30 Years of AIDS at UCLA
Three decades of cutting-edge research and state-of-the-art clinical care, as recalled by one of the university’s pioneer investigators

World Class Science and Personalized Care
Reflections on the UCLA CARE Center’s Last 20 Years

Song of the Open Road
For the tenth consecutive year, Charity Treks, a hardy band of humanists on wheels, pedals across New England in support of the UCLA AIDS Institute’s vaccine development programs
A Message from the Director

A crucial partnership enters its second decade; our Clinical AIDS Research and Education Center celebrates 20 years of caring for people living with HIV; and the AIDS epidemic itself is now 30 years old.

A Year of Milestones at UCLA

The faculty and staff of the UCLA AIDS Institute celebrated three key milestones last year. First, 2011 marked the tenth anniversary of the founding of Charity Treks, an all-volunteer organization that raises money, through its annual bike-a-thon, to help support HIV vaccine research at UCLA—an unwavering commitment that now spans an entire decade, and makes Charity Treks one of the Institute’s oldest allies in this quest. A report on this year’s ride, which netted more than $50,000 for the Institute, appears on pages 22–27 of this issue of Insider. More importantly, perhaps, the report gives us a chance to salute the organizational skills of Mark Stanis, the self-effacing prime mover behind Charity Treks—who holds the title of president of this unique non-for-profit organization but who is in fact its dogsbodies, man of all work, and head cheerleader.

Second, it has now been twenty years since Dr. Ronald Mitsuyasu established the Clinical AIDS Research and Education Center at UCLA. The CARE Center, as it is known, not only provides for the needs of close to a thousand HIV-positive patients each year, it conducts a broad range of clinical studies—of new treatments for HIV infection and new approaches to managing the side effects of these therapies (see pages 16–21). Dr. Mitsuyasu is justifiably proud of the fact that he is still seeing patients from the earliest years of the epidemic, well before the CARE Center itself came into existence.

Personalized care is what the doctors and staff at the CARE Center do best. And while the faculty members are world-renowned experts in HIV medicine and conduct cutting-edge research in the field of HIV and its co-morbidities, their strength lies in their attention to details and to individual patient needs.

The epidemic itself turned thirty on June 5, 2011, and provided an occasion for us to reflect on all that still needs to be done to contain—and, ultimately, extinguish—the HIV pandemic. Dr. John Fahey, who was involved in efforts to treat the first AIDS patients seen at UCLA—and who provided a diagnostic tool that was crucial to characterizing the baffling and deadly new syndrome—reflects on that time in his recently completed memoirs. That diagnostic device, as Dr. Fahey reports, was housed at the Center for Interdisciplinary Research in Immunology and Disease at UCLA. CIRID, as the Center was known, was one of only four such centers in the entire United States and had been funded by the National Institute for Allergy and Immunologic Diseases a mere three years earlier.

In 1981, conventional hospital laboratories did not have the capacity to measure how intact a patient’s immune system was, and therefore could not have identified the salient feature of AIDS, which is the slow destruction of the body’s ability to fight off infection. CIRID, on the other hand, was able to tell the physicians treating UCLA’s first AIDS patients that these individuals all had profoundly weakened immune systems. This, then, was a new syndrome—of acquired, not innate, immune deficiency. It is with gratitude and appreciation that we publish an extended excerpt from Dr. Fahey’s memoirs on pages 4–9 of this issue.

None of us who were involved, in the early 1980s, in investigating this fascinating—and frightening—new virus could possibly have guessed, back then, that we would spend the balance of our careers trying to find a cure for HIV infection, and a vaccine to limit its spread. We are all too aware that science has yet to find an affordable, effective cure for HIV infection, and researchers are still searching for a true sterilizing vaccine. But with your help we have made enormous progress in understanding the way the virus works, why it infects some individuals and not others, and why it is able to hide from the drug combinations that are currently used to suppress its replication.

Irvin S.Y. Chen, PhD
Director, UCLA AIDS Institute
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Thirty Years of AIDS at UCLA

1981–2011

Three decades of cutting-edge research and state-of-the-art clinical care, as recalled by one of the university’s pioneer investigators

Why UCLA? That was the question put to Dr. John Fahey by an East Coast journalist in 2006, on the twenty-fifth anniversary of the identification, by a group of UCLA researchers, of the disease entity we now know as AIDS. The tone of the question gave Dr. Fahey the distinct impression that the journalist couldn’t quite believe that this landmark discovery hadn’t been made at the NIH or at a major research center in Boston or New York.

After all, UCLA had graduated its first medical school class only thirty years before those researchers published their initial description of AIDS, in 1981—and at that time the university was better known for its basketball team than for its scientific and medical research. As Dr. Fahey reports in his recently completed, self-published memoir, there were several compelling reasons why AIDS was first described at UCLA, and not elsewhere.
In June of 2006, when the twenty-fifth anniversary of the discovery of AIDS was being recognized nationally, I received a telephone call from a journalist who asked me, with a certain incredulity, “Why was it that AIDS was discovered at UCLA?” I told the journalist that three factors accounted for our history-making discovery:

First, in a six-month period in 1981, four previously healthy young men with essentially identical symptoms were seen at the UCLA Medical Center. All of them were severely ill, with intractable and lethal infections of the lungs and other tissues. Clearly, then, what we were seeing was some sort of disease syndrome, not an isolated case.

