

LIVING WITH AIDS

This year marks the thirtieth anniversary of the first report on AIDS in the U.S. Today several Greenwich residents are at the forefront of the medical breakthroughs and incredible fundraising efforts

by **STEPHEN SAWICKI** illustration by **MATT COLLINS**



Florence Suerig knows AIDS. As founder with her husband, Karl, of the Greenwich-based Red Ribbon Foundation, which provides funding for organizations fighting HIV (the virus that causes AIDS), she knows the issues and the players. As someone seeking to raise money, she also has a feel for the community's level of awareness and concern about the disease. But above all, she knows AIDS in a deeply personal way: as a mother who lost a son to it.

It has been twenty years since Michael Faerman died. The details of his life—that he ran an animated film and special effects studio in New York, was an avid skier, had a wonderful sense of humor—fall short of capturing the actual man, and what he meant to those who loved him. What is unmistakable, however, is that his memory spurs Florence's determination to keep after AIDS, to shun complacency and to make clear that this disease remains a threat. It is true that fewer people die from it these days, that it has become more an ailment to be managed than the crushing death sentence it once was. But you would be wrong to think that's the final word.

"That's the biggest problem," Florence says. "People think, 'Oh, they've found medications to extend people's lives, so we don't have to worry about people dying anymore.' Well, that's not exactly the way it goes."

"Living with HIV." That's a term one sees a lot on public-health statistic sheets about the disease. For example, based on the most current numbers available, 33.3 million people around the world are living with HIV. In the United States, it's 1.1 million. In Connecticut, 10,574. And in Greenwich, sixty-six.

But for thirty years, America, too, has been living with HIV. That's how long it's been since the first report from the Centers for Disease Control and Prevention (CDC) about five homosexual men in Los Angeles who were afflicted with pneumocystis pneumonia, an unusual and potentially deadly lung infection, followed by other cases of rare cancers

like Kaposi's sarcoma and opportunistic infections. Acquired immune deficiency syndrome, as it would come to be known, had taken its place in the public consciousness.

We have traveled many miles since the melancholy days of the eighties and early nineties when so many died such awful deaths. But given the point Florence has raised, it seems a fair question: How then does it go, this battle against AIDS, at the dawn of its fourth decade?

Communicating the Right Message

Perhaps the most telling answer comes from Dr. S. Wear Culvahouse, a Greenwich obstetrician/gynecologist and a founding board member of the Red Ribbon Foundation. When asked if he is optimistic about a vaccine, he gives the longest of sighs. "Am I optimistic? I hope so," he finally says. "I have hope, but it has been a disappointing and frustrating fight for so many years. Every year we look for success; we look for something that gives us optimism; and I think we're turning the corner. So am I optimistic? Yeah."

That's the kind of response one hears from a lot of people who have seen this fight up close, a push-pull between their fondest wishes and sad experiences, all

with a resolve to press on in the way of long-distance runners. Undeniably, there has been much progress. But it bumps up against what's still undone. It's true that more people are living with HIV than ever before. But the United States averages 56,000 new infections a year, according to the CDC. Eighteen thousand Americans die from AIDS each year. And since its inception, the disease has taken 25 million lives around the world.

Dennis Torres of Family Centers Inc., which runs StamfordCARES, an AIDS assistance program for residents of lower Fairfield County, finds himself sending different signals about the disease to different audiences. It's a back-and-forth between educating one segment of the population about the dangers of HIV and

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assuring another that things aren't so bad. "It's really up to us to figure out how to get the message out and strike the delicate balance that there is treatment, that it's not a death sentence, and yet it's not something that you want to get, so don't let down your guard, but if you have it we're here to help," he says.

"It can feel like talking out of both sides of your mouth at times, but it's a delicate balance. We have to target both. We have to target people who are HIV negative and want to stay negative, and we want to support them. And we have to bring people who are HIV positive into care and support them as well, and lend them hope."

Tom Mahoney, of the Greenwich Department of Health, oversees an HIV-STD prevention program, which includes a twice-a-week testing clinic at Town Hall. He also heads the nonprofit AIDS Alliance of Greenwich, which provides financial assistance, support groups and other services. Today's teenagers, he finds, tend to know less about the disease than those of the bad old days, when AIDS was more in the news. Like Florence Suerig, he also detects an unsettling complacency about HIV with much of the public.

"People say, 'All I have to do is take medication and I'll live forever.' But it's not a panacea," Mahoney says. "Medications work differently in all of us. What people don't always consider is the cost of the medication. It can average about \$1,500 a month. That's significant. And there can be side effects. But people tend to look at Magic Johnson and say, 'He's had it since the nineties, he's still fine, and he hasn't developed AIDS, so what's the big deal?'"

