



### DEAR READER

When did AIDS begin? For many, it was in 1981 when reports of Kaposi Sarcoma (KS) and *Pneumocystis carinii* (*jiroveci*) pneumonia were documented in gay men in the United States. Of course, the virus had probably been spreading unnoticed for quite some time before that—with the current epidemic being established at least since the early or mid-1970s. So, the year 2006 marks 25 years of AIDS as our society has come to know it. We have made great progress in dealing with HIV/AIDS, and yet we have not been able to stem its spread nor curtail its relentless decimation of human life.

A quarter century is a long time, and certainly a sufficient enough milestone to allow for some reflection as we continue to meet the challenges this virus presents. Therefore, this issue of *RITA!* (a companion to this year's first issue, "HAART at 10," which chronicles the first 10 years of highly active antiretroviral therapy) focuses on voices from this 25-year-old epidemic. Specifically, these voices are of people in Houston who are dealing with HIV/AIDS personally or professionally. These are voices of doctors, patients, advocates, and survivors, including some graduates from Project LEAP (Learning, Empowerment, Advocacy, Participation), an advocacy training program funded by Ryan White Title I and conducted by The CFA. The essays are simple and unembellished snapshots representing the many different perspectives we have reached 25 years into HIV/AIDS. I hope they provide inspiration and rededication to continue the fight to end AIDS, whether by donating time, skills, or money to the cause.

In this tenth year of The Center for AIDS Information & Advocacy (CFA), *RITA!* has been the means by which we reflect on the meaning of 10 years of HAART and 25 years of AIDS. While we know that we have made great strides in the development of treatments for HIV disease, we also bear witness to a modern-day plague that has distinguished itself from any plague past or present. History will never forget the stigma of AIDS, the viral extinguishment of human life and resources, and the undeniable truth that a *lack of political and economic will* lies at the heart of why AIDS currently kills more than 8,000 a day worldwide. As a society, we will one day be held accountable for not having done more to end AIDS.

The truth is that this epidemic is complex. Its success is inversely proportional to our failures. Where educational and healthcare infrastructures are weak, the epidemic remains strong. Human conditions of poverty and marginalization provide fertile ground for new infection. To end AIDS as we know it will take much more than we are currently giving, but it is possible. Perhaps in another 25 years, we will look back on how humanity identified, contained, and cured a disease within just a half century. Who knows?

Finally, please consider supporting The CFA. Publications remain among our most expensive programs, postage and printing in particular. If you enjoy reading our coverage of HIV research and treatment developments, advocacy and policy updates, and much more, please consider a year-end gift. A donation envelope is included with this issue. We cannot continue our work without your support.



Very truly yours,  
The Center for AIDS Information & Advocacy



Thomas Gegeny, MS, ELS  
Senior Editor



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## Looking within

By John Sahm

My story begins in 1990 when a doctor suggested that my ailing partner and I get tested for HIV. David's health had been poor for many months—I am not sure why we did not think to test; perhaps *we were living in denial*. At testing, David had around 100 T cells and I had around 400 (the scientist in me will quote medical markers often). We had just moved to Houston from Kansas and though an AIDS diagnosis offered little hope in 1990, the fact that we were in the big city with good medical resources gave us some hope. Almost all of our new friends and acquaintances would now come from the HIV world, and this continues to be the case for me to this day. The first thing testing positive taught us was that it was time to stop fussing about all the unimportant things in life and start having more fun. We began to travel as often as we could. I was taking way more vacation time than my employer allowed, and I'm still not sure how I got away with that!

David's first hospitalization was for pneumonia in December of 1991. I had understood that we could treat pneumonia and most of the other opportunistic infections we were susceptible to, so his sudden death was quite a shock to me. Here again, I learn more about denial.

In the early days, we measured our health by counting T cells. Immediately after David's death, I watched my T cells drop from more than 200 to only 21 in May of 1992. We only had 2 drugs available to us at that time, and each had failed me because of toxicities. The scientist within me was taught that a person with 21 T cells would probably

experience rapidly declining health. Obviously, this possible outcome did not suit me at all.

Medical science at the time had little to offer me, so I was prompted to seek out alternative treatments. Luckily, I stumbled upon a very welcoming self-healing group that was all about love and spirituality. Michael Wilson facilitated this unique group of like-minded people who were all seeking answers to their questions about life, love, loss, etc. I met my current life partner, Reed, in this group. He and I have been searching together for life's truths for many years now.

Although learning to love ourselves and others unconditionally was the underlying thread in this group, we were also offered alternative techniques to heal the body and spirit. Every week we explored a new healing option that was outside of the conventional medical wisdom. Typically, I would take the ideas that I thought I could work with and leave the rest. Some seemed like *snake oil* to me, but the group always had multiple testimonials on hand to back up the claims. After trying many of these alternative healing methods, it became apparent to me that it wasn't so much the treatment itself that was healing but rather my *belief* in it. If you can gather enough convincing testimonials surrounding your desired outcome, you can begin to believe practically anything.

A primary truth for me was that *my thoughts and beliefs shape my experiences*. Now was the time for the scientist in me to deny medical evidence that did not suit my desired outcome. I had already had

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some experience with denial, so I thought this would be easy. Easy it was not, and to this day I struggle to fend off scientific and other societal beliefs that don't suit my desired outcome.

I also learned in this healing group that what I put my intentions towards will grow and prosper, while what I ignore will wither and die. All our major religions teach this in one way or another. Judeo-Christians might say "you reap what you sow" or "do unto others. . ." while a Buddhist might explain it as "cause and effect." I try to check my intentions and motives often because this is a very powerful truth for me that can be applied to everything I do. The healing group disbanded in the mid 1990s, but its lessons in unconditional love, spirituality, and healing stay with me to this day. On a good day, I feel I can shape my experiences to be whatever I command, all based on my intentions and beliefs.

Yet I still rely on traditional medical therapies when they become available to me. You'll find me first in line for promising new drug studies. Unfortunately—for whatever reason—antiretroviral therapies only work a short time for me before my virus becomes resistant. (*Mental note to myself: change this belief!*) For this reason, I use HIV therapies in a sort of *sprint and coast* fashion. To date, this has worked well for me, though sometimes I find that I coast without active treatment for too long usually because the pace of new treatments has not kept up.

For a while, a theory floated about that drug holidays allowed the virus to revert to wild type and

thus become susceptible once again to drugs that it was previously resistant to—even if only for a short while. I admit I have used this theory recklessly many times. While waiting for the Phase III trial of T-20 to become available, I took one of these holidays. After all, it could only increase the effectiveness of my new regimen, right? It took much longer for me to get the T-20 than I had expected, leaving me on a drug holiday for nearly 8 months, during which time my health declined. At the screening for the T-20 trial, I had only one T cell.

Luckily, T-20 has been the most effective drug for me to date. I was able to spring back from this low point to enjoy more than 3 years of excellent health. In 2001, I achieved an all-time high of 38 T cells. And during these 3 years, I've continued to grow exponentially in my personal relationships by learning how to love unconditionally in new ways.

But the effectiveness of T-20 wore off after a couple of years, and I've now been coasting again for a long time—far too long. I'm now looking forward to the CCR5 inhibitors. These studies have been dangling in front of me like a bunch of carrots for a year now. One by one, the drug studies are being cancelled for varying reasons, and it's beginning to look like CCR5 inhibitors will not be an option for me. So once again, I am turning inward to my spiritual side for my healing. I'm confident that I'll succeed.