Second, a young physician who looked after those four patients, Dr. Michael Gottlieb, realized that his patients had an altogether new disease. Deaths due to *Pneumocystis carinii* pneumonia, and to the other systemic infections that the four individuals presented with, had not previously been described in young, apparently healthy men. These infections—so rare that when one was diagnosed, the government mandated that it be reported to the Centers for Disease Control in Atlanta—had in common that they were seen only in people with severely compromised immune systems, such as individuals undergoing rigorous chemotherapy.

The third, and in many ways the most important, reason was that Dr. Gottlieb and his colleagues had access to the Clinical Immunology Research Laboratories in the Center for Interdisciplinary Research in Immunology and Disease at UCLA. CIRID, as the Center was known, was one of only four such centers in the entire United States. It had been funded by the National Institute for Allergy and Immunologic Diseases a mere three years earlier, and I had been designated the principal investigator on this grant, which was designed to facilitate interactions and cooperation between laboratory and clinical research in
immunology. This is exactly what happened with AIDS: CIRID was able to tell Dr. Gottlieb and his team that their patients all had profoundly weakened immune systems. This, then, was a new syndrome—of acquired, not innate, immune deficiency.

In 1981, conventional hospital laboratories—at UCLA and across the nation—did not have the capacity to measure how intact a patient’s immune system was, and therefore could not have identified the salient feature of AIDS, which is the slow destruction of the body’s ability to fight off infection. All of the immunological data contained in UCLA’s initial report, which was written by Michael Gottlieb and his clinical colleagues and appeared in the CDC’s Morbidity and Mortality Weekly Report on June 5, 1981—and all the data that appeared in a follow-up paper published later than year in The New England Journal of Medicine—were generated in UCLA’s CIRID laboratories. The cited funding sources for those measurements were my NIH grants.

The Clinical Immunology Research Laboratory at UCLA found that our initial patients had strikingly low numbers of T lymphocytes and severely impaired immune function, and by the time the first four cases were reported in The New England Journal of Medicine in December of 1981, the lab was also able to confirm that our patients had severely reduced subsets of what are known as T helper cells. In short, the very components of the immune system that exist to combat systemic infection had been virtually wiped out by some as-yet-unexplained process.

Furthermore, the CIRID laboratory found that the levels of T helper cells (now commonly referred to as CD4 cells) in these patients were lower than the levels of T suppressor cells (known now as cytotoxic CD8 cells). Later in 1981, when we began to see patients with less advanced disease, we found that the levels of T suppressor cells were actually elevated. In these patients, the difference between CD4 reduction and CD8 cell increase was even more striking than it had been in our first cluster of patients.

Some clinicians began to use the T helper/T suppressor cell ratio as a measure of disease progression. The median normal ratio, in healthy individuals, was 1.6—and ratios of 1.0 or less became an informal yardstick for disease diagnosis. While easily comprehensible and relevant markers of disease progression are vital to the practice of clinical medicine, I resisted this focus to the CD4/CD8 ratio because CD4 T cell decline, not the ratio, was the central pathology of this new disease entity. The CD4 cell level was sufficient for diagnosis, prognosis and assessment of therapy.

CD8 cell increases are a common feature of AIDS during most of the course of HIV infection. Presumably, this compensatory rise is due to T lymphocyte self-correction mechanisms that compensate for CD4 T cell decreases. The finding of declining CD8 cell levels is an ominous sign of pre-terminal illness, and in this context CD8 measurements are certainly clinically relevant.

The first phase of AIDS research at UCLA

Even though only a few cases of the new disease entity had been seen, Dr. Richard Krause, Director of the National Institute of Allergy and Infectious Diseases, NIAID, and his deputy, Dr. Jack Whitescarver, who were in Los Angeles for a conference on asthma in October 1981, were notified about the existence of this new syndrome, which appeared to result in lethal cellular immune deficiency in previously healthy homosexual men. As it happened, I was on the advisory council to NIAID at the time, and I brought this new disease to the attention of the council.
members, who supported the efforts of the Immunology Division of the NIAID Extramural Program to make funds available for research on the new disorder.

These alerts led to identification of the disease elsewhere. I contacted Dr. Dan Stites, head of the clinical laboratory at UC San Francisco, who soon found patients there with very low T cells. Dr. Susan Krown, of the New York Sloan-Kettering Cancer Center, notified me that her institution saw occasional male patients with severe lymphocytopenia not related to cancer therapy. Evidently, this disorder was not restricted to the Los Angeles area; it was occurring elsewhere in the country, suggesting that AIDS was more widespread than we originally suspected.

In order to expand research on AIDS, and to involve colleagues at UCLA and elsewhere, it was necessary to secure funding for research reagents and equipment. It was possible to reassign some funds at UCLA under the original CIRID award (which was renewed in 1983). In addition, funding was made available from a federally financed program on the immune system and cancer—because in the early years of the epidemic many AIDS patients presented with cancer, in the form of Kaposi’s sarcoma or, less commonly, lymphoma. As a result, some of the funds available at UCLA under that program project could be used for AIDS-related research. Also, there were two federal training grants, one from the National Cancer Institute (NCI) and another from NIAID, which provided funding that was used to introduce new young investigators to the challenges and opportunities in HIV/AIDS research.

In subsequent years, UCLA researcher Dr. Roger Detels obtained substantial research grants to fund the Multicenter AIDS Cohort Study, and Dr. Janis Giorgi secured grants from NIAID for her work on cellular immunity in HIV infection. During this same period Dr. Ronald Mitsuyasu developed the Clinical AIDS Research and Education (CARE) Center with broad support, which included state and pharmaceutical industry funding. (The CARE Center at UCLA turns twenty this year. A report on its first two decades appears on pages 16–21 of this issue of Insider.)