It's that kind of attitude that Florence and Karl Suerig and the Red Ribbon Foundation must overcome in their fundraising efforts. The organization owes its existence to what was to have been a one-time benefit called "Jazz for AIDS," in honor of Michael's memory. The musical event, held in the Coleman Auditorium at the Greenwich Library, was such a hit that the couple realized they were on to something. Thus was born, in 1994, the full-fledged nonprofit, which throws a gala every two years, then gives what it raises to AIDS causes.

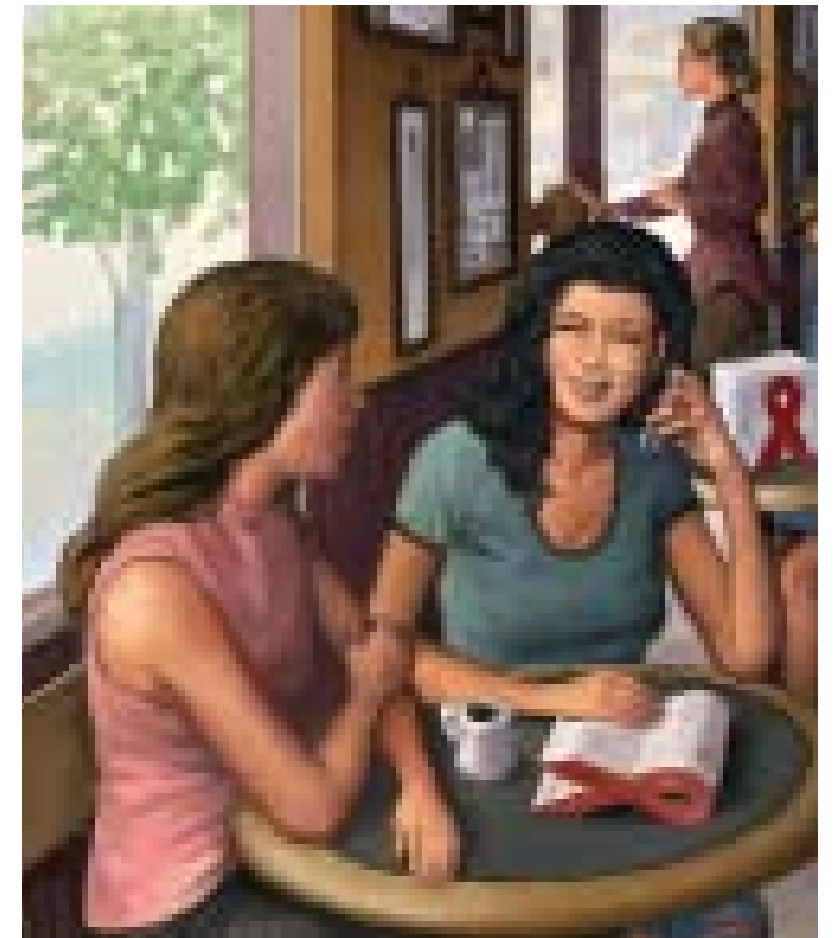
A Growing Effort

To date, the Red Ribbon Foundation has granted about \$2.3 million for research, prevention and

treatment programs. Its recipients are based in the United States, though they can operate anywhere in the world. Roughly half of the foundation's donations go to programs in the tristate area, says Nicole Hazard, executive director. The rest goes abroad, mainly to sub-Saharan Africa. During its last round of grants, in May, the foundation distributed \$217,000.

As the AIDS pandemic has evolved, so has the foundation. "I personally have begun to see it more as a worldwide problem that we need to address," says Florence. "I don't think we can live in a cocoon anymore. Africa is ravaged. So we've been trying to help some African groups and schools. Whether or not local people will respond to helping Africa, I don't know. But we need to think globally."

One group that fits nicely into that strategy is Sekolo Projects, whose focus is on Namibia, southern Africa, where 25 percent of the population is infected with the virus. The Old Greenwich-based nonprofit is





run by Elizabeth Robinson, who grew up in Riverside and graduated from Greenwich High School.

Started in 2004, Sekolo Projects concentrates on teaching youth in Namibia about HIV, and fostering conditions to keep them risk free. Elizabeth, who fell in love with the country when she worked there as a volunteer, saw the ongoing need for AIDS education. So it was that she and her husband, Geoffrey Silver, a documentary filmmaker, produced a video that teachers could use to get the word out to young people. When Namibia's Ministry of Education developed its own curriculum, Sekolo Projects moved on to support programs, providing financial assistance to AIDS awareness clubs and local groups that help with basic needs and building self-esteem.