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**John Sahn** is a member of the Ryan White Planning Council in Houston/Harris County. He chairs the Council's Advances in Medical Treatment and Medications Committee.

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## My past and future involvement with AIDS

By Susan M. Miller MD, MPH

My first awareness of an unusual illness affecting patients was during medical school. One of my colleagues had just returned from a clinical rotation in New York City, where he had seen a case of Kaposi's sarcoma and *Pneumocystis carinii* (jiroveci) pneumonia. I remember thinking, "I'll never see these kinds of medical diagnoses."

Those were famous last words.

During my residency program in 1983, I experienced a needle stick while taking care of a patient with "Gay-Related Immune Deficiency" (GRID). I was focused on inserting a central line in a critically ill patient and did not notice the initial trauma. Even afterwards, I did not experience a sense of personal risk. We truly did not know what we were dealing with back then.

Unfortunately, many physicians, nurses, and hospital personnel were hostile and judgmental during the early stages of the epidemic. It was difficult to find consultants who would assist in the care of my patients. One particular moment was especially galling. A physician called me screaming, "How dare you send me THAT kind of patient! I thought we were friends. I have a family to take care of. Don't you ever call me again." He remains unnamed but not forgotten.

In 1986, I became aware of the potential for compassion, inspiration, and dedication within the Houston community. The Center for Immunological Diseases opened under the auspices of Dr. Peter Mansell. Although it was known as the "AIDS

Hospital," a community of patients, physicians, nurses, social workers, and administrative staff came together with a central goal of healing and caring. No one was refused treatment because of an inability to pay. In 1987, the CDC held a conference in Atlanta, Georgia to discuss the results of a clinical study involving the use of AZT. On the day of the conference, 8 patients in that hospital died. This was perhaps my earliest low-point. The facility did not have an intensive care unit because a diagnosis of AIDS was a terminal illness. Patients succumbed rapidly in spite of our burgeoning "expert" knowledge. However, when Peter and Dr. Gary Brewton returned from the conference, we began to administer AZT and a new foundation of hope appeared. For the first time we saw the potential for partial immune recovery. Although AZT caused anemia, seizures, myopathy, and immune reconstitution syndrome, patients began to reverse their HIV wasting with subsequent improvement in their CD4 lymphocyte subsets.

Instead of patients dying within 6 months of their first AIDS diagnosis, they began to live 2, 3, 4 years longer. Instead of dying with CD4 counts of less than 200, they lived with CD4 counts of less than 50.

With prolonged suppression of immune function, we began to see new additional "opportunistic" infections including Cytomegalovirus (CMV), *Mycobacterium avium* intracellulare (MAI), Candida Esophagitis, Histoplasmosis, Toxoplasmosis, and Cryptosporidiosis. The vast majority of us had not received formal training in the management of these illnesses during our medical school or resi-

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dency programs. We all learned how to handle these illnesses post-graduation. The patients taught us, and we taught each other.

As patients began to live longer, we then heard the societal and political cries about how expensive it was to treat HIV. Hospitals, insurance companies, politicians, physicians, and health experts emphatically stated that society could not afford to continue taking care of these individuals. Through necessity, we rapidly became ethicists and health policy experts. The gay community was an essential voice of advocacy for all populations affected by HIV. Through its organizational skills, oratory, wisdom, and political savvy, federal funding was designated based on demographic needs. The HIV scientific community was instrumental in the development of many new medications, many of which are now even standards of care for cancer and transplant patients. A partial list of these medications includes ciprofloxacin, erythropoietin, lamivudine (for the treatment of hepatitis B), fluconazole, ketoconazole, itraconazole, ganciclovir (to treat CMV), ribavirin and interferon (to treat hepatitis C), rifabutin (to treat MAI), and famciclovir (to treat Herpes Simplex). Because so many individuals were chronically immune suppressed, people were rapidly enrolled in clinical trials and became an essential foundation in the licensing of these medications.

The next turning point in the epidemic occurred in 1997 with the widespread availability of protease inhibitors. These medications used in combination with other antiretrovirals, namely the nucleoside and non-nucleoside reverse transcriptase inhibitors, truly changed HIV into a more chronic illness. Immune recovery became durable and sustainable. Our patients were able to return to work and no longer had to sell their life insurance policies to third party brokers known as “viatical settle-

ment companies.” In-patient hospitalizations diminished and the insurance companies began to pay for the combination “cocktail” therapy known as highly active antiretroviral therapy or HAART.

The downside of the successful re-integration of our patients into society has been their relative invisibility within the current epidemic. Societal factors still impact access to care for many patients living with HIV. Poverty remains a significant risk factor for the acquisition of HIV as well as a cause of premature death. The next generation has not witnessed the high frequency of death that we experienced 25 years ago. The availability of HAART in the US has diminished the sense of urgency about HIV/AIDS, and the emergence and anonymity of the Internet has fueled a resurgence of high-risk sexual behaviors. This is a different societal problem than specific high-risk behaviors that are driving the epidemic in other parts of the world.

Since 1998, my work in HIV/AIDS has been focused on Russia (Tomsk, Siberia, and Sakhalin). Russia, India, and China are 3 areas of the world with the fastest rising epidemics. In Russia, there are also co-epidemics of injection drug use and multi-drug-resistant tuberculosis. Since 1992, Russia has a declining population that is not solely attributable to HIV and tuberculosis. The death rate in Russia is 13 per 1000, and the birth rate is 8 per 1000. Only in the last 5 years have we seen the initial acceleration of the HIV/AIDS epidemic in that country. I am very frightened by the changing epidemiology in Tomsk. In the first 9 months of 2005, 62% of their new HIV cases have been in women. This represents a significant and rapid developmental change. Three years ago, less than 25% of their new cases were in women. With the assistance of the NIH, we have established an institutional review board (IRB) with an international

“Federal Wide Assurance” number, creating a research infrastructure to examine this issue.

Estimates suggest that 1.2 million people are already infected with HIV in Russia. President Vladimir Putin has vowed to provide HAART for 15,000 people in 2005, and 30,000 people in 2006. This public health response is insufficient for many reasons. First and foremost, the dogma of stigmatization remains an integral political response for many government officials. For example, people are ineligible for HAART unless they have been drug-free for 6 months. And, because methadone and buprenorphine are illegal in the former Soviet Union, achieving sobriety remains a significant obstacle. The anticipation that HIV would rapidly die out in the intravenous drug-using population and subsequently disappear was obviously misguided. Furthermore, as in many parts of the world, needle-exchange programs are illegal within Harm Reduction education. Inadequate condom distribution remains a secondary problem. An infrastructure for medical care and sustained distribution of

reliable (generic) medications does not currently exist. Many health care providers remain fearful of treating these patients and echo the behaviors seen during the early days (and in some cases today) in our own epidemic.

The global sex and drug trades (including trafficking), political and economic instability, stigma, tyranny, and disproportionate infection of women add further complexity to the pandemic. A cohesive, international solution for this pandemic is vital. In many cultures, women experience discrimination based solely on gender. Hence, their access to earlier diagnosis and appropriate treatment will be and are impaired. As a society continues to marginalize specific subpopulations, its ability to provide a basic safety net is hampered. The advocacy voices that were heard in the US are silent *and silenced* in

*“The global sex and drug trades (including trafficking), political and economic instability, stigma, tyranny, and disproportionate infection of women add further complexity to the pandemic.”*

many of these countries. Perhaps in our 25-year history with HIV and AIDS, there are potential solutions for humanity. Hence, our new goals must be to maintain our stamina, vigilance, vision, and dedication in order to achieve success.



