Beginning in 1987, a team of Vermonters built a statewide network — a safe place for people with HIV and AIDS to receive the best of care. Today, with improved medications, the response to the disease has changed, but the caregivers are still at work.

"I never used to ask when they'd gotten their last tetanus shot," says Deborah Kutzko, A.P.R.N., of her HIV-positive patients at Fletcher Allen’s Comprehensive Care Clinic, for whom tetanus was low on the list of concerns.

25 YEARS OF CARE AND ADVOCACY

by Sarah Zobel | photographs by Raj Chawla

SO MUCH HAS CHANGED for the better in the quarter century since infectious disease specialist and Professor of Medicine Christopher Grace, M.D., and his colleagues founded the network of Comprehensive Care Clinics (CCC) that serve people with Human Immunodeficiency Virus throughout Vermont. Twenty-five years ago, patients with HIV/AIDS contracted disfiguring and deadly infections and cancers, suffered terribly, and were doomed to die. The human toll on the patients, most of whom were still young, and on their loved ones was catastrophic. Mostly they needed hospice care, or a plan that included it eventually. Today they need job training and routine cholesterol checks. Their future has been altered in that most of them now have a future.
“Now we’re doing tetanus shots and mammograms and colonoscopies because we fully expect them to live a normal lifetime.”

“That’s been the biggest change in HIV practice,” says Kemper Alston, M.D., professor of medicine and director of infection prevention at Fletcher Allen, “the shift from a traditional hospital-based, hospice-based illness model to more of a social one.” Behind that change is the significant advancement in medications that control the level of the Human Immunodeficiency Virus. While in the early years of the epidemic patients had to take fistfuls of pills several times a day — sometimes 30 to 40 daily pills laden with highly toxic medications — the advent of protease inhibitors in 1996 led to the development of highly active antiretroviral treatment (HAART).

“That was a game changer,” says Grace, who in addition to directing the CCC is director of the Infectious Disease Division at the College of Medicine and Fletcher Allen. “It’s almost like a switch was turned, and outcomes changed.” As a rule, today’s patients, so that, for example, a Bennington patient who called in with diarrhea wouldn’t have to make the nightmarish drive all the way to Burlington or Albany or Boston to be seen by medical personnel.

“We created a ‘medical home’ before the term was invented,” says Grace, surrounding the patient with all points of care that he or she might need, including doctors, nurses, social workers, psychiatrists, and dieticians. The word “cocoon” came to frequent conversations about the clinics.

The clinic nurse is on site at each of the satellite clinics. The clinic physicians, psychiatrist, and dietician drive to the satellite clinics monthly, while working with the clinic nurse by phone between visits. These clinic days can be long ones, with round trips of 200 to 300 miles in addition to the hours spent providing care to a full day’s schedule of patients. Vermont winters add to the challenge of making this model of care work.

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Funding for the expanded clinics came from a 1994 Special Projects of National Significance (SPNS) grant under the Ryan White HIV/AIDS Program through the U.S. Health Resources and Services Administration (see sidebar). Grace and Kutzko spent two years planning the clinic program, which entailed patient and hospital surveys, data collection, grant writing, innumerable meetings with AIDS service organizations, local hospitals, administrators, patients, and patient advocacy groups. The hospitals were very supportive, and more than willing to provide space for the clinics, generally located within other departments, partly for purposes of confidentiality. They named them the Comprehensive Care Clinics because they knew patients might shy away from an “HIV Clinic.”

“We certainly had HIV/AIDS patients here in the community,” says Tom Huebner, Rutland Regional Medical Center CEO, “and we had interns and family practitioners dealing with it, but they didn’t have the level of expertise that was needed, so we said yes almost immediately.”

Northeastern Vermont Regional Hospital’s CEO Paul Bengston echoes that sentiment.

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The CCC Genesis

The Special Projects of National Significance (SPNS) from the Federal Health Resources and Services Administration (HRSA) provided a grant to establish the satellite clinics in Rutland, Brattleboro, and St. Johnsbury. According to the “shift from a traditional hospital-based, hospice-based illness model to more of a social one.” Behind that change is the significant advancement in medications that control the level of the Human Immunodeficiency Virus. While in the early years of the epidemic patients had to take fistfuls of pills several times a day — sometimes 30 to 40 daily pills laden with highly toxic medications — the advent of protease inhibitors in 1996 led to the development of highly active antiretroviral treatment (HAART).

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"Without a lot of fanfare, it was set up and running pretty quickly," he says, noting that the only real concern expressed was by patients, who were worried about confidentiality. That has not proved to be an issue.

In Burlington, the clinic was initially housed in the oncology department at University Health Center. "We were at the very end of a hall, which was perfect," says Kutzko, since the majority of patients hadn't even told their families and friends of their HIV-positive status. "We had our own little waiting room, and people would just hang out. We tried hard to make it a safe place." Many of those patients were waiting, covered with Kaposi's sarcoma, but they were treated warmly by the staff, who jokéd with them and were welcoming.

"That's what you have to do when you're treating a bad disease with toxic medicine," says Grace. "You have to create that welcoming atmosphere."