"As a virus, HIV spreads regardless of borders or boundaries," says Elizabeth. "I also think that the knock-on effect, the impact of HIV in terms of its ability to destabilize a population, is huge. When HIV impacts 25 percent of a population, it's impacting

25 percent of the education sector, 25 percent of the health system, 25 percent of the governance. And so the whole social fabric is put at risk, [which feeds] the growing seed of sentimentalist religious thought and terrorism. A social fabric that is fraying at the edges is a great risk to the entire world."

Victory over AIDS may not be at hand, but in the past year those who are invested in the fight have had reason to feel heartened. Last fall, Pope Benedict XVI remarked that condom use by a male prostitute with HIV might be justified. Speculation ran rampant that the Roman Catholic Church was signaling recognition of the importance of protection in combating the virus. If so, that could make a big difference in Africa and much of the Third World.

And last year, President Barack Obama announced a long-awaited national AIDS strategy. It calls for a 25 percent reduction of new infections, which have remained disturbingly steady for years, by 2015. Among other initiatives, it seeks to get more of the newly diagnosed into care sooner, which would keep them healthier and prevent new infections. StamfordCARE's Torres, for one, was encouraged by the president's plan. He's also happy that HIV has become integrated into routine healthcare, that efforts are underway to get more people tested, and that it's once again a major subject of conversation.

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"I might be looking for a job in five years," he jokes.

AIDS researchers, meanwhile, have also seen advances. Most encouraging was the news this spring of a breakthrough study that showed that early treatment of HIV patients with antiretroviral drugs dramatically reduces transmission of the disease. Participants who were treated while their immune system was still healthy were 96 percent less likely to infect their partner. The \$73-million trial, which was led by the University of North Carolina at Chapel Hill, involved 1,763 predominantly heterosexual couples in nine countries. And though other studies have pointed toward the same conclusion, this was a possible game changer. So convincing were the results that the trial was shut down early. For AIDS workers, it is a sign of hope that concerted efforts to get people treated, especially in AIDS-ravaged Africa, could finally curb the spread of the disease. News reports were littered with seldom-heard reactions from experts that included terms like, "amazing," "phenomenal," and "bowled over."

After years of failed attempts, scientists have also been cheered by a newly developed vaginal microbicide gel, also with the drug tenofovir, that prevented HIV infection in 39 percent of the women tested in a South African trial. That number climbed to 54 percent for those participants who used the gel most conscientiously. Like Truvada, a gel would offer users protection without their sexual partner's knowledge. That would be a plus, especially for impoverished African women who might face the choice between selling themselves for sex or being unable to feed their children, or whose husbands might visit prostitutes yet take violent umbrage at the suggestion of using a condom with their wife. Further trials, however, are still necessary. Tests, too, are underway involving rectal gels.

Cure vs. Vaccine

The elephant in the room, however, continues to be whether scientists can come up with a vaccine for AIDS. Among the problems facing researchers, the virus is notoriously evasive; it is constantly changing before the immune system can catch up to fight it. Dr. Jeffrey C. Laurence, director of the Laboratory for AIDS Virus Research at Weill Cornell Medical College in New York, for one, predicts we won't

THROUGH THE YEARS

A look at the major events of the past thirty years

- 1981 CDC publishes first report on the disease.
- 1983 French researchers, led by Luc Montagnier, isolate the virus that would be found to cause AIDS. Disease is named acquired immune deficiency syndrome.
- 1984 Robert Gallo and a team of American scientists isolate the virus, determine it causes AIDS.
- 1985 Actor Rock Hudson dies of AIDS. Ryan White, a hemophiliac with AIDS, is barred from his middle school in Indiana for fear of the disease.
- 1986 The virus that causes AIDS is named human immunodeficiency virus.
- 1987 FDA approves AZT, the first drug treatment for AIDS.
- 1990 Ryan White dies at age 18.
- 1991 Basketball star Magic Johnson reveals he is infected.
- 1992 FDA approves Hivid, to be taken in combination with AZT, first multidrug treatment.
- 1996 FDA approves two protease inhibitors, which when combined with other AIDS drugs, makes virus undetectable; deaths begin to drop.
- 1998 First trials of would-be vaccine commence in the United States.
- 2004 First two-in-one drugs, Truvada and Enzicom, become available, simplifying HIV drug regimens.
- 2006 FDA gives approval to Atripla, the first three-in-one pill.

see development of a vaccine in his lifetime. “Every other disease that we have a successful vaccine for we’ve had a biologic model for,” the Greenwich resident says. “That is, we have a vaccine against polio because (not everyone gets) polio when they’re infected. They develop antibodies to it and the antibodies are protective. We can take those antibodies and inject them passively into another person and prevent that person from getting polio. Every single other disease we have, including the worst one, rabies, we have a vaccine for because not everyone dies of it.