In the early 1980s, before large government grants became available to investigators wanting to conduct AIDS research, the flexibility of drawing upon funds from our existing CIRID grant from NIAID, our NIH training grants, and the NCI-funded program on immune function and cancer were enormously valuable: funds from those sources allowed us to assemble resources and provide facilities for researchers at UCLA who wanted to undertake AIDS-related studies that utilized their own research experience and capacities.

**Early breakthroughs**

In the course of developing methods for measuring blood levels of CD4 and CD8 cells, we determined that healthy men had between 600 and 1200 CD4 cells per cubic millimeter of blood, with a median of about 900/mm$^3$. The first AIDS patients seen at UCLA had CD4 levels under 100/mm$^3$. Subsequent studies found CD4 T cell levels of 200 or even 150/mm$^3$ in patients with clinical AIDS.

These striking data had two important clinical applications. First, we could test homosexual men and others at risk for AIDS—to identify those with CD4

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**In the period October 1980-May 1981, 5 young men, all active homosexuals, were treated for biopsy-confirmed *Pneumocystis carinii* pneumonia at 3 different hospitals in Los Angeles, California. Two of the patients died. All 5 patients had laboratory-confirmed previous or current cytomegalovirus (CMV) infection and candidal mucosal infection…. The patients did not know each other and had no known common contacts or knowledge of sexual partners who had had similar illnesses.”**

Reported by MS Gottlieb, MD, HM Schanker, MD, PT Fan, MD, A Saxon, MD, JD Weisman, DO, Div of Clinical Immunology-Allergy; Dept of Medicine, UCLA School of Medicine; I Pozalski, MD, Cedars-Mt. Sinai Hospital, Los Angeles; Field services Div, Epidemiology Program Office, CDC.

Editorial Note: *Pneumocystis pneumonia in the United States is almost exclusively limited to severely immunosuppressed patients. The occurrence of pneumocystosis in these 5 previously healthy individuals without a clinically apparent underlying immunodeficiency is unusual…. All the above observations suggest the possibility of a cellular-immune dysfunction related to a common exposure that predisposes individuals to opportunistic infections such as pneumocystosis and candidiasis.”*

Excerpt from the CDC’s *Morbidity and Mortality Weekly Report* of June 5, 1981
levels well below the normal range. Even if these individuals had no clinical evidence of AIDS, they were considered to have a “pre-AIDS” state, making them candidates to develop full-blown AIDS in the future.

Secondly, by testing CD4 levels at regular intervals, we expected to be able to gauge the rate of disease progression in these patients, even in the absence of specific information about the cause of the new syndrome.

At this point Dr. Roger Detels, a professor of epidemiology at UCLA and dean of its School of Public Health, proposed an epidemiologic approach to asking many of the key questions raised by AIDS, and we developed a study plan. Three basic premises underlay this study when it was initiated at UCLA in late 1981. One was based on the observation that the first group of men with AIDS were 28 or older. Dr. Detels, noting that most homosexuals began engaging in same-sex activity before age 21, suggested that it would be advantageous to follow healthy homosexual men in the age range of 18 to 30, with serial health checks and laboratory measurements to compare those who did develop AIDS with those who did not—in the hope of identifying factors that might contribute to the syndrome’s development.

The second premise was that, by measuring CD4 levels, a pre-AIDS state could be detected in study subjects who had no obvious symptoms. Because CIRID had the laboratory capacity to detect low CD4 levels, we anticipated that we could follow the course of disease by serial blood measurements of CD4 cells.

The third premise was that, in addition to collecting clinical, social and behavioral information on our study subjects, we would collect and separately store plasma and blood cells on each visit. New research questions were continually arising and methodologies were in a state of flux. These serial stored samples would facilitate future research on issues not yet raised.

One pressing need was to find and organize the populations at risk. To do so, Dr. Detels went to the gay students’ club at UCLA, and explained to its members that a lethal new disease was spreading in the gay community in Los Angeles—and that we needed the students’ help to find out more about the causes of this disease and how to prevent it. These UCLA undergraduates responded enthusiastically, and in the next 18 months, 150 enrolled. A wide range of healthy, gay non-students, ranging in age from 19 to the mid-thirties, was also enrolled. Dr. Detels set up a site off campus where these young men could come for periodic health check-ups and blood sampling.

The issue of how frequently this sampling needed to take place also had to be settled, and three-, four-, and six-month intervals were considered. At the time, the course of the disease was not known, but some of our early patients lived as long as eight or ten months after they first developed symptoms of AIDS. (Only much later would we come to appreciate that the median time from infection to symptomatic disease was roughly nine years.) Our decision to collect data and blood samples at six-month intervals was based, in part, on reducing the procedural burden that more frequent follow-up would have imposed.

The Multi-Center AIDS Cohort Studies

In 1983 NIAID announced a project that was almost identical to the UCLA AIDS Epidemiology Study, which began in 1981. UCLA and other sites received funding to characterize the disease and identify its etiology. This national program was known as the Multi-Center AIDS Cohort Studies, or MACS. Dr. Detels was the principal investigator at UCLA and the principal epidemiologist of the five-member MACS governing body.

At UCLA, 1,600 healthy homosexual men enrolled in MACS, and the 150 individuals from our original cohort were rolled over into this study. When HIV was confirmed, in 1985, as the etiologic agent that causes AIDS—and diagnostic tests became available to detect whether an individual had been exposed to the virus—it was found that about half of the 1,600 men in UCLA’s cohort were infected with HIV when they enrolled in the study. Of the 800 men who were uninfected at the time they entered the study, some 150 subsequently became infected. To date, data from MACS have resulted in more than 1,100 scientific publications.