*Susan M. Miller, MD, MPH is currently a Research Associate Professor at the University of Houston and is certified as an HIV specialist through the American Academy of HIV Medicine.*



## The day AIDS got personal with me

By Steven L. Walker

It's hard for me to believe, but it's been 20 years since AIDS got personal with me. Like for so many others around the world, this was a signal that the disease was "real." On a hot summer day in 1985, I was playing tennis with my best friend, Ken, whom I had never beaten after 3 years of playing against him. But something about that day was different: I was winning! Though I didn't know it then, that was the day that AIDS got very personal with me.

I couldn't help but notice that something wasn't right with Ken, however. His eyes were as yellow as lemons. And he kept complaining about a pain in his side. Instead of celebrating my first-ever victory over him, I called Ken's mother, a nurse, who immediately took him to the hospital, where he was diagnosed with Hepatitis B.

When he told me about the diagnosis, I immediately remembered a speaker I had heard at one of our classes; there was some sort of link between AIDS and Hepatitis. Though I did not remember the exact details, I asked Ken if he thought he should be tested for HIV as well. He scoffed at the idea, screaming, "What, do you think I'm gay or something?"

It would be another 2 years before we came out to each other (running into each other at a gay bar helped that process). By then, Ken was living in

Houston's Montrose area, and he had still not been tested for HIV. In almost every one of our conversations, I would attempt to interject the latest news I had read about HIV treatments, or of locations that offered free HIV testing, or the growing statistics of HIV cases among African Americans. When AIDS gets personal, you know it, and even without an official diagnosis, you just know it.

*"Even though we don't see the end of the epidemic today, we have to keep moving forward as though we will reach it tomorrow. To do anything less would make meaningless any of our successes to date."*

That began my AIDS activism: my desire to make sure people were at least aware of their status. This included my interest in being vocal about HIV/AIDS, and more importantly, my desire to make sure that people who looked like me were included in educational campaigns. Though we were gay men (and at that time, the majority of AIDS reports were among gay men), Ken was like

many of my peers: educated about the disease in general, aware of the modes of transmission, and knowledgeable about the link between infection with HIV and other sexually transmitted diseases. Yet, he would not personally assess his risk. By not identifying the disease as something that could happen to him, he was convinced that he was not "one of those kinds of people."

Over the past 25 years, medical and scientific advances have revolutionized the treatment of HIV

disease—so much so that HIV/AIDS is often referred to as a “manageable” health condition. Activism has secured federal, state, and local resources to ensure that persons with HIV/AIDS have access to the necessary treatments. Community-based organizations have taken the lead in providing an array of services, from prevention to hospice.

There are some negative aspects of HIV/AIDS, from my perspective, that have persisted over the past quarter century of AIDS. First, there still isn’t a cure! As good as the treatments have been for people living with HIV/AIDS, the fact remains that they are only treatments. We still haven’t figured out how to purge the virus from anyone’s body. And we have to be realistic; people still die from AIDS-related causes. We have to keep it real.

Second, we still have to struggle to keep AIDS on the radar screen. At the moment I write this essay, the Ryan White CARE Act has not yet been reauthorized, despite calls from the President and community activists to do so. Just this past year, funding for AIDS has had to compete with relief efforts for a tsunami, earthquakes, and hurricanes along the Gulf coast—all of which captured the world’s attention. At a time when federal resources are



scarce, several billion dollars were recently earmarked for avian flu preparedness. *We have to remain involved.*

Lastly, and most disappointing of all, people are still being infected with HIV. The number of people infected each year in the US has been virtually unchanged. The number of new infections among teens is astounding. Many of these young adults today, like Ken 20 years before them, don’t identify themselves as at risk. The Centers for Disease Control and Prevention (CDC) estimate that each year 40 thousand people contract HIV in the US, virtually unchanged over the past 2 decades. A few years ago, a State of Emergency was declared to address the unacceptable rates of HIV infection among African Americans in Houston, yet the data show very little change. *We have to remain vigilant.*

Over the past 25 years, AIDS has gotten personal with millions of people around the world and thousands in Houston. AIDS still affects us. We have to continue to serve those who need assistance. We have to continue to fight for resources. Even though we don’t see the end of the epidemic today, we have to keep moving forward as though we will reach it tomorrow. To do anything less would make meaningless any of our successes to date.



## From day one

By Maria Velasquez

My name is Maria. I'm 25 years old, and I guess you could say HIV/AIDS is all I've ever known. I was born with HIV but did not show any signs of it until I was 5 years old. My parents were also diagnosed with the virus at this time. I had a normal childhood except for the fact that I had to take medicine and go to the doctor all the time. However, I had everything a "normal" child could ever want.

It wasn't until I turned 11 years old before I began to understand the disease my parents and I shared. That was the same year my mother had been hospitalized for an extended period of time. Then the day came that I always dreaded and will never forget. My father came home and told me that my mom had passed away. I was devastated, and I cried for what felt like eternity. Only 6 short months later, my aunt gave me the news of my father's passing. It was as if he could not hold on to life without his beloved wife. At that moment, I felt dismal and everything seemed surreal. With my mother's death earlier that year, I realized this disease would take my father as well, but I never imagined it would happen so soon. I went through the funeral hardly shedding a tear. Not because I did not love my parents, but because I loved them so much that I became numb. I was more upset that they left me here alone.

Although I was so young when these 2 life-changing events happened, I remember saying to myself,

*"With my mother's death. . . I realized this disease would take my father as well, but I never imagined it would happen so soon."*

"what's done is done, just move on with life." And that's exactly what I did. My dad arranged for me to live with my aunt, uncle, and cousins. I continued to go to school and do all the same things I was doing before. It was difficult to adjust to living with my aunt and uncle because they were more strict than my parents ever were. However, over time I adjusted and even ended up learning a lot from my

aunt. She taught me how to cook, clean, and do my own laundry; all the things that my mother had always done for me. My aunt also took me to church every Sunday, and I chose to be baptized at the age of 12. I graduated from high school in 1999 with all the same dreams and goals that my friends and peers

had, such as college, marriage, children, a career, and more.

Because of the great medical advances of today, those dreams and goals are all possible. When I was first diagnosed as a child with the virus that causes AIDS, my doctors never expected me to live to the age of 18 much less 25. Now, I have made a living for myself. I own a home and a car, I have 2 dogs, and I have attended college. I also have the most wonderful support system anyone could ever ask for. I have a wonderful family, marvelous friends, and a loving boyfriend of 2 years. They have all been completely supportive, and they are all there for me 100% of the time. I always have someone there when I am sick, when I am healthy, for holidays and birthdays, or whenever I just want to talk.



I couldn't ask for more.

I think HIV/AIDS today is a lot different from when I was younger. Back in those days, many

people lacked knowledge of what the disease was and how it could be contracted. But now, despite fairly widespread knowledge of the virus, the stigma of HIV/AIDS still exists. People are likely to stereotype others living with the disease as homosexuals, prostitutes, or drug users. I personally have not had any negative responses when telling people I have HIV, but I can read the curiosity on their faces: wondering about my parents and who they were.