“As far as we know, nobody has ever been spontaneously cured of HIV. So we don’t have a model.”

Other scientists are out to prove his prediction wrong. In the past couple of years, two separate research teams have uncovered antibodies capable of blocking most strains of HIV. Last summer, the Vaccine Research Center of the National Institute of Allergy and Infectious Diseases (NIAID) reported finding two antibodies, from an African-American, that could block 90 percent of the HIV strains from infecting human cells. And in 2009, researchers from the Scripps Research Institute and the International AIDS Vaccine Initiative told of two antibodies from an individual in sub-Saharan Africa, that counter 80 percent of the strains. (The antibody donors, who were HIV positive, developed the antibodies too late to beat back the virus.)

The hope is that these findings, and others like them, will be the break scientists need to develop an effective vaccine. They know how the HIV-fighting antibodies work. The big challenge is to be able to coax people’s immune systems into producing them for themselves. But

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even if that fails, the newlyfound antibodies might have applications in drugs, gels or gene therapy.

While conceding that the discoveries offer “a glimmer of hope” for a vaccine, Dr. Laurence thinks a cure is more likely. He points to a case that came out of Germany three years ago in which a man with HIV had developed leuke-

mia. Chemotherapy proved inadequate in treating his cancer, so he was given a transplant of bone marrow stem cells. His doctors, figuring they had an opportunity to tackle the AIDS virus along with his leukemia, rejected dozens of potential donors before finding one with the genetic mutation CCR5-Delta 32, which is known to be resistant to HIV.

That his leukemia was beaten back by the transplant was good news. That he showed not a trace of HIV was unprecedented. The patient, Timothy Ray Brown, an American, went public last year, granting an interview to the German magazine *Stern*. “He’s now three years off all AIDS drugs, off all leukemia drugs, off all drugs, doing perfectly fine and happy,” says Dr. Laurence.

Yet in large part the response to this accomplishment has been underwhelming. Part of the problem is that the treatment Brown received is impractical, and too dangerous, to be implemented on a wide scale. Such transplants can be deadly. They’d also be impossible to offer in developing countries. And in America, at least, insurance companies generally restrict the number of matching donors to just two, as opposed to the sixty that Brown’s doctors looked at before finding what they wanted.

All the same, Dr. Laurence says, this opens the door for new approaches to finding a cure. The question becomes how



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do scientists engineer this same mutation in an individual's own bone marrow stem cells? And then, how do you get it into every cell in the body? Perhaps drugs will be developed that would behave like the mutation, which could somehow be transplanted with the person's own bone marrow.

"It's now a technology problem and this gives us a lead," says Dr. Laurence. "It can be done."

Dr. James Sabetta, director of infectious diseases at Greenwich Hospital, can speak firsthand of what has been accomplished in the fight against AIDS. He was still in training, working as a fellow at Yale-New Haven Hospital, when he read the CDC's first report about the gay men with pneumocystis pneumonia. The very next day, he saw a patient with the same condition.

Since then, the medical landscape is vastly different. "There's more information

available," says Dr. Sabetta. "People are less afraid to be tested and more open about the whole situation. And I think that's because there's some treatment for it that's efficacious."

With the new antiretroviral drugs and three-in-one pill Atripla (and a four-in-one pill on the way), individuals who learn early that they have HIV can get most of their treatment on a local level. Some people might want to see a specialist at an AIDS center for their initial treatment or second opinion, but for the most part patients don't need to go to a research institution or big hospital for HIV care unless problems arise, like resistance to the drugs or bad side effects. (HIV drugs have been known to cause osteoporosis, heart disease, diabetes, liver and kidney problems, among other ailments.)

"If the person is doing well on a standard regimen, it's not necessary," says

Dr. Sabetta. "On the other hand, there are definitely people with more experience in terms of the volume of patients seen at academic centers. There's no question about that."

Thirty years after we first learned of it, AIDS is still with us. Much has changed in the fight to eradicate it. And it has changed us, as a people and as individuals. What remains the same is a resolve that seems indefatigable in the face of setbacks, frustrations and grievous loss. Florence Suerig is a case in point. "It's devastating when one of your children becomes ill and is not going to recover," she says. "It's devastating. So you live through that. Some people die with their child and some people, like my husband and myself, decide to try to help other people so you can go on and feel like you've done something rather than that you've done nothing in the face of such a horror."

