



25 YEARS OF CARE AND ADVOCACY

by Sarah Zobel | photographs by Raj Chawla

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.

+ 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.

“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.

Professor of Medicine and Comprehensive Care Clinic founder Christopher Grace, M.D., listens to a patient at the clinic in Rutland.

“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 patient only needs to take one pill, once a day. The drawback is that the medications cost in the range of \$22,000 to \$28,000 per year. Most insurances cover some or all of that, but for patients faced with a 50 percent copay or those without insurance, the Ryan White Care Act fills the gap.

“There is virtually nobody in our clinic who should be on drugs who isn’t because they can’t afford it, which is truly wonderful,” says Kutzko.

The goal of the program in 1987 was to develop a model of care for those with a complex, deadly, and socially-stigmatizing disease that could be delivered in a rural state such as Vermont, where the level of medical expertise was limited. The team felt that the direct personal relationship between

the patient and the care team was key, so the model used a specialty outreach design that focused on bringing the expertise to the patient in their own community. The clinic program is actually four clinics, specifically placed in each of Vermont’s geographical quadrants. The initial clinic was established in 1987, about five years after the first reported case of the disease in Vermont, and is located in the Fletcher Allen Infectious Disease division in Burlington; it’s still the largest of the four. The three satellites are in Rutland (founded in 1994), Brattleboro (1995), and St. Johnsbury (1996).

The idea behind the clinics was to bring medical care to the patients, so that, for example, a Bennington patient who called in with uncontrollable 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* comes up frequently in 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



(Top) Professor of Medicine Kemper Alston, M.D., treats patients at the CCC clinics in both Brattleboro and Burlington. (Above) Deborah Kutzko, A.P.R.N., has been a part of the CCC staff since the program’s inception.

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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.



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.” Grace and his colleagues have published their results, which show that the model provided the same expert care to rural Vermonters with HIV as they would have received in any urban university program.

“We certainly had HIV/AIDS patients here in the community,” says Tom Huebner, Rutland Regional Medical Center CEO, “and we had internists 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 Bengtson echoes that sentiment.

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 HRSA, SPNS is intended to assist in the development of “innovative models of HIV treatment, in order to quickly respond to emerging needs of clients served by Ryan White HIV/AIDS Programs,” particularly among underserved populations.

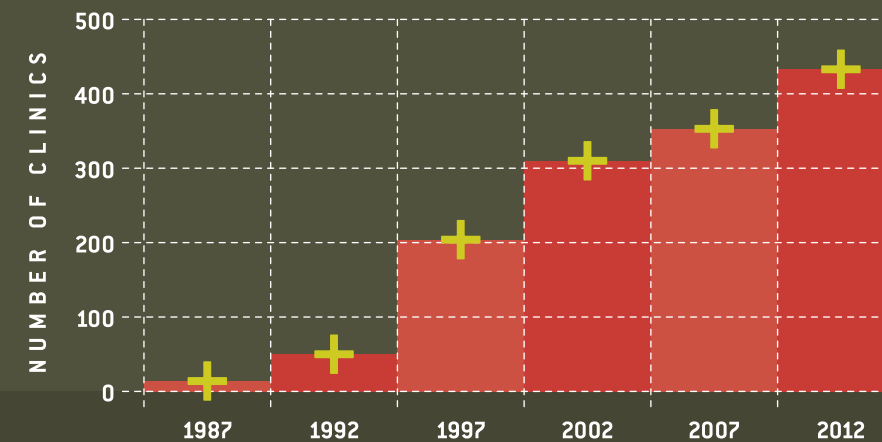
The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was signed into law in 1990 to provide HIV-related treatment to any patient with insufficient insurance or finances to cover it. The Act has been amended and reauthorized four times since then — in 1996, 2000, 2006, and 2009 — and is due to expire this year. At the time of the initial reauthorization, in 1996, Sen. Jim Jeffords was a member of the Health, Education, Labor and Pensions committee (HELP), overseeing the legislation. A close personal friend, David Curtis, a Montpelier native with whom Jeffords had clerked in the 1960s and who would later chair the Vermont Democratic Party, was openly HIV positive and urged Jeffords to support the Act.

