



30 Years of AIDS in Niagara County

The first reports of the deadly new disease that seemed mostly to affect young gay men in San Francisco and New York came 30 years ago in the summer of 1981. But there were no signs of Acquired Immunodeficiency Disease Syndrome in Niagara County until it was reported during AIDS Awareness Week in July 1985 that two residents had contracted the disease.

A year later, those two plus one new additional victim had died.

These were days of panic and fear. There was no cure. No effective treatment. AIDS seemed to be a death sentence. By the end of 1986, Niagara County had a fourth AIDS patient. In Erie County, 15 of its 30 AIDS patients had died.

Authorities were scrambling to find ways to curb the disease, which they knew was spread through blood and bodily fluids. In 1987, the Niagara Falls Fire Department issued surgical gloves for protection. Firefighters responding to accidents “have become aware of their vulnerability, and they’re becoming a little apprehensive,” said Deputy Fire Chief Robert Miller.

The only gay bar in Niagara Falls, the Crazy Horse Saloon, held an “AIDS Prevention Nite – Kill the Killer Disease,” on Feb. 28, 1987, giving away a condom with every drink. “Safe sex – that’s what it’s all about,” said bar owner John Alquist. “People have this misconception that if you’re not in jail or gay, you can’t catch the disease.”

President Ronald Reagan that summer suggested mandatory Human Immunodeficiency Virus (HIV) testing for immigrants and for couples getting marriage licenses. That idea met some skepticism and was never implemented. “When you get to that point, you may as well do mass screening,” said Dr. Steve Grabiec, who was then president-elect of the Niagara County Medical Society. “And I don’t think that’s practicable or desirable.”

Brent Nicholson Earle, who had been born in the Falls and grew up in Lockport, was a gay off-Broadway actor and playwright in New York who saw 70 friends and acquaintances die of AIDS. In March 1986, he set out on a 9,000-mile run around the perimeter of the United States to draw attention to the epidemic. It took him 20 months and he drew a lot of publicity. All over the country he got police escorts into towns and cities, but when he reached Lockport, the police refused. "Why?" he wondered. "Oh, I think it has to do with bigotry and prejudice against gay people." But then as he set out down Transit Road into Lockport, then-Mayor Raymond C. Betsch and his son suddenly showed up and escorted him in. At City Hall, old childhood friends were waiting to cheer him, and the mayor issued a proclamation.



Brent Nicholson Earle

Earle, who learned in 1989 that he was HIV-positive, went on in 1990 to run from San Francisco to the Gay Games in Vancouver, and in 1994 from San Francisco to the Gay Games in New York. He's been profiled in Parade magazine, and was named by People magazine as one of "20 individuals who shaped the '80s." Today at age 60, he lives in New York and remains an AIDS activist.

At the beginning of 1988, Niagara County's cumulative AIDS tally remained at four. "Everyone figures that Niagara County is protected for some strange reason," said Diane Kraft of the then-new Niagara County AIDS Task Force.

Such complacency wasn't warranted. By Aug. 31, the tally had doubled to eight, including seven who had died. (HIV-positive diagnoses that had not advanced to AIDS were not tracked in those days.)

HIV/AIDS education in the schools became a priority. Planned Parenthood organized a troupe of Niagara County high school students to do improv performances about AIDS. A state "AIDS van" visited LaSalle Junior High with interactive lessons about the disease. Dr. Maria Crea, a pediatrician who was then vice chief of medical staff at Niagara Falls Medical Center, bluntly told a group of students: "You have to realize that somebody who has AIDS is going to die. The only safe sex is not to have it."

Dr. Crea, who is now executive director of the medical societies of Niagara, Genesee and Orleans Counties and president of the Health Association of Niagara County Inc., was reminded recently of that quote from 22 years ago, before the existence of effective treatment for HIV/AIDS.

"It's still a terrible disease," she said, pointing out that treatment isn't always 100 percent effective and sometimes has serious side-effects. "We have effective treatments for heart disease, too," she said, "but that doesn't mean you want to have a heart attack." Her basic advice remains intact, she said: Abstinence or faithfulness in relationships are the only ways to be absolutely certain of not sexually contracting HIV.

By December 1989, there had been 19 Niagara County residents diagnosed with AIDS, 11 of whom had died.

By Oct. 31, 1990, the count was 37 cumulative AIDS cases and 21 cumulative deaths. Five months later, 42 and 23. Four months after that, 54 and 31.

Although the virus was spreading, the introduction of the first effective antiviral drug, AZT, was beginning to give hope of survival. The death rate among Niagara County patients diagnosed with AIDS through 1988 had been 100 percent. Beginning in 1990 the rate began to fall.

By mid-1992, there were 62 cumulative AIDS cases and 42 cumulative deaths. A year later, 75 and 56.