In addition to a clinician and a nurse practitioner, each clinic is staffed with a social worker. New patients routinely meet with the nurse practitioner and social worker before seeing a physician, which was a fairly unique approach to care. Both Postlewaite and Kutzko have been with the clinic from its inception until her retirement earlier this year. Some of the more common barriers included issues around money, insurance, transportation, and the anticipated stigma, as well as a sense of resignation in the early days of "What can they do for me since I'm going to die anyway?" she says. In addition, many patients had pre-existing psychiatric issues, while others suffered reactive depression in response to their diagnosis.

"It's like a big family," Michael says. "We have a lot of partners and even parents who come to visits," she said, "and we try to make family members feel comfortable coming to clinic if the patient wants them there."

The question of an HIV-positive patient's "profile" is part of the reason new cases go undetected, often for years. So one of the goals of the clinics' medical teams is to encourage primary care doctors to routinely test for HIV, rather than waiting until all other possible avenues have been considered. Kutzko describes a new patient who exhibited classic HIV symptoms, including swollen lymph nodes and significant weight loss, but who nevertheless wasn't diagnosed by his doctors for five years. "It's not something they think about," she says. "There's this myth that we don't have HIV here in Vermont, or it's just too embarrassing to ask the question." Others might be concerned that their patients will feel judged, or that assumptions are being made about their lifestyle choices. Grace maintains that in areas where HIV is not prevalent, it is just not on physicians' radar. He and his colleagues want to change that. The Centers for Disease Control recommends routine testing for everyone between the ages of 16 and 64, as a matter of standard medical care, will help.

Deborah Kutzko has been the driving force behind a protocol that encourages local obstetricians to routinely test pregnant women; Fletcher Allen now has a policy that every woman who comes to the hospital to deliver must be tested. According to Kutzko, roughly 17 percent of the CCC's patients are women, and to date, no pregnant woman in their care has given birth to an HIV-positive infant. "That's because after the first trimester, every HIV-positive mother-to-be is given enough medication to get her viral load down to an undetectable level. Newborns are continued on medications, administered at six-hour intervals for one month, and then tested intermittently until 18 months. Tanya (not her real name), 42, an alcoholic, was pregnant when twins when she learned she was HIV positive. Like Gary Barto, she didn't fit the profile, so even though she'd been sick before her pregnancy and undergone extensive blood tests and the removal and biopsy of a lymph node, it wasn't until the time of glucose testing, around 24 weeks, that she was also tested for HIV. Through she was careful to avoid alcohol and to properly take her medications during the remainder of her pregnancy, when her twins were six months old, she was overcome with despair and reversed that approach. She stopped visiting the CCC and her husband, Michael, had to force her to take her pills. Eventually, she went back, but with trepidation, concerned that she would not be welcomed.

"The reason I'm here today is because they never judged me," Tanya says, explaining that the entire staff was "pro-Tanya" -- even providing Christmas presents for her children, unsolicited. "It's like a big family," Michael says. One that gently encouraged Tanya to take her medications, while helping her feel empowered to do so.

"I could think when I saw them was, I have HIV," she says of her pills. That's a common sentiment, one that adherence nurse Casey Lapointe, R.N., encounters routinely. One patient who was diagnosed years ago had stopped taking his medicine around the year 2000, and only recently decided to come back to the clinic for care. He told Lapointe, "When I take those pills, I'm reminded of HIV every day, and I don't want that." She suggested he...
It’s the keeping track of medications that at least one patient cites as a significant benefit of the CCC. Michael, 49, has been a patient in the St. Johnsbury clinic for close to 15 years. He was diagnosed in 1984, while living in Burlington, by a physician who told him he had less than five years to live, the longest life expectancy at the time. He was told to find a specialist, but that would have meant traveling to New York or San Francisco, so instead he did nothing for a decade (“I think I got through the first ten years by picking myself,” he says, laughing). When he did get around to seeking treatment, Associate Professor of Medicine Mary Ramundo, M.D., the St. Johnsbury clinic’s physician, tried various combinations of medications before finding the one that was effective. Michael says that having the clinic religiously monitoring him meant they were more quickly able to find the combination of medications that would work to control the virus, in a way that a general practitioner could not.

The St. Johnsbury clinic is the smallest of the four. Ramundo says she averages between 12 and 15 patients, many of whom are brought over from the nearby Northeast Correctional Complex. Because of the clinic’s relatively small size, there is no on-staff social worker. Instead, it has an extremely close working relationship with the Vermont Committee for AIDS Resources, Education and Service ( CARES ), so every time the clinic’s location has changed, the St. Johnsbury Vermont CARES office has moved alongside it. For someone like Michael, who lives just a few miles away, having the clinic nearby literally meant the difference between life and death. Echoing the comments of many CCC patients, Ramundo says she appreciates Ramundo’s expertise and the fact that she knows him as an individual.

“We have a one-on-one relationship, and I’m talking to somebody who’s knowledgeable,” he says.

In Brattleboro, Alston hears the same thing. His patients know he drives 150 miles each way to see them, and they are grateful.

“They know that with less than perfect weather conditions, it’s sometimes a big deal to get them,” Alston says, “so the attendance is really good and they’re appreciative, and at some level they realize they’re getting specialty care in their little clinic.” In Brattleboro, uniquely among the clinics, Alston shares duties with a practitioner could not.

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