Curtis testified before the HELP committee: “As you know, . . . AIDS is a disease that can strike anyone, whether it be a white, Anglo-Saxon, Protestant lawyer like me, or whether it be women, children, or people of color. . . . It is also expanding and growing in rural areas such as Vermont, and that is a problem that we need to deal with as well. My experience in Vermont has been that the majority of people with AIDS . . . are considerably less advantaged than I am, and I would ask you to seriously consider these people in your deliberations and the reauthorization of this Act.” Curtis died in 1999.

In 2000, with Jeffords then chair of the HELP committee, Vermont CCC director Christopher Grace, M.D., was invited to testify. He reinforced the fact that although the “AIDS epidemic has traditionally been considered a phenomenon of large metropolitan areas . . . [it] has crept insidiously into all rural areas of the United States.” Grace also noted that the fear that many patients feel about telling their families, friends, employers, and even doctors about testing positive is compounded in close-knit, rural communities.



U.S. Senator Jim Jeffords in 1996 with David Curtis and Senator Nancy Kassebaum of Nebraska.



THE GROWTH OF COMPREHENSIVE CARE CLINICS ACROSS THE U.S.

Funding from the 1990 Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has allowed the number of comprehensive care centers in the nation to grow more than thirty-fold. The “Vermont Model” has become the approach for delivering HIV care in rural settings.



One CCC patient, Kris (at left, in his kitchen) waited three years before telling his family of his HIV-positive status. Above, he apportioned his medications for the week.

“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 wasting, covered with Kaposi’s sarcomas, but they were treated warmly by the staff, who joked 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 Kutzko and the team social workers have sat in primary care physicians’ waiting rooms so they could be on hand when patients were given HIV diagnoses.

“A lot of ground work is done before a new patient comes in to see the doc,” says

Grace. “We wait until some of the social and psychiatric issues are stabilized before we even see them, because if they’re not stabilized then they’re not going to take their meds.”

Once the proper medications have been successfully established, ideally patients only need to be seen every four to six months. There are those who visit more often, particularly for help with psychosocial issues.

“I always looked at my job as handling barriers to care: what do we need to do to make sure that person comes back for the next appointment?” says Ellen Postlewaite, M.Ed., the Burlington clinic’s social worker 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.

“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.”

— Deborah Kutzko, A.P.R.N., Infectious Disease Nurse Practitioner, Fletcher Allen Comprehensive Care Clinic

A psychiatric nurse practitioner and a dietician were brought on board to round out the team — the two now travel to each of the satellite locations monthly. Postlewaite also routinely helped patients get community support from various AIDS service organizations, confirmed that they were set with insurance or some form of coverage, and that they had needed social support.

“In the beginning, I tell people that if you choose to talk to someone, make it someone who has the ability to support you,” says Postlewaite, adding that there are still plenty of patients who don’t feel comfortable talking about HIV and AIDS outside the clinic walls. Kris (not his real name) is one such individual. After testing positive in 2000 he waited three years before telling his family. They all live locally, and he didn’t want the news to adversely affect the family’s reputation.

“There’s a lot more education now about how HIV does not equal AIDS does not equal death,” says Kris, 39, but at the same time he feels there’s still plenty of ignorance on the part of the general public. He thinks many at-risk Vermonters aren’t getting tested because they don’t understand that HIV is still something to be concerned about.

“Oh, HIV. Isn’t that taken care of? Don’t we have that cured yet?” Those are words people have said to me,” says Kris, explaining that, while he wants to educate

people, “as soon as I step out and say something, then I’m the poster child. I want to believe that the stigma is over, but once I take that step, it’s all over. I don’t want HIV to be why people are looking at me.”

Gary Barto is another CCC patient; he’s been seeing Dr. Grace since 1992, and he and his wife, Susan, helped with hospital administration training services when the Rutland clinic was getting going. The Bartos helped deliver a primer on HIV patient care to doctors and nurses on staff there. “They were going to be the hand holders,” says Gary, “and they needed to know that it was safe to hold hands.”