The sickness and death was taking an emotional toll not only on patients, but on the people who loved them or survived them. At the Niagara Falls Catholic Worker House, 931 Niagara Ave., John Orta started a support group for families. "If you look at how the disease has destroyed our families with fear and everything else, it seems the virus is winning," he said. "It's time we turn this around and do the conquering."

On Dec. 1, 1994, the Niagara County AIDS Task Force marked World AIDS Day, as it has every year since. There was a candlelight procession from Abate Elementary School to the Earl W. Brydges Library for a remembrance program. One attendee, Carole Baum, whose 25-year-old son had died of AIDS four months earlier, lamented the lack of treatment options available in Niagara County. Her son had traveled up to five times a week to be treated by physicians in Buffalo. "We need facilities here," she said. There were then 94 people living with AIDS in the county.

A milestone in the fight against intravenous transmission of HIV by needle-sharing drug users occurred in 2000, when the State Legislature changed the Public Health Law to authorize a demonstration program to expand access to sterile hypodermic needles and syringes. The Expanded Syringe Access Program became effective January 1, 2001 and as of the summer of 2009, became a permanent program. Today, pharmacies throughout Niagara County can sell up to 10 syringes to persons over 18 without a prescription, and they also accept returns of used syringes.

Today, 17 years later, more than 180 people in Niagara County are known to be living with HIV or AIDS. Highly Active Anti-Retroviral Therapy – "HAART" aka "The Cocktail" – has turned the disease for most into a chronic, manageable condition requiring only one or two med dosages a day. However, some very long-term HIV/AIDS patients are experiencing greater or lesser degrees of mental or physical impairment, perhaps due to the toxicity of the treatment regimen or to its inability to completely eliminate the virus from spinal fluid. Scientists aren't sure. Research is continuing.

Meanwhile, access to treatment for Niagara County residents still means travel. There are no physicians in Niagara County who are HIV-certified treatment specialists. This means that HIV-positive Niagara County residents must go to Buffalo, 20 miles away from Niagara Falls, or to Rochester, more than 80 miles away for health care.

Erie County Medical Center and AIDS Community Services in Buffalo are the region's designated AIDS treatment facilities, and neither maintains a presence in Niagara County. Many HIV-positive individuals move to Buffalo to be near their care providers.



Community Missions' Marks Place residence, no longer in use.

Because some AIDS patients were homeless or had nowhere to go after being released from ECMC, Community Missions of the Niagara Frontier opened Mark's Place in an old Victorian mansion at 1011 Michigan Ave. in the Falls in September 2004. It provided transitional housing for up to four people – “a buffer zone between institutional care and independent living” is how Program Supervisor Brian J. Planty explained it. In 2009, Community Missions closed the Michigan

Avenue residence and added two rooms for residents with AIDS at its main facility at 1570 Buffalo Ave. in Niagara Falls. Benedict House in Buffalo also houses some AIDS residents from Niagara County.

Besides HIV/AIDS education and prevention activities, one of the major missions of the Niagara County AIDS Task Force is to make residents aware of the services offered by its member agencies. For example, the Greater Buffalo Chapter of the American Red Cross has extensive transportation assistance available to HIV-positive Niagara County residents who need to get to Buffalo for health care. The Red Cross also offers temporary housing funds for HIV/AIDS patients. Details on those and many other relevant programs and HIV-related topics are posted elsewhere on this website.

These days, because of the wonderful medical advances in treating HIV/AIDS, a dangerous complacency is taking hold locally and nationally. Yes, people are living for decades with the virus, but additional people are catching it, too. In 2008, the latest year for which statistics are available, about 30,000 new cases were diagnosed nationally, including 10 in Niagara County. Symptoms sometimes don't occur for years, so many people are unknowingly living with the virus, perhaps 250,000 nationally.

The only way to be sure is to be tested. HIV testing is offered 10 a.m. to 3:30 p.m. Mondays and Wednesdays at the Niagara County Health Department's clinic at 1001 11th St. on the third floor of the Trott Building in Niagara Falls. It is also offered 8:30 a.m. to 5 p.m. Monday through Friday at the Community Health Center of Niagara, 501 10th St., Niagara Falls.

Those who take the test and get a negative result can put their minds at rest. Those who test positive can begin prompt anti-retroviral treatment to prevent AIDS and maintain a healthy immune system. They also can take steps to protect others, such as by practicing safe sex and by informing previous sexual partners that they, too, need to be tested. And HIV-positive women who are pregnant or want to become pregnant can learn how to prevent mother-to-child HIV infection.

Thirty years after HIV/AIDS first surfaced, no end to the epidemic is in sight. Researchers are working on a vaccine and a cure, but for now prevention is the only certain defense. That means abstinence or mutual faithfulness in sexual relationships, practicing safe sex, and not sharing needles.