



UPDATE

vol. 11 no. 4

AIDS COMMUNITY RESEARCH INITIATIVE OF AMERICA

HIV Treatment Education: Community Perspectives

HIV treatment education for people living with HIV/AIDS (PLWAs) and their care providers has long been central to ACRIA's mission. Relatively early in our existence as a community-based clinical research site, our patients were telling us that they desperately wanted to learn more about the health issues that were impacting their lives. ACRIA responded by developing a program that could provide culturally and linguistically appropriate information for PLWAs and care providers.

Our desire to learn more about the role and challenges of other educators has resulted in the Fall 2002 issue of *ACRIA Update*. We invited people who provide various kinds of community-based HIV treatment education to share their experiences. Our contributors come from many geographic areas, work with varied populations, and offer a wide range of treatment education services – from individual counseling to group

workshops to creating written materials. Some are volunteers, doing remarkable work with little or no assistance. Others work at established AIDS service and advocacy organizations, with the support and resources that such agencies can ideally supply. Still others are clinicians working within a healthcare setting.

The contributors discuss some of the challenges effective treatment educators face – the ability to listen, to offer non-judgmental support, to understand the difference between offering information and offering advice, to recognize our personal biases and limitations, and, perhaps most importantly, a firm belief in everyone's ability to learn and make decisions that are right for them. We've gained a tremendous amount from reading the perspectives on treatment education in this *ACRIA Update*. We hope that you find the newsletter interesting and informative as well.

J Daniel Stricker, Editor in Chief

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James Learned *Director of Treatment Education and Editor of ACRIA Update*

Reclaiming Individual and Community Power

Long-time AIDS activists, advocates and/or educators have witnessed and often contributed to a subtle but significant shift in the way that people with HIV/AIDS (PWAs) are viewed. Early in the epidemic – until the mid-'90's – people with HIV usually referred to themselves as just that – *people*. Now, even the most dedicated and sensitive service providers and clinicians are more likely to refer to PWAs as their *clients* or *patients*. The difference isn't just

semantic. The possessive "my client" or "my patient" implies ownership. It informs the way that power is distributed and the degree to which each individual PWA is expected and, sometimes, allowed to participate in and decide the course of his or her own care.

Each contributor to this issue of *ACRIA Update* offers distinct ideas of what constitutes effective treatment education, but the commonality

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fall
2002

Efrain Rosa 1956-2002

It is with great sadness that we report the death of Efrain Rosa on July 27, 2002. As a treatment educator at ACRIA, Efrain had a powerful impact on the many lives he touched. He was a man with a mission: to use his own life experiences to reach people with HIV. His understanding that HIV was only one of many hurdles people with this disease face made his work particularly effective. His legacy lives on in the countless individuals who benefited from his tireless dedication. We miss him.

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ACRIA is an independent, non-profit, community-based AIDS research and treatment education organization dedicated to rapidly improving the length and quality of life for people living with HIV/AIDS. ACRIA studies new treatments for HIV-related diseases through its clinical research and conducts a comprehensive treatment education program. Bulk copies of *ACRIA Update* are available free to agencies that provide services to people living with HIV/AIDS. For more information, call Jonathan Deardoff at 212-924-3934 ext. 121.

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Integrase Inhibitor

This trial will study the pharmacokinetics, safety and antiviral effect of S-1360, one of a new class of experimental anti-HIV medications that inhibit the integrase enzyme.

This is a ten-day study for people with HIV who have not taken antiretrovirals. People 18 years and older, with a viral load between 400 and 50,000 copies and a CD4 count over 50 may be eligible for the study. They must not have taken any protease inhibitors, nor been on any NRTIs for more than 2 weeks, nor have taken more than one dose of any NNRTI.

People in the study will be compensated up to \$1,050 while they take part in the study to cover time lost from work, transportation costs, etc. **For more information call Dr. Yuriy Akulov at 212-924-3934, ext. 124.**

Ampligen and HAART: Protocol AMP 719

This trial will study the effects and safety of adding Ampligen to HAART and see if it helps to lower viral load.

Adults with a CD4 count over 300, and a viral load between 500 and 30,000 may be eligible for this study. The first 10 people in the trial will receive infusions of Ampligen twice a week, and take HAART. Later groups will either receive infusions at entry or receive them 6 months later.