The men in the UCLA MACS group have an amazing record of retention in the study: 92% of those enrolled remained in the study for at least a quarter-century. (Most studies are lucky to retain that many study subjects for one year) These men have already made enormous contributions to our knowledge about AIDS, and they now are helping us study the effects of aging and of other diseases on infected individuals, not to mention the long-term impact of antiretroviral therapies on the occurrence of cardiovascular disease, neurologic deterioration, and so forth.

Confronting the enemy

In the first years of the AIDS epidemic, the UCLA faculty responded vigorously to this grave threat to public health, conducting wide-ranging research on the pathogenesis, immunology, epidemiology and treatment of this new syndrome. The university also developed programs for physician education, but broad-based community education programs, and related efforts to reach
"Four previously healthy homosexual men contracted Pneumocystis carinii pneumonia, extensive mucosal candidiasis, and multiple viral infections. In three of the patients these infections followed prolonged fevers of unknown origin. In all four cytomegalovirus was recovered from secretions. Kaposi’s sarcoma developed in one patient eight months after he presented with esophageal candidiasis. All patients were anergic and lymphopenic; they had no lymphocyte proliferative responses to soluble antigens, and their responses to phytohemagglutinin were markedly reduced ... The inversion of the T helper to suppressor/cytotoxic ratio suggested that cytomegalovirus infection was an important factor in the pathogenesis of the immunodeficient state. A high level of exposure of male homosexuals to cytomegalovirus-infected secretions may account for the occurrence of this immune deficiency."


Once the cause of AIDS had been identified, Dr. Detels and others who were conducting epidemiology studies at UCLA needed to partner with virologists—to discover, for example, why some patients sickened and died within a few years of infection while others remained clinically stable for a decade or more. The blood and plasma samples collected during the first years of the AIDS epidemic were to prove invaluable in answering such questions.

At UCLA in the mid-1980s, Dr. Irvin Chen and colleagues were already investigating the so-called human T cell leukemia viruses, once suspected of being the cause of AIDS. Dr. Chen had previously identified a distinct form of this virus, known as HTLV-2, and had characterized the mode of action of human retroviruses like HTCL. With the discovery of HIV—another human retrovirus—Dr. Chen shifted his research focus, and vigorous HIV research programs were developed independently of CIRID. Among those programs were novel pathogenesis studies conducted by Dr. Jerome Zack in mice with functioning human lymphoid cells. It is a measure both of UCLA’s commitment to HIV/AIDS research and to the scientific challenges posed by this pernicious antagonist that both these men are still deeply involved in the field, Dr. Chen as the longtime director of the UCLA AIDS Institute and Dr. Zack as the administrative director of the Center for AIDS Research within the AIDS Institute.

Readers interested in the full story of UCLA’s decades-long commitment to containing—and, ultimately, eradicating—the HIV pandemic will find it in “AIDS from 1981,” the eleventh chapter of Dr. Fahey’s memoir about his long and illustrious career. The entire manuscript is available at www.johnfaheymd.com.
Left Behind: Rose’s Story

She lives a mere 15 miles from the UCLA's state-of-the-art AIDS clinic, but this urban castaway, like all too many homeless and impoverished HIV-positive Americans, is unable to access even the most basic medical services.

Ask any group of bright, well-informed American high school students where the highest rates of HIV infection are found, and the chances are good that many of those students will cite South Africa, which does indeed have the highest incidence of infection of any major country on earth: almost 12% of the adult population carries the virus. The brightest and best-informed students may identify the tiny kingdom of Swaziland, inset into the northeast corner of South Africa—where the infection rate is a staggering 26.1%. What not one of these students is likely to know is that the very highest rates of HIV infection found anywhere on earth occur right here, in South Central Los Angeles—among African-American men who have sex with other men. Close to half of these men are already infected with the virus that causes AIDS.

We understand the deadly synergy of poverty, ignorance, cultural taboos, discrimination, and deep-rooted stigma—factors that collectively fuel the raging HIV epidemic in South Africa. What we too often fail to recognize is that those same factors are at work here at home, where ruthless stratification of health-care delivery dooms some to an early death even as it sustains others, like Tom Gillman, a long-term survivor who is also a long-time patient at UCLA's Clinical AIDS Research and Education Center (see “World-Class Science and Personalized Care” on pages 16–21).

Rose, at left, applying makeup to a face that betrays every day of the three hard decades of her life, is among the condemned. This is her story.
Rose was introduced to crack cocaine when she was 13, and she has been an addict for twenty years. The same adults who hooked her on crack—and stole her adolescence in the process—also taught her how a pretty 13-year-old can pay for the drugs she uses: through prostitution. And in so doing they stole her self-respect, her dignity, and her chance for a stable, productive, satisfying life. When she has a roof over her head, she entertains her Johns there; during the periods when she is homeless, she works the streets. Interestingly enough, it is not the crack pipe (lower right) that transports Rose out of her enduring misery, it is drawing. She has never had an art lesson, but she does have some native talent, and she covers the walls of the rooms she inhabits (opposite) with fantasy visions of an alternative life, one in which there are strong, loving men to protect her from the men who prey on her.
The wages of a career in prostitution are successive sexually-transmitted diseases… and children. Over the last 20 years Rose has borne five, by as many men. Her two oldest, both boys, are in jail, and the next-eldest, a daughter, is also a prostitute and sometimes works the streets with her mother. Rose’s younger daughter and youngest son, raised separately and unaware that they were related, fell into an incestuous relationship which Rose broke up as soon as she learned of it. She has, by her account, been in jail numerous times—although she sometimes avoided arrest by having sex with the officer who collared her. She was almost killed by gang members, was raped numerous times, and was recently evicted, yet again, from the place where she was living. Lately, she has been staying with her 70-year-old mother, who is also a crack addict. Perpetually on the move, Rose has accumulated few possessions, but one that she clings to is a pen topped with her namesake flower. In this picture it sits on the night table, standing silent guard while Rose’s mother sleeps in the bedroom they now share.
Dr. Ronald Mitsuyasu, founder of the CARE Center, confers with Tom Gillman, who has been his patient for 28 years and counting.
When Tom Gillman was first referred to UCLA for treatment of what would come to be recognized as AIDS-related Kaposi’s sarcoma, he was seen by a lone oncology researcher and his nurse. Now, 28 years and several office relocations later, Tom is still receiving his HIV primary care from the same UCLA doctor. But more importantly, he is still alive to tell the story, determined that “something else will kill him besides HIV.”