The couple speak candidly about Gary’s infection (“I can be open about it in certain circles,” he says, “but it’s not something I run around broadcasting”), in part because he didn’t fit the patient stereotype. He says he doesn’t know how he contracted the virus — he’s not “the one people think of” — and was shocked when he tested positive 11 days before the couple’s wedding. Susan has accompanied Gary to every appointment at the clinic, which Kutzko says is common. “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 “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

Christopher Grace, M.D., holds a patient report that shows a positive reaction to medication.

“It’s a huge lifestyle change to say, ‘Now you have to take pills every day of your life for the rest of your life, and by the way, you can’t miss more than five percent of your meds.’”

— Casey Lapointe, R.N., CCC adherence nurse

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 standards recommending routine testing for everyone between the ages of 16 and 64, as a matter of standard medical care, will help.

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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 with 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

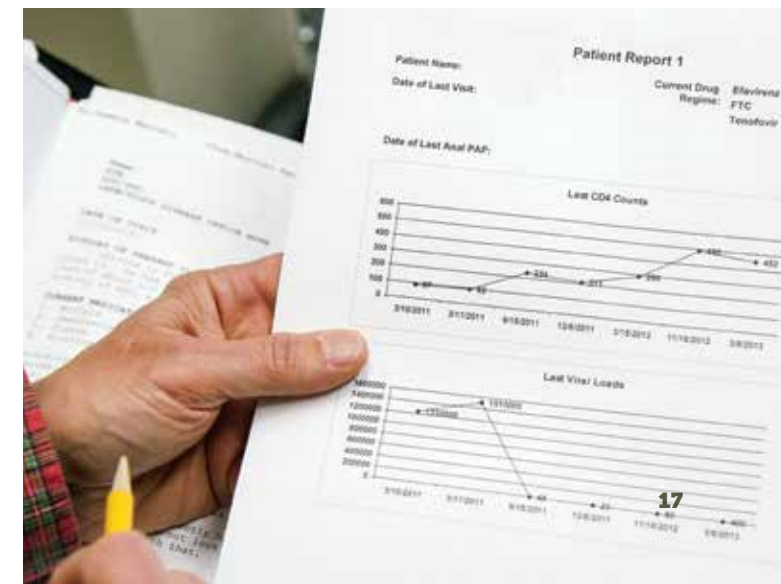
she was also tested for HIV. Though she was careful to avoid alcohol and to properly take her medications during the remainder of her pregnancy, when her twins were six months old, she was overcome with despair and reversed that approach. She stopped visiting the CCC and her husband, Michael, had to 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.

“All 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



think of them differently, as being what's keeping him alive, for himself, and his partner, and even his job. Two months later he returned, telling her that he had a new outlook toward the medication.

The role of adherence nurse evolved as the hospice nurse's job was phased out. It's not a common part of most medical teams because the decision to take medications as prescribed is individual. In the case of HIV, however, it's a public health issue.

Lapointe, whose patients affectionately call her the "pill police," sees some patients every week, filling their pill boxes and ensuring that they understand the importance of taking their medications routinely. Others use alarm watches or figure out the best place to keep the pill bottle so they don't miss a dose — that often means the bedside table, which isn't an option for the many CCC patients who are homeless.

"We ask what life looks like for them," says Lapointe, recalling one patient who kept his medication in his socks until, he says, someone stole them. "It's understanding what their day to day looks like," but also recognizing that not everyone has a routine. For patients who start the day with a cigarette, Lapointe suggests keeping pills next to the cigarette box.

"It's a huge lifestyle change to say, 'Now you have to take pills every day of your life for the rest of your life, and by the way, you can't miss more than five percent of your meds,'" says Lapointe. She hopes her job may one day be rendered moot, as advances in care continue.

"It's a wily virus," says Postlewaite, "and it mutates around the medications." Because they're strong drugs, there are also concerns about long-term side effects, including bone demineralization and renal function.



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



Associate Professor Mary Ramundo, M.D., sees patients in the St. Johnsbury Comprehensive Care Clinic. She works closely with the St. Johnsbury Vermont CARES office located in the same facility.