I don't look at this disease as a death sentence anymore; it is more like a disability I can cope with. I'm just a young woman living with HIV, and I plan to live a long, happy, and healthy life.




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*Maria Velasquez works as a case manager at the People with AIDS Coalition–Houston.*

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- *RITA!*
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## Edward's lesson

By Shannon Schrader, MD

HIV—What was HIV? I had not even begun to address my own sexuality, much less given any thought to treating this disease, when I began searching for a residency program. In the late 1980s, there was limited HIV education in my medical school. The rural state of Kentucky did not have people with HIV—or so I was told.

My residency interviews took me to the University of California in San Francisco and Bronx Lebanon Hospital in New York. At one point during each of my interview trips, I was pulled aside by a resident in training, and privately told that I would only see HIV-positive patients if I chose to attend their program. Having never been exposed to patients with HIV in medical school and having some fear about the epidemic, I purposely ranked those residency programs at the bottom of my list. Baylor College of Medicine was my first choice.

Ironically, after arriving in Houston to attend Baylor in 1989, HIV fell into my lap during my experience at Ben Taub Hospital, and while covering the practice of a mentor of mine, Dr. Susan Miller. She took me under her wing and groomed me for what has become the most important and life-changing part of my medical career, treating HIV-positive individuals.

My very first HIV-positive patient, Edward, for whose care I was solely responsible, was taking DDI powder as monotherapy in an expanded

access program. Ed seemed to visit my office on a regular basis, often with no specific medical problems. He and I would just sit and talk, and I grew very fond of him. He helped me grasp the simple notion of how important it is to be present during an examination: physically, mentally, and emotionally. Upon Edward's death, his family asked me to deliver the eulogy at his funeral. This puzzled me because I was only his physician. Although I declined the family's request, Ed's funeral was the

one and only funeral that I have ever attended for a person under my care. I learned a lot about my mortality from that experience, which led me to make the decision to celebrate with patients during their lifetime on earth, rather than after they are gone. Later, Edward's family told me that he had visited my office so frequently

because I had been the only person in his life that would "touch" him (during an examination), and we always ended the visit with a hug. And really, all I'd done was listen to him!

Since then, I have been blessed as the HIV component of my practice has grown more than I could have ever imagined. I am thankful for referrals from physicians and patients, but I am especially humbled by referrals from my patients. I am grateful that I can participate in research, allowing me to continue learning new and better ways to treat the people who have entrusted me with their care. As the face of HIV has changed and patients have multiple treatment options available, I have been blessed with long-term patient-doctor relationships.

*"I feel I get more from my patient's office visits than they may receive from me."*

The blessings that I receive each and every day from my patients are what keep me showing up for work. I feel I get more from my patient's office visits than they may receive from me. I often learn from my patients, and I feel part of my job is to empower them to live their lives to the fullest. I continue to practice what I learned was so important to Edward—end an office visit with a hug. I

have also learned that sometimes all I have to do is listen—without judging.

Ironically, I feel that I am the one who receives healing from each patient encounter and, as long as patients continue to show up, I will continue to give everything I have to give. I am the one who wins at the end of each day.



*Shannon Schrader is an HIV-treating physician. He is director of The Schrader Clinic.*

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## Houston and HIV

By Dena Gray

The theme for World AIDS Day 2005 is *Stop AIDS: Keep the Promise*. This theme emphasizes the critical role of advocacy and the importance of keeping our foot on the neck of this epidemic. Our collective attention on this 25th year is turned to those in leadership, calling for increased financial commitments and policies that reflect and answer the needs of the community.

What does this mean for the city of Houston and HIV/AIDS services? How does the theme apply to us? Houston has remained one of the top 6 cities in the nation with severely disproportionate HIV statistics. We have participated in local, state, and federal efforts, but it was not until the last 10 years that HIV appeared on the radar of many who were simply unfamiliar with it. Since then, Houston has been a strong leader in the fight against HIV/AIDS, and the relationship between community and the political leadership has had a critical impact on increasing those efforts. This has not been an easy accomplishment, but looking back, we can definitely see where change took place because of such efforts.

It was not until the late 1990s that HIV's impact on communities of color in particular, garnered steady city- and state-wide recognition. In 1999, Mayor Lee P. Brown, along with Harris County Judge Robert Eckels, announced a State of Emergency against HIV in the African-American community and issued a Call to Action. Soon afterward, several resources were re-allocated to support that call. What had traditionally been lacking in terms of advocacy efforts with policymakers was a clear dia-

logue within the community on the true impact of this disease.

Prior to this emergency call, the epidemic in Houston among communities of color was increasing at alarming rates. In addition, the epidemic was largely being ignored by those communities it was impacting most. This made advocacy difficult because the information was not being shared or analyzed collectively to achieve better outcomes. HIV educators had been forced to use scarce resources to blanket communities with prevention materials and health services that had limited success. A large portion of the prevention and care dollars available were going to few agencies and oftentimes the services provided did not meet the needs of nontraditional communities, particularly communities of color. As advocates, many of us found ourselves in adversarial relationships with federal funders and policymakers.

For underserved communities in the Houston area, the climate towards HIV started to shift after the mayor's Call to Action and institution of an HIV State of Emergency Task Force. The community had collectively developed a strategy to educate local city officials as well as county and federal leaders. There was a persistence of door knocking, event planning, and political protesting that generated visibility for the HIV-positive community and stressed the importance of funding for prevention efforts. Through these ongoing advocacy efforts, Houston's HIV community continued to increase its political base. City Councilmember Annise Parker, one of the first political advocates for

HIV/AIDS on Houston's City Council, lent her support to calls for increased resources early on in the epidemic for the gay/lesbian community. Her support continued with the call for action in the African-American community. The State of Emergency further expanded the opportunity for collaboration and education with nontraditional providers and allies from other service communities, including those involved in substance abuse and mental health issues. For many of us in the struggle for resources, this was a milestone.

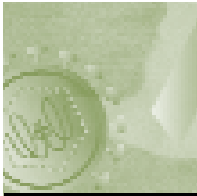
In 2001, Ada Edwards was elected City Councilmember in District D. Soon afterward, HIV advocates saw a surge in attention to the epidemic and its relationship to the Black community and youth. Advocates found themselves talking about HIV disease with anyone that the Councilmember Edwards could bring to the table. . . including in 2004, then-incoming Mayor Bill White, who has continued the task force under his administration. Through Councilmember Edward's leadership on the State of Emergency Task Force, HIV educators and testers were able to reach nontraditional communities that had never been served.

Today, the relationship between community advocates for HIV prevention, treatment, and housing work closely with elected officials to ensure that attention remains on this disease. Houston is fortunate to have had the ability to combine advocacy efforts from different communities with political access to increase services available to the entire city. . . not just one population. As a result of these same advocacy efforts, decision-makers have included community advocates at the table. Many of our local advocates have made a national name

for themselves through their efforts and have taken the call to the nation's capital. Houston is represented on several national efforts, and funding is coming into the city from sources once unavailable to us.

Everyone has a role to play in stopping this epidemic. The World AIDS Day call to *Keep the Promise* is directed toward our City Council members, as well as state and federal legislators and senators, and is critical. But we cannot expect our elected officials and decision-makers to do this work on their own. We have to continue to make our presence known through dialogue and planning. For the past few years, The Center for AIDS has conducted Project LEAP (Learning, Empowerment, Advocacy, and Participation), which is a program designed to educate HIV-positive persons and encourages advocacy. We need programs such as this to continue so that HIV advocacy efforts can continue.