Ronald Mitsuyasu, MD, founded UCLA’s clinical program in HIV in 1981 out of necessity. When AIDS was first described at UCLA, Dr. Mitsuyasu, who was working as an oncologist alongside Dr. Jerome Groopman, started seeing patients with Kaposi’s sarcoma (KS). Dr. Mitsuyasu quickly recognized that these new AIDS patients required specialized care, so with limited supervision and minimal support, he began to see and treat them. He started a research program on HIV/AIDS with Drs. Michael Gottlieb and Yvonne Bryson at UCLA in the hope of finding ways to help these patients. He received funding from a series of independent grants, and hired Susie McCarthy as a research nurse in 1983. Together, they set out to face the challenges of HIV head on, dedicated to working purely because patients needed care, in spite of the fears among many health providers and the general public surrounding HIV/AIDS.

At the time, so little was known about HIV/AIDS that even with the most cutting edge research, the process of understanding the disease was slow, and patients were dying. And, in addition, there were social stigmas. Although McCarthy was never personally afraid of working with HIV-positive patients, her family was affected by her career choice. McCarthy’s daughter came home from school in tears one day: no one wanted to play with her because they thought she would get HIV since her mom was working with HIV patients. The lack of knowledge and education about HIV and how it could be transmitted made for an especially arduous task of educating patients, their family members, other providers and the community-at-large. McCarthy recounts the secrecy surrounding HIV at the time:

“One day a patient brought his mother to the clinic with him. He wanted us to explain to the mother about HIV. It was really very emotional. The mother had no idea that her son was gay, and that he had HIV. She was very appreciative that we talked to her. But this lack of knowledge was really something to see—the interactions with the son and the mother, and us talking to her.”

In spite of all the difficulties, Dr. Mitsuyasu and McCarthy were making a difference. Gillman remembers his first visit to Dr. Mitsuyasu’s office as being one of entering “the most welcoming, wonderful environment.” More importantly, the experimental treatment for his KS lesions worked. Gillman describes the experience as a kind of medical miracle:

“We were setting the standard of care then, because no one knew what it was. I asked Dr. Mitsuyasu, ‘What’s your experience with KS?’ He didn’t have any. I had a number of lesions. The first regimen was six weeks, during which I gave myself a shot twice a day of massive amounts of interferon. Six weeks later, I went in to have an anoscopy, and the lesions were gone. This was astounding, and had not been observed in anyone else up to that point, as I understand it. I did another six to eight weeks of treatment, and at the end all my lesions were completely gone. More importantly, they’re still gone.”

Over the next few decades, UCLA’s HIV research program expanded to address the continually changing needs of patients. Dr. Mitsuyasu’s clinic moved from the oncology department offices to the basement of UCLA’s old hospital, where he started his own HIV-dedicated patient care and research program. And even though Gillman describes that windowless space as a “dungeon,” it was a relief to many patients to receive care in a private place where they wouldn’t be seen (and potentially stigmatized) by other patients.

In 1990, the UCLA Clinical AIDS Research and Education (CARE) Center got its official name with the development of UCLA’s unique HIV program. The next move was to a more spacious office with a lobby and multiple exam rooms to accommodate more patients. Gillman recounts being greeted here with a joke to help lighten the difficulty of the transition. The greeter was Mike Marcial, the CARE Center’s manager, who has worked at the center for 14 years—or, as Gillman describes it, “forever.”

Twenty years later, the UCLA CARE Center has come a long way. What started as a two-person operation in a side wing of the oncology department, under the direction of Dr. Mitsuyasu, has grown into a thriving off-campus clinic that sees more than 900 patients annually and is home to specialists in HIV treatment, prevention, HIV-related co-morbidities, and long-term complications of both the infection itself and the treatments for it. The CARE Center has been housed at its current off-campus location, on Pico Boulevard at Roxbury Avenue, since August 2005. This dedicated HIV clinic includes a spacious waiting room, six examination rooms and a procedure room, all devoted to serving the HIV-infected patients seen by nine experts in infectious disease, including Dr. Mitsuyasu, and supported by more than 25 research and clinic staff. In its remarkable transition from a “dungeon” and shared offices to a dedicated clinic, a community outreach team and global partnerships, the UCLA CARE Center has maintained its core values of patient-centered care and world-class research.
Gretchen Crews was not doing well five years ago. She had lost so much weight that friends expressed concern about her skeletal figure and commented on how sick she looked. When personal stress compounded her poor physical health, she decided to check in to the emergency room. On the way there, she decided to call her HIV doctor of nine years, Dr. Margrit Carlson, who is the CARE Center’s Clinical Director. Dr. Carlson suggested that Gretchen come to the clinic first, to see if she could do anything to help. Recounts Crews:

“I went to the CARE Center, and Dr. Carlson put me in one of the rooms. She got blankets and tucked me into the bed, wrapped the blankets around me, and held me for a minute. ‘You know what sweetie,’ she said, ‘we’re going to take care of you.’ That kind of care, to me, is worth a million dollars. That moment when she wasn’t a doctor but a friend, telling me it is going to be okay and giving me a hug and a little TLC. That was really what I needed that day. You don’t learn that in medical school. That’s the kind of doctor Dr. Carlson is, and that’s why it doesn’t matter what I have to do to see her. I feel so safe with her.”