The study will last 48 weeks during which time participants will make 21 visits to ACRIA. All blood tests, study visits and study drugs will be provided at no charge to the participants. Once enrolled in the study, there will be a reimbursement of \$25 per visit to cover lost time from work, transportation costs and/or meals. **For more information, call Dr. Douglas Mendez at 212-924-3934, ext. 126.**

Ampligen and Treatment Interruptions: Protocol AMP 720

This trial will study whether Ampligen can extend the time people can interrupt HAART, before viral load rebounds.

Adults who are taking HAART, and who have a CD4 count over 400 and viral load below 50, will take HAART and receive infusions of Ampligen, or take HAART without Ampligen, for 2 months. Then, HAART will be stopped and viral load will be checked weekly. If viral load rises above 5,000, HAART will be restarted. If viral load drops below 50 for 2 months, HAART will be stopped again. This pattern will continue for the rest of the study. People who don't receive Ampligen can take it after 14 months.

The study will last approximately 128 weeks during which time participants will make 128 visits to ACRIA. All blood tests, study visits and study drug will be provided at no charge to the participants. Once enrolled in the study, there will be a reimbursement of \$25 per visit to cover lost time from work, transportation costs and/or meals. **For more information, call Dr. Douglas Mendez at 212-924-3934 ext 126.**

Editor's Notes

- All material in *ACRIA Update* is presented for educational and informational purposes only, and is not intended as medical advice. All decisions regarding one's personal treatment and therapy choices should be made in consultation with a physician.
- *ACRIA Update* refers to all drugs by both their commercial and scientific names upon their first reference in an article. Thereafter in the article, they will be identified with the name by which we feel they are most commonly known, either commercial or scientific.

James Learned *(continued from first page)*

among their perspectives is striking. Avoiding the temptation to reduce individuals to a CD4 count and viral load result, they recognize that each person with HIV is a distinct human being with different needs and desires who makes different choices depending on his or her personal experience and circumstances. Class, race, ethnicity, gender, economics, life experience, and a host of other factors inform an individual's treatment decision-making process as much as – often more than – information about HIV and treatment. In their varied ways, these educators challenge a power structure that prefers to pigeonhole people with HIV as one faceless mass, to be dealt with in pretty much the same way regardless of huge individual differences.

Long before the phrase “treatment education” was used, communities devastated by AIDS challenged power to save the lives of themselves and those they loved. Early in the epidemic, PWAs and their colleagues took their cues from the women's health movement, learning everything they could about the virus and the mysterious, deadly opportunistic infections that were occurring. People who had understood nothing of basic biology in school educated themselves about the intricacies of the immune system, read and critiqued the results of clinical trials, and shared what they learned with their community. With some notable exceptions, those in power – people within the healthcare system, private industry, and government, including public health – showed little interest in ending an epidemic that affected “expendable” communities – queers and junkies.

With little support, desperate PWAs looked into any and every treatment with even a hint of potential. In hindsight, some of these treatments seem ridiculous, even harmful. But as we continue to learn more about HIV, some currently accepted treatment strategies might, in the future, seem equally ridiculous. We can only know as much as we know. Our current understanding will evolve. We've made enormous progress over the past two decades, largely thanks to self-taught community members' involvement in the research and education process. As treatment educators, realizing the limitations of our knowledge can be humbling. The trick is to not allow intimidation to keep us from studying, questioning, learning and sharing treatment information within our communities.

1996 was a pivotal year in the history of HIV treatment. The approval of protease inhibitors, the relatively uncritical acceptance of the *hit hard, hit early* treatment model, the hopeful theory of viral eradication, and optimism about the promise of com-

bination therapy suddenly made treatment issues both clearer and more complicated. In many respects, ownership of HIV disease was taken from PWAs and claimed by the medical establishment. Previously, treatment information was disseminated to the community mainly by the community – through PWA coalitions, buyers' clubs, ACT UP chapters, newsletters like *AIDS Treatment News*, and organizations such as Project Inform, Treatment Action Group and many others.

With the complexities of combination therapy, AIDS was redefined as almost exclusively a medical issue. The medical model took hold as healthcare providers and public health officials couldn't imagine that patients could understand Highly Active AntiRetroviral Therapy (HAART) and the attendant diagnostics. There were lots more drugs, with difficult-to-pronounce names. Too difficult for your average PWA. The goal was to convince people with HIV to get on – and stay on – combination therapy. The focus became compliance, as though compliance was the only variable in the success of treatment for each individual – and as though treatment was necessarily the best choice for everyone.