HIV is still ravaging our communities. The number of persons requiring care continues to outpace the dollars put into the system. We have to step-up our efforts and not become complacent with the accomplishments that have been achieved. We are asking our government officials and representatives to listen, to learn, and to act on HIV/AIDS. Therefore, as community, we must continue to inform, to fight, and to serve. This is the only way that we collectively can attempt to keep the epidemic in check. Without an ongoing and open dialogue, HIV can slip into obscurity. Our work is not done. We have to keep alive the promise and goal of an eventual elimination of HIV/AIDS.



## One day I woke up with HIV

By Lucy Falcon

It was the summer of 2001, July 27 to be exact. As I drifted in and out of consciousness in a quarantined room at St. Luke's Episcopal Hospital in Houston, I could hear my oldest sister whispering on the telephone. She had this intense sadness and disbelief in her voice. Poor Ana, she had traveled all the way from Berkeley to be with my family during my sudden mysterious and serious illness. I could vaguely make out what she was saying. . . "I just can't believe this. . . . How am I going to tell her. . . ? How could this happen to my family?"

I wasn't sure what she was talking about, or to whom, but could it be about me? Oh, I was just so tired, and the meningitis, fever, and pneumonia made my head hurt so badly; everything ached, and I just wanted to sleep forever. Couldn't the doctors just find out what was wrong with me and make it all better? She continued to whisper to whomever it was she was talking to on the other line. "It's just so ironic that you and I will now share this connection between us, that we will have this in common, that our families will suffer the same pain," I heard her say. What connection? Who are you talking to, I thought to myself, and what are you talking about?

*Then it dawned on me* that she was talking to her husband, David, a physician in Berkeley. Because he was communicating with my doctors, he must have just told her the news. I thought to myself, what

connection did they have that involved me? As I lay there and pretended to be asleep so I could hear the rest of her conversation, I started to realize that the connection she was referring to was her brother-in-law, Andy, who had lost his battle to AIDS just a few years before. Andrew was a beautiful man who had dedicated his life to the ballet as a dancer. A tragic story, like so many others, but was this going to be my story too? Is this what she meant?

I laid there trying to understand and accept what was happening. Was I HIV-positive too? How could this happen to me? I had recently divorced my high school sweetheart of 20 years, and we had 2 children. I could count the men I had been with on one hand. *This didn't happen to people like me*, it happened to people like those I saw on TV. It happened to white, gay males. It happened to people who shared needles when doing drugs—I didn't do drugs. It happened to people in questionable professions—I was a "good girl." It happened to poor African Americans, didn't it? I am NOT the "face" of AIDS, am I?

Well, yes, I am. That was my rude introduction to the world of HIV/AIDS.

That was 4 summers ago, and I am as strong, independent, and content as I have ever been. Although my battle thus far has been more emotional than physical, I know the day will come when

*"Although my battle thus far has been more emotional than physical, I know the day will come when I will be medically challenged. . . ."*

I will be medically challenged, and I will take that in stride as well. Until then, I am here. I am alive. I love my life, my children, my family, and all those who surround me, who love me, and who accept me as I am. I have forgiven the man whom I loved, who told me he had leukemia knowing that he did not, but was too afraid to disclose. I refuse to dwell on the tragic sadness of that betrayal. Instead, I have accepted and embraced what God has chosen for me. I make no excuses, I make no apologies, but I do take responsibility. I may not like it, but I have stopped asking myself, “Why?”

HIV/AIDS does not discriminate. It sounds like such a cliché, but it just doesn’t discriminate. I am here to say that it happens to simple, middle class, educated, professional people. It happens to people who live in nice houses. It happens to people who drive nice cars. I didn’t think that it could, but it does. I’m here to say that we all share the face of AIDS, whether we are infected or affected. Anyone who thinks otherwise is a fool. And, if HIV/AIDS has not affected you personally at this point in life, then what of the next generation? Your children,

their children, and their children—a new infection is just one person away.

So, now what? Here we are 25 years into this epidemic, and what has changed? Not a whole lot, in my opinion. If anything, we’ve become complacent.

But what can be done by one person, one organization, one government, or one medical community? We all must work together, even though it can be so overwhelming at times. I believe there is much we can do, little by little, bit by bit. We can start by having faith, love, acceptance, forgiveness, education, and compassion when dealing with this disease. We cannot lose sight of what we all have endured since the beginning of AIDS. We cannot forget the millions who have died, and the many more that will follow. We can talk about HIV and AIDS, instead of acting like it only happens to people who somehow deserved it. **Nothing hurts more than that.** We cannot forget that this disease will eventually touch everyone in a personal way, if it hasn’t already. You can start by making a difference, your difference, today

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*Lucy Falcon is a 2005 graduate and valedictorian of Project LEAP (Learning, Empowerment, Advocacy, and Participation).*

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## History and hope

By Tori Williams

Hope dies last. And, drugs are hope for people with AIDS.

That is what Joel Martinez (who founded The Center for AIDS) taught me. I remember having lunch with Joel in his law office in 1983, twelve years before he founded the Center for AIDS. I had no idea what he was talking about when he told me he had Gay-Related Immune Disease (GRID), the “new gay men’s disease.” Twenty-three years later I can tell you that although I understand HIV/AIDS in my head, my heart still translates that information into ferocious anger. We wore that anger like clothing throughout the first decade of the disease.

We worked hard to give comfort, but people with AIDS died anyway. It took outspoken, upper-class, gay white men in food stamp lines and at clinics for the indigent to draw attention to the enormous holes in our medical and social service systems. Agencies like AIDS Foundation Houston raised 80% of its budget from passing around a hat at local gay bars. Little blue-haired ladies from local churches and synagogues formed Care Teams. They carried bars of soap in their purses when they went to local hospitals to change sheets and feed patients with AIDS. No one knew how the disease was transmitted, so hospital staffs were afraid of “those” patients.

Politically, we wore t-shirts that said, “Louie, Don’t Shoot!” in response to a Mayoral nominee who told the media that his solution to the AIDS problem would be to “shoot the queers.” He thought the microphone was turned off. People chained them-

selves to the doors of drug companies, the Centers for Disease Control (CDC), and other government buildings in an effort to draw attention to the disease. Gay men wore bizarre-looking wigs in an effort to hide their identity and protect their jobs while picketing the Social Security Office. They were desperately trying to draw attention to the fact that people were dying before their disability claims could be processed.

The demonization and marginalization of people with AIDS only made prevention and treatment more difficult. A brave young hemophiliac named Ryan White stepped forward, allowing politicians and others to feel safer embracing a cause populated by these “innocent victims.” Elizabeth Taylor, Princess Diana, and Carolyn Farb showed their moxie and helped others see AIDS as the terrible disease that it is.

In those early days, we formed extraordinary friendships and worked long hours. The first AIDS hospital in the country opened in Houston and closed just 12 months later. Fortunately, Houston grassroots efforts created other firsts that lasted longer: McAdory House (the first of several residential facilities), The Assistance Fund (which provides money for insurance premiums), FIRM (the largest religious response to HIV/AIDS in the country, which provides Care Team support and education), the Pet Patrol (which provides pet care so that people with HIV/AIDS can keep their companions), and more. We surprised ourselves at how creative we could be when we had so little with which to work.

