all-round high, at 84 percent.

There are people who have been HIV positive for years, who take their meds every day. And people who have been disabled and able at work. If you take your meds every day, you'll do well. You do have section of population who will be virally suppressed before they adhere to their treatment plan. And you have those who quasi take care of themselves and fall off and say maybe I'll take a break. In two months, could be back in the upper stratosphere. And it could become resistant. And then you have the group who pay no attention to their care because of their psycho social situation. Transsexual population. But we're not seeing a large portion of the population that is not taking care.

The phrase "treatment as prevention" is pervasive today. Medication cannot only virally suppress patients, reducing the amount of HIV in their blood to undetectable levels, but it can prevent the sexual transmission of the virus. PrEP, or pre-exposure prophylaxis (PRO-FE-LAXUS), can lower the chances of individuals at high risk for HIV from getting the disease. Those who had an unprotected sexual encounter with someone whose HIV status is unknown can take a post (POST)-exposure prophylaxis to prevent an infection. Unlike in the '80s, intravenous drug users today can walk into a pharmacy to get clean needles.

Belloise says he still occasionally sees patients with T-cell levels like in the '80s, patients with very compromised immune systems. This is mostly the homeless and the mentally ill. Yet, the majority of the HIV infected patients he sees may never even get an illness diagnosis.

Don't use AIDS any longer, our epidemic is predominantly HIV positive. They will never have an AIDS diagnosis, put on medication early. Won't even have HIV illness diagnosis, just HIV infection as long as they take their medication every day.

To date, more than 100,000 New Yorkers have died from AIDS-related causes. Both well-known people like Arthur Ashe and Perry Ellis and Halston, and those whose families chose to abandon them as they lie dying in isolated city hospital rooms. And while an estimated 125,000 HIV positive people live in the city today, 20 percent of whom don't realize they are infected, they have a right to believe they now have a future.

Dr. Berger met last week with a recently diagnosed HIV positive patient.

I told this patient that he will live a long life if he takes his medications.

In addition, she recently wished a happy birthday to another HIV positive patient… on his 80th birthday.

Thank you for joining us on SBH Bronx Health Talk. For more information on services available at SBH Health System, visit www.sbhny.org. Thank you for joining us.