Personalized care is what the doctors and staff at the CARE Center do best. And while the faculty members are world-renowned as experts in HIV medicine and conduct the most cutting-edge research in the field of HIV and its co-morbidities, their strength lies in their attention to details and to individual patient needs. Long-term patients like Crews, who has changed health insurance providers on multiple occasions to be able to stay under Dr. Carlson’s care, attest to how much the doctors at CARE do just that—care.

When Octavio Vallejo first came to see Dr. Judith Currier, who has served as the CARE Center’s Associate Director since 1998, he was in very poor health. Vallejo had developed resistance to the vast majority of HIV medications available at the time, and he was highly dissatisfied with the care he had been receiving elsewhere. Before Dr. Currier prescribed a new drug regimen for Vallejo, she ran a battery of tests to determine his resistance to various medications, eventually deciding on a drug combination that kept his HIV viral load low for the next ten years. As he puts it, “She brought me back to life.” But what stands out to Vallejo, even more than the expert clinical care that Dr. Currier provided, was her non-judgmental approach to that care. As Vallejo observes:

“Her support has never wavered, even when I did things that I was not supposed to be doing. For instance, I got liposuction in Mexico, because I had developed a big breast from my old medications and it was very uncomfortable. I disappeared... and I came back two or three days after, and all Dr. Currier asked was, ‘What did you do?’ She was really supportive, and all she said was, ‘We are going to have to keep an eye on you.’ In Mexico they give you the procedure, but they don’t take care of you afterwards. The CARE Center is completely different. Even when you do something ill-advised, you still get a big welcome.”

Vallejo’s continued good health gives him confidence to try novel approaches to treating his HIV infection, in an effort to give back to the greater community. He considers himself part of the team at the CARE Center, and feels strongly that his participation in clinical trials is a way to pay it forward. He is, for example, one of only a handful of patients at UCLA who is enrolled in a novel study examining how gene therapy may potentially help control HIV infection. And although he feels a little nervous about this new experimental treatment, he takes comfort in knowing that he is in good hands. And he is proud to be involved in the quest for better treatment options.

Gretchen Crews, CARE Center patient and scuba-diving enthusiast

“At the CARE Center you receive the most incredible care in terms of quality, but also in terms of somebody who genuinely cares for you.”

Octavio Vallejo, gene-therapy study participant and community educator
Dr. Raphael Landovitz came to UCLA from Boston in 2006, to work with Dr. Currier to help bridge the gap between HIV therapy and prevention strategies. HIV prevention increasingly involves drug treatment, not just behavior modification, and Dr. Landovitz, as an expert in HIV prevention with a deep understanding of disease complications and complexities, is a strong addition to the CARE Center team. As he explains, people come to the CARE Center for opportunities to participate in the most cutting-edge clinical trials, including exciting new research on gene therapy as a potential treatment strategy and examinations of new possibilities for HIV prevention, such as a once-a-day anti-retroviral medicine that may reduce the likelihood that an HIV-negative individual will become infected. But, as Dr. Landovitz notes, these patients stay at the CARE Center for the personalized care provided by doctors who are genuinely passionate about their work, and about giving their patients the best quality care.

This passion is evident throughout the organization. Faith Landsman, who has worked as a CARE Center Research Administrator for the past six years, facilitates the clinical research process by communicating with UCLA’s ethics board to ensure that participants understand the research and are being kept safe. She takes a profoundly personal approach to her work: “I know some of the people who are being affected by the research. It is really important to me that the research is done ethically, that it is understandable to participants. These are human beings. Friends of mine are participating in some of our ongoing research right now. I always think, ‘Would this person understand what I’m talking about here?’”

At the UCLA CARE Center, reaching out to the community is embedded in the culture. Many of the study patients, like Vallejo, see their participation in clinical trials as an opportunity to help other patients infected with HIV. And the CARE Center faculty and staff are dedicated to service in the community—and worldwide. Dr. Jordan Lake, who came to the CARE Center in July 2008, sees her work as a blessing: “I love my job, and I feel so lucky to get to work every day seeing my patients,” she says. She conducts metabolic research studies, which are becoming increasingly important among patient populations who are living longer and suffering from both weight gain and the metabolic complications associated with long-term treatment with HIV medications. She also dedicates time each week to seeing her patients at the Valley Community Clinic, where she works to gain the trust of patients from largely marginalized communities. She sees her role as comprehensive: She is not just a doctor but also a resource for linkages to support. And she appreciates that quality care is more than just writing a prescription:

“I recognize that I need to help patients see that, first of all, I don’t judge them. And second, I do understand the challenges they have. Most of them have not had positive encounters with the healthcare system before. When you can successfully develop a relationship, everything else falls into place. I love working with the patients who have so many challenges in their lives, to help them get through the other challenges first. I strive to address all aspects of care, not just taking their medications.”
Kieta Mutepfa, who has served as the CARE Center’s Community Health Liaison for the past nine months, declares that “the CARE Center is a group of highly qualified, highly trained, yet profoundly compassionate individuals who are committed to finding a cure to HIV/AIDS.” While a cure for HIV is still a distant hope, near-normal lifespans with minimal complications are, increasingly, the reality for many HIV patients, thanks to advances in treatment made possible by the clinical trials that are at the forefront of the CARE Center’s mission.