We volunteered, and through volunteering we learned to change adult diapers, transfer a person from a bed into a wheelchair, and sit with a stranger through the night. We also learned to recognize burnout.

On a lighter note, as a Pet Patrol volunteer, I remember learning that an 8-year relationship with a cat is, for many gay men, their longest, most successful relationship. And yet, we kept taking the emotional risk of loving one more person. Joel met a wonderful man, fell in love, and surprised himself when he wanted to marry him. People who were extraordinarily sick sought to heal relationships with old friends, parents, and siblings. And, volunteers kept agreeing to open their hearts “one more time” to help a stranger.

The second decade of HIV/AIDS brought drugs, and hope. Although people still die of AIDS and related conditions, it is now unusual to lose a friend 6 months after diagnosis. The Ryan White CARE Act was created in 1990. Since then, millions of dollars have been made available on an annual basis to local communities so that they can provide “professional” care to people living with HIV/AIDS.

Sadly, the disease has moved into the heterosexual community and minority populations are dispro-

portionately affected. But, because of medication, perinatal transmission has been all but eliminated, at least here in the United States.

In the mid 1990s, resources were more plentiful and sufficient to fund medical care, medication,

food pantries, transportation, and other services specifically for people with HIV/AIDS. But with recent cutbacks in government funding and greater competition for private dollars, HIV-planning bodies have difficult choices to make. If they allocate funds for “support” services, there will be fewer dollars for medical care at a time when newly infected people continuously

*“We wore t-shirts that said, ‘Louie, Don’t Shoot!’ in response to a Mayoral nominee who told the media that his solution to the AIDS problem would be to ‘shoot the queers.’ He thought the microphone was turned off.”*

enter the care system and all people with HIV/AIDS in the US are generally living longer. The federal government and local planning bodies have begun to require that people with HIV/AIDS turn to more “mainstream” charitable sources for food, transportation, and emergency housing. Federal funding is complex, and there are no simple answers. But, in the fight against AIDS, drugs have provided hope. This is why it is so important to make drugs available to those who need them in the United States and throughout the world. We cannot let hope die—no one wants to go back to the early years of the epidemic.

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*Tori Williams is Manager of the Office of Support for the Ryan White Planning Council in Houston/Harris County. She is also the 2005 recipient of the Humanitarian Award of the Houston Black Tie Dinner.*

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## Pediatric and adult HIV/AIDS treatment: Still worlds apart

By Mark W. Kline, MD

Born with HIV infection in 1992, Jane Queen's prospects for life were bleak. Riddled by chronic, recurrent infections, Jane's blood platelets were low, predisposing her to easy bruising and bleeding. She contracted chickenpox twice, once requiring hospitalization. Only a miracle could restore her health.

Jane's miracle arrived in the summer of 1996 when she became one of the first children in the world to receive highly active antiretroviral therapy (HAART), powerful combinations of HIV medications that can near totally suppress the ability of the virus to reproduce within the body. Jane's miraculous road to health was detailed in an October, 1999 *Houston Chronicle* feature story by Leigh Hopper, entitled "Worlds Apart." Jane and thousands of other HIV-infected American children whose lives were slowly being extinguished in 1996 are thriving today.

Sadly, nearly a decade after Jane's miracle appeared, 2 million children living with HIV/AIDS in the developing world still are waiting for their miracles. Earlier this year, UNICEF estimated that no more than 25,000 of these children (about 1%) currently receive antiretroviral treatment. For most of the rest, life will be short and painful, ravaged by terrible opportunistic infections and cancer. Ultimately, most will simply waste away and die—half before the age of 2. About 510,000 children died from HIV/AIDS last year alone, one every minute of every hour, every day.

And yet, it doesn't have to be this way. In the face of stifling pessimism surrounding the treatment of

HIV-infected children in the developing world, and in a setting of pervasive HIV-related stigma, the Botswana-Baylor College of Medicine Children's Clinical Center of Excellence in Gaborone, Botswana treats more than 1,400 HIV-infected children, more than any other center worldwide. Funded by the Bristol-Myers Squibb Foundation, the center has become a focal point in Botswana and southern Africa for health professional training and community education on pediatric HIV/AIDS. In partnership with the government of Botswana, the center has catalyzed the establishment of Africa's first-ever national HIV treatment program for children. With support from the Abbott Fund, Bristol-Myers Squibb, the US Centers for Disease Control and Prevention (CDC), and others, the programs of the Botswana-Baylor center are now being replicated across Africa—in Uganda, Lesotho, Swaziland, Malawi, and Burkina Faso—with others to follow. This global Children's Clinical Centers of Excellence Network will accelerate training of pediatric professionals and share best practices regarding pediatric HIV/AIDS care and treatment in the developing world.

We have learned a great deal over the past few years about how to deliver treatment to HIV-infected children living in some of the world's poorest places, and we sit on the cusp of a new era of hope for HIV-infected children and families in Africa and other parts of the developing world.

Pediatric HIV treatment never just happens. Political commitment to children's health is essential. Most health professionals consider pediatric HIV treatment inherently more complex than the

treatment of HIV-infected adults. Excuses for not treating children are legion. Many health professionals believe that children don't respond well to treatment, making drug therapy almost futile, or that the drugs are too strong or too toxic for children, or that too little is known about dosing or monitoring treatment. These are myths. Africa currently lacks a critical mass of health professionals—people who have seen with their own eyes and experienced the miracle of a seriously ill or dying HIV-infected child restored to health by HAART. Time and again, African health professionals who train in our centers in Houston or Botswana have stated that this has been the most valuable part of their experience. Seeing is believing.

The expense of antiretroviral therapy remains a concern, particularly in the poorest countries. Fortunately, substantial resources are now being provided by the President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis, and Malaria, but more is needed. Unless HIV-infected children in the developing world are to remain therapeutic orphans forever, funders must consider setting aside resources specifically for the care and treatment of children. Manufacturers and others must work together to ensure that pediatric formulations of antiretroviral medications are made available at cost parity with comparable adult formulations. No matter the reasons, it is unacceptable that some medications used to treat HIV-infected infants or toddlers are priced substantially higher than the equivalent medications used in the same settings to treat HIV-infect-

ed adults, thereby pricing children out of access to treatment.

Scaling up the care and treatment of hundreds of thousands of HIV-infected children will take a commitment to partnerships. Governments, academic and health care institutions, community and faith-based organizations, and business communities in both the developed and developing countries all have a role to play. We are stronger and better together than apart.

In addition, treatment programs must address the critical shortage in almost every setting of professionals trained in pediatric care and treatment, with a clear recognition that children are not merely "small adults." Poaching of African health professionals by the wealthy countries and deaths of health professionals from HIV/AIDS have exacted a heavy toll on African health care. Here, American professionals clearly have a role to play as an AIDS Corps, if you will, of physicians, nurses, pharmacists, and others willing to give 1 or 2 years to treat HIV/AIDS in Africa.

It is time to re-frame discussions of HIV/AIDS care and treatment in the developing world. Rather than being paralyzed by the enormity of the problem and its many barriers, we must attack the scourge that is pediatric HIV/AIDS *because* it is difficult. The reward? Miracles like Jane's on a global scale: gifts of health, gifts of life, and satisfying a moral and public health imperative.