As combination therapy resulted in dramatic drops in opportunistic infections and deaths, various organizations developed formal treatment education programs to help clients sort through the information and make informed treatment decisions. Funding soon became available from pharmaceutical and government sources, and many, perhaps most, of these treatment education programs turned into well-intentioned treatment adherence programs. Now, the focus of many community-based programs was also compliance, often at the expense of the whole person philosophy that had been integral to the PWA self-empowerment movement of the 1980s and early '90s. Helping people on treatment develop adherence strategies is important, of course, but an individual is more than the drugs he or she takes.

The dramatic shift in the balance of power continues. The power that the PWA community fought for and gained over so many years rests again primarily with the healthcare system, private industry, and government. This isn't to say that we haven't gained allies within these powerful entities. Many researchers, medical providers, and even some government officials understand and support the PWA self-empowerment movement. Power is not finite. There's plenty to go around. Effective community-based treatment education offers people the tools they need to negotiate the healthcare system, promote their own best interest and gain the power to make informed

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Paula Braitstein

Senior Policy Advisor on Health Promotion, British Columbia Persons with AIDS Society, Vancouver, British Columbia

Growing up, I always knew that I wanted to be a doctor. But by the time I finished high school, I decided that I would never be able to handle the science involved. Then in 1992 I landed a job with an AIDS organization in the Yukon Territory of Canada, and by early 1994 I was coordinating the Treatment Information Program for a PWA coalition in Montreal, Quebec. Before I knew it, I was reading immunology textbooks trying to understand HIV immune pathogenesis and attending scientific talks by the likes of Tony Fauci.

I have come to understand that the language of science and medicine developed historically in a way that placed doctors and scientists in an elite position in our society – because nobody else could understand what they were saying, it was commonly understood that that meant they were the only ones who could understand what they were talking about. The reason that the stereotypical doctor in the white coat is intimidating is because we assume they know everything and we know nothing. Sometimes I think the white coat gets worn, like a coat of armor, to reinforce that fallacious notion.

One of the most important legacies that people living with HIV/AIDS will have left behind once this dreadful epidemic is over is the collective awakening to the fact that science does not belong only to scientists, and medicine most certainly does not belong only to doctors.

From 1995 to 2002, I was privileged to have been the Director of the Treatment Information Program (TIP) for the British Columbia Persons with AIDS Society. The mandate of BCPWA is to empower its members (who are all HIV+ and number over 3,500) through mutual support and collective action. This mandate reflects the essence of how and why TIP has been so successful. TIP is essentially run by a team of 20, unpaid, HIV+ people. They have varying educational backgrounds, and are of diverse genders, ethnicities, cultures, ages, and HIV risk groups.

TIP provides individualized treatment counseling over the phone and in-person; we conduct question and answer sessions with various support groups and community-based organizations; and we provide workshops that are generally known as “Treatment ABC’s.” These workshops occur both in Vancouver and throughout the province of British Columbia via a “traveling road-show” of peer treatment counselors, an HIV specialist doctor, and an HIV specialist nurse, each of whom speaks to their peers about HIV disease, its treatments, and related issues.

Health Canada conducted a nation-wide survey in Canada a few years ago. They sought to determine what kinds of mechanisms were most useful and wanted by people both infected and affected, in terms of how they want to get their treatment information. The survey showed that, almost universally, people living with HIV want to get their treatment information from their peers and

in a “direct-contact” way. In other words, although the Internet and 1-800 lines have important roles to play, the most significant opportunity for transmitting information and supporting PWAs in becoming empowered medically is one person at a time. Standardized information can be useful, but ultimately it is only a tool to be used in the context of a broader discussion. The best way to deliver treatment information, at least in Canada, is to recognize that people accessing both medical information and medical care are undergoing a process – a process of empowerment, a process of becoming medically literate, and a process of taking charge of their health.