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— Kemper Alston, M.D., professor of medicine and director of infection prevention

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 pickling 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 medicines 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 has literally meant the difference between life and death. Echoing the comments of many CCC patients, he 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 there," 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

physician from Dartmouth-Hitchcock Medical Center, Jeffrey Parsonnet, M.D., in an arrangement that was established at the outset. That means a doctor is on site every two weeks, rather than every four, as in St. Johnsbury and Rutland (where Grace is the physician on staff).

All sites have enjoyed minimal personnel turnover, and that continuity has not gone unnoticed. Grace attributes that longevity to "the dedication of the staff, being part of an important mission for Vermont, and, I like to think, a well-run program."

"For patients, when things are chaotic, having the same caregivers is reassuring," says Alston. "That's been a huge attribute of this clinic." The ratio of providers to patients at all four locations mean individualized care not found in other HIV clinics, particularly those in larger cities, where physicians can have thousands of patients, some of whom might eventually fall through the cracks, Alston says. He has patients who have moved to Florida and then come back, once they'd spent time sitting in waiting rooms and realizing "what a good thing they had here."



In Vermont, roughly 30 to 50 new patients come to the clinics each year for treatment. According to Erin LaRose, grant manager

at the Vermont Department of Health (VDH), the Green Mountain State "owns" 420 HIV cases and serves 588 people with HIV who are owned elsewhere. The CCC clinics see roughly 450 of those patients. VDH surveillance information suggests there are another 100 or so individuals who are HIV positive but don't know it.

As always, one key to limiting new infections is reaching those who are most at risk. The CCC, spearheaded by Postlewaite and the VDH, have worked together to establish *gettestedvermont.com*, which they're using to spread the word about all aspects of HIV, from infection to testing and treatment. Clinic staff are also contacting service providers working with vulnerable and notoriously difficult to reach populations — those dealing with poverty, domestic violence, and drug treatment — to let them know that no client will be refused testing and treatment. Those are the people whose numbers are rising.

"We're seeing more people whose native intelligence is hovering around the mentally disabled level," says Kutzko. "Or it's people who are having sex for a place to live, or folks who are destitute or regular drug users. It's a hard place to get people tested."

But it's testing that could play a major role in minimizing the spread of the virus, since data have shown that some 21 percent of U.S. residents who are infected with HIV are not aware of it. Until there is

a cure, the route to cutting down on new cases depends on suppressing viral loads, thereby minimizing the risk of transmission. That's a different approach than

early responses, which focused more on behavioral change, including safe-sex practices — "which quite frankly never really worked," says Grace — and had little


effect on checking the nearly 50,000 new cases per year that consistently appear in the U.S.

"A lot of the younger folks grew up in an era where there was always HIV around them," says Kutzko, "and they're more blasé about it" because they don't see people dying from it. Indeed, the rates of sexually transmitted diseases — including chlamydia and gonorrhea — in all populations are soaring, both nationwide and locally. Even syphilis, once thought to be under control, is on the rise, particularly among men who have sex with men, and potentially contributing to new incidences of HIV.

Daniel Daltry, MSW, who is VDH Program Chief for HIV, STDs, and Hepatitis, says the Comprehensive Care Clinics are a resource for all infectious disease — particularly HIV, of course, but also for STDs.


"I feel like I have a golden resource in my pocket," says Daltry, "knowing that Comprehensive Care is there for anyone who tests positive, or for someone who might have a complicated infectious disease."

For patients, acceptance is perhaps one of the most important pieces, second only to regular and proper use of medications.

"It's always on my mind, it's always something I think about, but now it's become a background, a sub-line to my life," says Kris. "For the first five years or so, you're always thinking about it — when life is going to end — and you're constantly thinking about your mortality. The last five years or so, it's just become a background thing to me. I don't think about it every day. I don't think about my mortality. I just take my meds and think about it every three months when I get my checkup, and make sure my health stays in check." 



At left and above, sights in the waiting room at the Comprehensive Care Clinic in St. Johnsbury.

 Read the 2010 peer-reviewed journal article authored by Vermont CCC clinicians on "The Vermont Model for Rural Health Care Delivery" in the *Journal of Rural Health*. Go to: uvm.edu/medicine/vtmedicine