Compassion is an integral part of what makes the CARE Center unique, and as Mutepfa says, “All CARE Center staff are a part of that compassion, from the administrative staff and management to the coordinators and outreach team.” Mutepfa is certainly an inspiring example. Her commitment to her work comes from personal experiences, such as visiting a renowned psychology professor on his hospital deathbed in the last days of his battle with AIDS, as well as befriending and living with HIV-infected individuals in Sunshine House, an apartment complex in Washington, D.C., for families of people infected with HIV.

Compassion at the CARE Center comes in many forms. Maricela Gonzalez, who is the CARE Center’s AIDS Malignancy Consortium study coordinator, has learned that listening is one of the best services she can provide her study participants. Her advice is to “really listen to what the patients need and just hear them out.” By putting herself in her patients’ shoes, she is able to better understand their needs and support them as they deal with HIV. In the end, it’s all worth it for her, she says with a smile: “To me, it’s the five minutes with the patient of ‘Hey, how are you?’ when you see them in the hallway and they hug you. That’s the best feeling in the world.”

Another exemplar of the CARE Center spirit is Marcial, who has been working in “medical customer service,” as he describes it, for the past 25 years. He takes pride in his work, and genuinely loves interacting with patients. He strives to make visits to the CARE Center seamless, and aims to ensure that patients never have to wait when they arrive for their appointments. But most importantly, he welcomes people to the CARE clinic with a genuine smile and friendly hello, and takes time to listen to people’s needs and solve problems by finding the right answers. He believes in treating people with respect and takes pleasure in holding patients’ hands or giving them a hug. Patients at the CARE Center take comfort in his friendly face and quality service, and they often call Marcial to just ask him how he is doing.Treating people with dignity and respect is a mantra heard at all levels of the organization.

The reach of the CARE Center stretches not just throughout Los Angeles but around the globe, to communities that are impacted by HIV and AIDS. When she’s not advocating for better health and social services for her patients at the To Help Everyone (THE) Clinic in Los Angeles, Dr. Risa Hoffman spends much of her time working with Thomas Coates, PhD, Director of UCLA’s Program in Global Health, in Malawi—to help expand the ability of the country’s services to take care of people living with HIV. Her research there is focused not only on getting medications to people who need them, but also on women’s desire to have children, and assisting them in safe family-planning. As the HIV program in Malawi grows, more faculty at the CARE Center are taking time to visit the clinic site there, which adds to the depth of the CARE Center’s understanding of the HIV epidemic on a global scale.

Los Angeles is a community burdened with unique challenges in the field of HIV. Mutepfa and Alejandro Ponce, who serve as the CARE Center’s community health representatives, work together as the CARE Center’s outreach team to address some of these issues on a person-centered level. They strive to educate at-risk populations, especially young men of color who have sex with men—a group that has the highest incidence of HIV infection in the county—on ways to protect themselves from infection and to find treatment and care. Mutepfa and Ponce are also
developing ways to enhance the transparency of the CARE Center’s operations and programs by inviting community members to attend educational lectures, volunteer at the CARE Center, and participate in monthly Community Advisory Board (CAB) meetings. These CAB meetings are an opportunity for patients and interested community members to engage in conversation with providers to express their unique concerns and to learn about the latest trends in research. Mutepfa often gives clinic tours to community members, so that she can introduce them to her colleagues and show them firsthand that “there are human beings with good intentions behind all of these clinical trials.”

Mutepfa hopes that the CARE Center will continue to play a key role over the coming years in educating people about the HIV epidemic. She believes that as more community members come to understand the HIV virus and the side effects of treatment, they can find ways to deal with it. New work on HIV prevention, such as the soon-to-open trial on pre-exposure prophylaxis, or PrEP, will be highly significant, as will the AIDS Malignancy Consortium’s cancer trials, in helping to provide solid information on new treatments. “This information can be used to educate communities, especially young African-American and Latino men who have sex with men—and who may not be aware of these methodologies—about the options now open to them,” Mutepfa says. Dr. Landovitz expresses similar hopes: “I think the CARE Center has its work cut out for it in taking a leadership role in leading the diverse communities at risk for HIV forward, and in studying and implementing new HIV prevention technologies.” Even with the challenges, he is confident that the CARE Center can rise to the occasion and continue to forge new territory in order to develop better options for people in HIV treatment and prevention.

For more information about the UCLA CARE Center, please visit them online at www.uclacarecenter.org and on Facebook at www.facebook.com/uclacare. For details about any of the CARE Center’s currently enrolling trials, or if you are interested in participating in a research study, please call their research team at 310-557-9062 or email them at CAREoutreach@mednet.ucla.edu. To make a donation in support of the UCLA CARE Center’s mission, please contact Becky MacFarlane at 310-557-1898.

“We have the opportunity to interact with diverse communities to provide comprehensive and compassionate care, both in Los Angeles and around the world.”