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There are many debates and unknowns in the field of HIV treatments, and it is a rapidly evolving field. There are very few right answers, and even fewer right answers that are right for all the people all the time. Therefore, making an informed decision takes time and requires a variety of sources of information and perspectives. It requires a level of self-confidence that does not come from reading a fact sheet and a feeling of being empowered that cannot be attained by asking ‘an expert’ a question. People living with HIV/AIDS are

the experts of their own bodies, and only they can make the right decisions for themselves. Doctors, staff at AIDS service organizations, treatment activists, are all really just resources that people living with HIV/AIDS can consult. They may be trained in a particular field, and they may have expertise on a particular subject. But the best decision is an informed decision, and an informed decision takes time, patience, and education.

People working in TIP, both paid and unpaid, do not claim to be experts, and we proactively tell people we don’t give advice. We listen, offer suggestions of reading materials or websites, suggest alternatives, explain concepts (such as drug resistance), discuss what has worked and what hasn’t with others, help people to see both sides of an issue, and ultimately facilitate their access to the information they need. We believe that the best way to help people maximize their health is for them to understand why they’re doing what they’re doing. For example, telling someone that they have to adhere at least 95% of the time to their antiretrovirals is going to be ineffective (since hardly anybody can for any length of time) unless the issue of drug resistance and cross-resistance is explained. Once somebody understands why adherence is important, they will be more open and motivated to adhering as much as they can. They may also decide that, because the stakes are so high, they’re not ready to take HAART.

I categorize myself as a “wanna-be doctor” and I drive a lot of doctors crazy, both because I challenge them and because I encourage PWAs to challenge them too. I’ve received a few phone calls over the years from irate doctors who are furious that I’ve encouraged their patients to ask questions. In my opinion, that’s a sign that I’m doing my job. ■

Tito Ramirez Case Manager and Treatment Advocate, Treatment Education and Advocacy, Comprehensive Health Center, San Diego, California

As a gay man who fled Mexico in 1994, I understand the injustice, discrimination and abuse endured by homosexuals there. Mexican society as a whole disapproves of homosexuality. Public opinion is dominated by the official view of the Christian and Catholic Churches – homosexuality is a sin. This disapproval is combined with a “machista” or chauvinistic philosophy that requires men to be manly and women to be feminine.

There is tremendous societal pressure on gay men to remain closeted in Mexico, so many marry and have children. Openly gay and transgendered individuals are persecuted daily and sometimes murdered in all parts of Mexico, their bodies often unclaimed by family members. These so-called “crimes of passion” are seldom solved; legal authorities may not bother to investigate. The city, state and judicial police are frequently involved in the abuse, torture and extortion of gay, lesbian and transsexual individuals. I have witnessed and experienced these scenarios myself.

Mexican men who test positive for HIV come to the United States if they possibly can. There are two main reasons. Once identified as having HIV, they are assumed to be gay by family members, co-workers and, sometimes, spouses. Second, medical treatment and the costly antivirals are limited and often unavailable in Mexico. Only individuals with a significant employment history and membership in the Social Security medical system in Mexico are eligible to receive medications.

People with HIV in Mexican hospitals are isolated from other patients. Doctors and other healthcare providers often wear double gloves and masks when entering an HIV-positive patient’s room. A young Mexican mother who now receives medical treatment in San Diego was initially diagnosed in Tijuana. She spent three weeks in a hospital there. During that time, she was never touched by a nurse or a nurse’s assistant. Her meals were left outside the door of her room on the floor with the door closed.

Many gay men from Mexico who come to the U.S. seeking medical care and the freedom to be themselves petition for political asylum. I did it in 1997, and the INS granted my case in 1998. Since 1999, I have worked as a case manager and treatment advocate at Comprehensive Health Center (CHC), a community clinic in San Diego. Most of my clients are monolingual Latino men who can identify with me and whose situations often reflect those of my past. Although I may not disclose personal details, I do refer my clients to the support groups and immigration team that assisted me.

The Treatment Education and Advocacy Program (TEA) at CHC has as its primary goal the empowerment of individuals begin-

ning or changing antiviral therapy. Adherence is always stressed in the context of a client’s immediate circumstances and needs. For those who are homeless or living in untenable situations, I facilitate housing and other relevant referrals since stability is a prerequisite for a person who is serious about taking HIV medications. Stability includes economic security, mental health, recovery from substance abuse and other factors such as access to transportation and medical care.