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*Mark W. Kline, MD, is Professor of Pediatrics at the Baylor College of Medicine and Texas Children's Hospital in Houston, where he directs the Baylor International Pediatric AIDS Initiative ([bayloraids.org](http://bayloraids.org)).*

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## I chose not to fear

By Lisa Acogny

You may be at the end of your rope, but never be at the end of your hope. We must keep hope alive; we must believe that AIDS will be eradicated. There is power in belief—if no one believes they can make a difference, then no one will do anything to make a difference.

Without belief we have no believers, no educators, no advocates. Thanks to The Center for AIDS Information & Advocacy (CFA) and Project LEAP, I can educate and I can advocate. And maybe I can be a voice to speak on behalf of those who cannot speak for themselves, for those who don't know they need to be spoken for, and for those who can speak, but are not being heard.

I start my education here and now. "Every 16 seconds a woman is infected with HIV."

My mission is to make sure that for every 5 seconds of those 16 seconds, a woman is educated about HIV. "Every 29 seconds a woman dies from an AIDS-related illness." I believe that I have been chosen as an advocate for such women.

If I can help save one woman, then a generation has been saved. I challenge every reader to join me and help create a generation of people with the mission to abolish AIDS forever.

During the holiday season, as you see all the Christmas trees, imagine The CFA as a tree in the

forest of knowledge. The CFA empowers the HIV/AIDS advocate, just as a tree supports its branches. People like you and me are the everlasting leaves, which must drop and spread the word, changing the way in which we educate, empower, and fight to eliminate the **fear** that surrounds this disease.

I consider FEAR as "False Evidence Appearing Real," the mother of all misconception. An example of FALSE—"only bad people get infected with HIV/AIDS." Of course, the reality is that anyone and everyone are at risk of contracting this disease. An example of EVIDENCE—"people who have HIV/AIDS have a short lifespan." The reality is that thanks to medical science, people are living for decades with the disease. An example of APPEARING—"this disease is for the homosexuals and drug abusers." The reality is that HIV/AIDS has no sexual or social preference. An example of REAL—"I know I don't have HIV or AIDS." The reality is that most people have not been tested, and the only way to know for sure is to be tested.

*Have you been tested? Do you know your HIV status?*

I have learned that through the process of evolution, you can change the root thought of misunderstanding and negative perception in people about people.

*"I have learned that through the process of evolution, you can change the root thought of misunderstanding and negative perception in people about people."*

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Donald Neal Walsh reminds me that all people are made up of 3 parts: thoughts, words, and actions. Thoughts are the first level of creation. Words are thoughts expressed. Actions are words moving. After you read this essay, don't just take comfort in thoughts and words, but take action and move forward.

If Christianity can start with 13 people and spread to 125 million worldwide, just imagine what you could do if you were to share the facts and educate your family, neighbors, friends, and co-workers about HIV and AIDS. This is the "each one, teach one" system. I don't just say this to impress you, but to impress *upon* you the need for everyone to understand that this battle is not just for the people who are infected or affected, but this battle is all of ours.

We must learn as much as we can to help prevent the spread of HIV/AIDS. We cannot depend on agencies, governments, politicians, or teachers. It is our responsibility to make sure that there shall be no family left behind, no family left uneducated, no family left unprotected, and no family left untested.

Knowledge about HIV and AIDS is an important part of the battle, but it is also very important to be tested. As a mother raising 4 children alone, I cannot afford *not* to know my status. Knowledge is power and it is with this power that I give to my children the chance to love instead of fear.

I feel that Mac Anderson said it best, "Behind me is the infinite power, before me is endless possibility, around me is boundless opportunity." So, I choose not to fear. What do you choose?

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*Lisa Acogny is a 2005 graduate of Project LEAP (Learning, Empowerment, Advocacy, and Participation).*

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## Being on both sides of HIV

By Wayne Bockmon, MD

I remember the first time I read about a new clustering of odd infections and cancers among urban gay men. Even then, in 1981, I recall a feeling of uneasiness and dread coming over me. Initially drugs and lifestyle were blamed. As the epidemiologists did their detective work, it became clear. We were dealing with a new disease, one for which we were woefully unprepared.

As a physician and a gay man, I monitored this story as it slowly developed. It was both fascinating and horrifying. Those of us in medicine and in groups at-risk obsessed about it, argued about it, worried, and waited. By the mid-1980s, the disease was no longer something we just read about. It was here. My patients and my friends were getting sick.

It is painful to search my memories of the time between 1985 and 1995. Treating people with HIV certainly was not what I had envisioned for myself as a family practitioner. I remember the frustration, the futility, and the loss—the unimaginable loss. Medically, we had so little to offer. We became good at preventing everything we could, treating what was treatable in terms of opportunistic infections, and preparing our patients and ourselves for the day when all of that failed. By the late 1980s, a medical practice devoted to AIDS was one in which human suffering and death became commonplace. Our patients coped regularly with blindness, disfiguring tumors, dementia, uncon-

trollable diarrhea, and that awful experience of simply wasting away. People turned to all kinds non-traditional remedies out of desperation, and for the first time American physicians learned there was a role for such remedies.

Those of us treating HIV/AIDS coped with the emotional burden in different ways. We had to maintain a professional demeanor and as much optimism as we could muster, but it wasn't easy. I had to stop going to funerals at one point. It was just too hard. All of us had to build up a sort of emotional barrier; otherwise, we couldn't have faced the reality of the epidemic on a daily basis. Among the care providers whom I know personally, I still see the emotional scars of that experience.

*"In 1995, the battle came to my doorstep. I had the odd experience of being on both sides of the equation. That year I had to stop practicing medicine."*

In 1987, I recall seeing something that instilled my first glimmer of hope. I had a patient with dementia for whom we were able to get the new drug AZT. After only a few days on the drug, his dementia got markedly better. The effect was short lived, but clearly real. I knew then that it was a waiting game. Treatments would come with time. Medical science had a path to follow.

One of the things that strikes me as remarkable about the HIV/AIDS epidemic was the timing. The disease hit just at a time in history when science was developing tools to identify and treat viruses. Treating viral diseases was the frontier of medicine.



Photo by Zoë Jackson

We could target viral enzymes exclusive of their human counterparts. Computer modeling of molecules was feasible. By “accident,” we discovered how to amplify viruses and count them, allowing for an immediate determination of a drug’s efficacy. What if AIDS had hit 20 or even 10 years earlier? The serendipity of these events has made me question coincidences forever.

In 1995, the battle came to my doorstep. I had the odd experience of being on both sides of the equation. That year I had to stop practicing medicine. At the time I took the shock fairly well. I was very sick and no stranger to the processes and expectations that went along with this disease. My disease hit me hard. I had a couple of close calls. I’m here today because of 2 things. I had one of the best doctors in the business, and I did everything he said. Joe Gathe is my friend and my doctor. Joe

has not only one of the keenest minds in HIV medicine, but also something that can only be called instinct. Joe’s hunches are almost always right and his experiments usually work. I have been the benefactor of both.

In 2000, thanks to Joe and the generosity and guidance of Katy Caldwell (executive director) and Gordon Crofoot (then clinical director) at the Montrose Clinic, I ventured back into the thing I love the most—practicing medicine.

It’s a different world now.

For someone with my history, the ability to offer the treatments we have today seems nothing short of miraculous. To be sure, the drugs are hard to take and the side effects can be tough to live with, *but we are alive*. I find myself having to remind my patients that these drugs, problematic as they may be, are the only things preventing the progression of a disease that, otherwise, will almost surely kill them.