Dr. Risa Hoffman, women’s health specialist and world traveler

Dr. Judith Currier, Associate Director of the Center, meets with longtime patient Octavio Vallejo.
Song of the Open Road

For the tenth consecutive year, Charity Treks, a hardy band of humanists on wheels, pedals across New England in support of the UCLA AIDS Institute’s vaccine development programs.
Charity Treks was born out of disappointment... and determination. The disappointment came a decade ago, when a revved-up group of serious cyclists, most of them from the Eastern Seaboard, learned that Palotta TeamWorks had been forced to fold its operations, mere weeks before those riders were scheduled to participate in a long-anticipated, TeamWorks-produced AIDS Vaccine Ride through Vermont and New Hampshire. (For a report on the rise, fall, and rise of Palotta TeamWorks, see pages 22–25 of the Winter 2009–2010 issue of Insider, available online at www.uclaaidsinstitute.org.)

The determination manifested itself days later, when this band of dedicated men and women—who had been training for the vaccine ride, and raising money in anticipation of it, for the previous two months—decided that, TeamWorks or no TeamWorks, they would ride. And ride they did—following the route that Palotta’s group had chosen... and, in the process, establishing a precedent for future rides, conducted under the aegis of their brand-new not-for-profit, which they called, with exquisite logic, Charity Treks.

Mark Stanis, who works for the University of Virginia in Charlottesville, had made plans to participate in the Palotta vaccine ride—and that, until a few weeks before the departure date, was the extent of his commitment. Fortunately for the other riders, their nascent organization, and the AIDS Institute’s vaccine development programs, Mark has well-honed organizational skills, a gift for diplomacy, and no apparent fear of hard work. He stepped into the yawning administrative gap left by the sudden collapse of Palotta TeamWorks, serving as the straw boss of Charity Treks’ first, hastily organized ride, which, against all odds, succeeded in raising almost $100,000 for the Institute. David Thibault, Quinn Beckham, and Fred Ury also volunteered their services, and the four became the new organization’s first board of directors.

The other participants in that first ride had to good sense to give Mark a battlefield promotion—to president of their organization. The title has a certain cachet, but the actual job involves scouting each year’s route, well in advance, for potential hazards, prospective campsites, and scenic spots to stop for lunch. That, and he obtains the necessary permits and clearances, lines up precautionary medical services, and drives a truck-full of other riders’ bikes to the spot where the ride begins. We hope Mark likes being president, because it is clear to us that without his unstinting, year-round commitment, there would be no Charity Treks.
Last summer’s Charity Treks ride began in Montreal, crossed into northern Vermont, and angled eastward to its terminus, Portland, Maine. And no, the route was not all uphill, nor was it all about barked shins and pelting rain, although the riders did encounter a sudden shower toward the end of their first day’s ride—the only downpour they were to experience on their five-day, 430-mile marathon ride. For the most part, the cyclists kept to roads less traveled by, passing through bucolic, picture-postcard-perfect New England countryside (previous pages). When Nikki Hatch and Sarah Lee paused at the U.S.-Canada border (opposite, above), they had already covered 48 miles; their destination for that night was Burlington, Vermont, a mere 70 miles to the south. By Day 3 of the ride, the intrepid band had crossed into neighboring New Hampshire, where, to demonstrate their support of AIDS vaccine research, they wore red. Not red ribbons, mind you, but frocks fashioned out of whatever red fabric they could lay hands on (opposite, below). The iconic red ribbon did make an appearance, but not until the last day of the ride, when a hand-embroidered Charity Treks 2011 memorial afghan was unfurled (below) during the closing ceremony.
Side excursions are a regular feature of any Charity Treks ride. So it is hardly surprising that the most adventurous of the cyclists on this year’s ride took a slight detour in rural Vermont—to Moss Glen Falls. And it should be no more surprising that, once there, some of them took impromptu outdoor showers under the falls itself. An even more popular side-trip was the group excursion to the Dipsy Doodle Dairy Bar, in Northfield, New Hampshire, for that roadside restaurant’s justly famous lobster rolls—which John Burwell (far left) and David Kent consume with undisguised gusto. Like Burwell and Kent, most of the participants in Charity Treks’ tenth anniversary ride were veterans of previous rides, and over the years a special sort of camaraderie has arisen among them. Rob Seltzer, shown opposite, above, with his wife, Linda, calls this “the spirit of the ride,” and he says that all of those involved in the ride “make a habit of looking out for one another.”
Rob Seltzer (above), the lone Angelino on this year’s ride, has missed only two Treks in the last decade, and he took his then-fiancée on a ride before he married her. Linda Seltzer insists that this was not a try-out or an endurance test, but she acknowledges that participating in the ride, year after year, is a commitment: bicycles and camping gear have to be shipped on ahead; air tickets from the West Coast aren’t cheap. And then there’s the time involved, and the training rides that precede the actual Trek. But the Seltzers will tell you that the expense and effort are modest compared with the satisfaction that they derive for the ride. We salute them, our local heroes, and all those who rode with them (opposite, below). Dr. Beth Jamieson, a senior researcher at the AIDS Institute (near left), was in Portland in August to greet the riders as they reached the end of their journey—to thank them for their efforts on behalf of AIDS vaccine research at UCLA.
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30 Years of AIDS at UCLA page 4

Three decades of cutting-edge research and state-of-the-art clinical care, as recalled by one of the university’s pioneer investigators

Left Behind: Rose’s Story page 10

This urban castaway, like all too many homeless and impoverished HIV-positive Americans, is unable to access even the most basic medical services

World Class Science and Personalized Care page 16

Reflections on the UCLA CARE Center’s Last 20 Years

Song of the Open Road page 22

For the tenth consecutive year, Charity Treks, a hardy band of humanists on wheels, pedals across New England in support of the UCLA AIDS Institute’s vaccine development programs