



INSIDER

DEDICATED TO THE PEOPLE WHO MAKE THE INSTITUTE'S ACHIEVEMENTS POSSIBLE

Volume 8, Issue 2 Winter 2012

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

UCLA in Los Angeles

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

By Kathryn Rogers



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.



"The CARE Center is my safe haven."

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

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.



**"Come for the cutting-edge science.
Stay for the outstanding care."**

Dr. Raphael Landovitz, Assistant Professor of Medicine
and spin instructor

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."



"The CARE Center is interested in, and committed to, building solid relationships and nurturing community partnerships that are mutually beneficial."

Kieta D. Mutepfa, MSW, Community Health Liaison and women's rights advocate

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



"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

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.



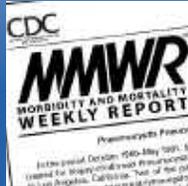
Dr. Judith Currier, Associate Director of the Center, meets with longtime patient Octavio Vallejo.

**UCLA AIDS Institute and Center for AIDS Research
David Geffen School of Medicine at UCLA
405 Hilgard Avenue, Box 957339
Los Angeles, CA 90095-7339
Phone: 310 794-5335
Email: aidsinst@ucla.edu
Web: www.uclaaidsinstitute.org**

**NONPROFIT ORG.
U.S. POSTAGE
PAID
UCLA**

Address Correction Requested

Inside *Insider* :



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