But tougher still is understanding how or why people become HIV infected now, especially those who are fully aware of the risks. This I will never understand. How can someone give up the one thing I would give everything to have back?

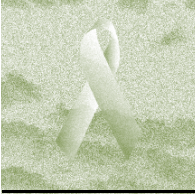
I turned 50 this year. HIV disease has dominated my existence for half of my life. After 25 years of HIV/AIDS, I hope we can remember all that we have been through and all that we have lost. And, I hope we have learned something in the process.

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*Wayne Bockmon, MD, is an HIV-treating physician and medical director at The Montrose Clinic in Houston.*

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## How HIV affected my life

By Jennifer Newcomb-Fernandez, PhD

My mother contracted HIV through heterosexual sex in 1986, a time when women—especially white, middle-aged, divorced moms from upstate New York—were not considered a group at risk. Because of the stigma associated with AIDS at that time, so early in the epidemic, my mother kept this information to herself. She told almost no one she was HIV-positive, including me.

Looking back, I can identify clues about my mom's illness. She had always been healthy and was never ill. She took care of herself and was always so full of energy. People would tell us we looked like sisters. And then, I noticed that she began to be sick more frequently. I was away at college and not really paying attention to matters at home. Hindsight is so much clearer and while I began to realize that something was terribly wrong with my mom, the idea that she had AIDS was unbelievable. Still, she was ill more frequently and staying ill for longer periods of time. Bits and pieces of information trickled down to me, and I learned that she had Toxoplasmosis. These days, the link between Toxoplasmosis and AIDS is so obvious. But back then, the connection was not readily apparent, especially when not thinking in the context of AIDS.

Surprisingly, I fully realized my mother had AIDS while watching the television news. I still remember that day. It was 1992, and I was 19 years old and a sophomore in college. While getting ready to attend my next class, I overheard the announcer explain that Arthur Ashe had just announced he had AIDS and was suffering from Toxoplasmosis.

In an instant, the pieces came together. I felt like someone had just punched me in the stomach.

A month later, my family finally acknowledged that my mom had AIDS. Two months later she died from pneumonia. In total, my mom lived 6 years after becoming infected. Two of those years were largely spent in hospitals. This was the age of AZT monotherapy, and there was little defense against the onset of opportunistic infections.

How has HIV affected my life? So much. I miss my mom so much it hurts. And she has missed so much of my life—college and graduate school graduations, birthday parties, weddings, births. She never met my husband, and she will never hug her grandchildren. Obviously, I am angry. Why my mom? I know that this is a common question for anyone with a terminal disease or for anyone who has lost a loved one from any cause. But why did HIV have to impact a middle-aged woman with no risk factors other than being recently divorced (from a marriage of almost 20 years) and joining the dating pool again? I knew the man who infected her—he died a few years before my mom died (though I didn't know his cause of death at the time). To this day, I do not know how he became infected, nor will I ever know.

When I tell people about my mom, they are shocked. Only gay men, drug users, and hookers were HIV-positive in 1986, right? Sometimes I think that if my mom had to get HIV, why not 10 years later, or even 20 years later in an era full of effective treatment options. And if she had to die,

why not breast cancer? Women who have breast cancer are celebrated and made heroes. Women with AIDS are stigmatized and avoided (this was especially the case in the US during the late 1980s). My mother was so ashamed of her disease she couldn't even tell her children. For years after her death, I would lie about how she died. I would mutter "cancer," when people asked. The obvious grief on my face stopped them from asking more. Sometimes I am angry with her. Why didn't she practice safe sex? And I answer, because she didn't know she was supposed to.

Unfortunately, she became infected when there were no viable treatment options. I call it the "caveman" era of treating HIV. I think those new to the field of HIV and AIDS do not fully understand how bad it was. In fact, my mother couldn't even be treated at our local hospital because they did not have the facilities, or the wherewithal, to treat someone with AIDS. Instead, she (and my family) traveled 60 miles each way to a

large medical facility that could deal with "infectious diseases." I am not minimizing the seriousness of HIV today in the US, only pointing out that great advances have been made.

As a scientist, I avoided the field of HIV for many years. It was too painful to relive everything, especially early on in the epidemic when there was no hope anyway. However, I often wonder if these events pushed me in the direction of science as a career. I often wonder what my life would be like if she had lived. My world was so much safer and secure with her there. Would I have moved across the country to Houston? Would I have been driven enough to pursue my PhD? Would I be married to my wonderful husband,

whom I met in Houston? And finally, would I be blessed with my wonderful and highly entertaining children? Life is strange. Now, as a mom myself, I write about HIV and AIDS as part of my career. Perhaps I have come full circle.



*"I am more and more convinced that our happiness or unhappiness depends far more on the way we meet the events of life, than on the nature of those events themselves."*

—Wilhelm von Humboldt (1767–1835)



## My American dream

By Bernie Vázquez

Diagnosis: HIV positive. This is always a hard situation to deal with. Imagine now if you were to deal with it in a different country, with different laws and a different culture. My experience is not different from the hundreds of immigrants from Mexico and South America that come looking for the American dream. The question is whether to stay and try to make the best of it or to come back to die with loved ones. Ten years ago, the idea of dying rapidly from HIV/AIDS was more probable than today, but still applies. The prospect of going back sick and dying is not a nice one, especially when it includes disclosure and rejection in most cases.

Having HIV requires new skills to learn, not only to start trusting the medical system (something that is not done in my culture) but also learning medical terminology in English. Although the American HIV community is very supportive, US immigration laws are not friendly to HIV-positive people: we are not welcome here. However, compassion is plentiful, and illegal immigrants always seem to find the care and support they need. The estimated numbers of immigrants with HIV/AIDS are not always accurate, many move around or use fake names. We know there are more infected people than reported. Some wait to seek care until they are very sick, and that is why immigrants have higher numbers of AIDS diagnoses in emergency rooms.

Many HIV-positive immigrants risk their health every year by going back to their countries to visit their families. This usually results in missed doses of medications and a lack of primary care and social services. However, the HIV/AIDS services in our countries seem to be increasing, and there was a rumor 2 years ago of “universal access” for HIV-pos-

itive people in Mexico. People were planning to return to Mexico in groups: *finally, we get to go back and be healthy*. Rumor had it that free medications were being given out everywhere.

Information presented at the North American AIDS Treatment Action Forum (NATAF) in Mexico (November 27–30, 2005) indicates that only 17 anti-retroviral drugs are approved in Mexico. Not all of them are provided by the government, and most medications for opportunistic infections and HIV-related diseases are not included. Social services and case management are non-existent, and patients seem to be grateful just to get their much-needed meds. The eligibility process is long and very detailed.

When I asked a group of Mexicans what I should report back to the HIV-positive Mexican Nationals in the US, they said, “Don’t come; stay in the US if you have services.” In the last 10 years, there have been many changes. While we have HIV medication in several countries such as Mexico, the prevention programs that were supposed to start 10 years ago are late, and the numbers of people infected are increasing, particularly among women. The perinatal transmission that is almost nonexistent in the US is still happening in our countries. Our families are crying for the many AIDS deaths now, much like was done in the US 10 years ago. It is my hope that we won’t wait 10 years to create support and advocacy networks to change the system.

I am an HIV-positive, Mexican, gay male receiving treatment and services in the US: I guess I am living my American dream.