A second important requirement is information about HIV and how the medications work. As a treatment educator, I give workshops in Spanish about the etiology of the virus, the effect of antivirals on CD4 count and viral load, short and long-term side effects of the medications, and the necessity of adherence. In an abbreviated form, I attempt to do the same thing with individual clients considering treatment or changing therapies. Unless they are stuck in denial, most HIV-positive individuals are receptive to and grateful for this information. Increased knowledge helps people empower themselves to take charge of their health.

Finally, a system of support is essential for the person who is ready to be adherent to medications. If family or friends are not available or supportive, the individual must look elsewhere. Currently in San Diego there are four active Latino agencies that offer counseling and support groups in Spanish. When I first arrived here, there was only one organization providing assistance to monolingual Hispanics. Additionally, there is now an HIV ministry affiliated with a local church. It provides vital information and spiritual support to infected individuals.

When stability, information and support are in place, there is a greater likelihood that a person will be adherent to medications. When the viral load goes down and the CD4 count begins to rise, the client understands what is happening and how the medications are working. Equally important, the individual may speak about “getting his or her life back” and the renewed pursuit of short and long-term goals once abandoned because of HIV.

How fortunate we are in San Diego and other cities in the United States. The infrastructure here provides treatment for persons with HIV regardless of ethnicity, social or economic class, and sexual orientation. In my opinion, it will be a long time before the Mexican government faces this epidemic with the same commitment evidenced here. As the small, independent agencies in Mexico struggle to help HIV-infected individuals, we can only hope that our example serves as a beacon of hope and promise for them. ■

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Clara LaBoy Physician Assistant,

Former Executive Director of Housing Works'East New York Adult Day Health Care Center, Brooklyn, New York

Not another HIV group!

We tend to forget that school was not a pleasant experience for most of our clients. As children, they often found it difficult to identify, whether culturally or ethnically, with their teachers and other school leaders. From what my clients have shared with me, there was a disconnect between what they were learning in school and what they were experiencing in the outside world, their neighborhoods and at home.

The majority of my clients have spent over half of their lives in jail, running the streets and living life on an endless high – unattached to anyone, including themselves. Many have stated that most of what they do know, reading or math skills, they learned in jail. Sitting in a classroom setting is difficult – they do not want to be preached to. They want their learning to be relevant for their continued survival – and they want to be in full control of how they are going to survive living with HIV/AIDS.

How, then, does a medical clinician attempt to address the need of client-based HIV education in an urban community clinic or day treatment setting that provides medical and mental health services to the triple diagnosed?

An effective facilitator needs to understand his or her audience and accept where each listener may be in their intellectual development. The facilitator must then foster a safe environment in which clients can openly express their lack of basic reading and writing skills. The facilitator must know when too much information is being offered and not enough is being absorbed. In this setting, how does a group facilitator achieve mastery in teaching basic biological processes using language that will not intimidate, but empower? For me, attaining this skill has been about realizing that my own school experiences were not very different from those of the clients. When the facilitator finds that commonality between herself and her audience, communication takes on a level of authenticity that can reach that audience.

There are some techniques that I have used to engage clients who may be easily turned off by the idea of listening to a lecture. My groups are arranged in a semi-circle to give everyone equal advantage in listening to and engaging the speaker. It also allows for eye-to-eye communication when clients are actively sharing their views. I enjoy writing on a blackboard and using visual diagrams to illustrate a point. Clients enjoy seeing concepts written down or in diagram form.

Another technique is to incorporate an interdisciplinary approach. I solicited the assistance of the Creative Arts Therapist to create a play about how HIV attacks CD4 cells and

how these cells lose their ability to modulate an immune response. The clients were amazed that roles could be attributed to biological processes. Many were able to explain the whole process of how HIV attaches to vulnerable immune cells and how it reproduces itself throughout the host's system.

Simple experiments, such as having clients measure their vital signs and relate these to physiological and disease processes, make the learning experience more meaningful. In addition, there is a sense of pride, a sense of greater understanding of how their bodies work. When they visit their primary care providers, they may feel more empowered to ask questions that will help them achieve greater adherence to their HIV medications.

The following are recommendations for effective client-based HIV/AIDS education:

- Discussions cannot be solely clinically based – “life issues” must be incorporated into a medical group. Clients with a history of substance use, homelessness and other psychosocial issues need to understand how and why they were susceptible to the virus in the first place.
- Clients enjoy taking on an active role in designing groups. Curriculums are not effective because they are too predictable, and clients can feel frustrated about not having the opportunity to discuss issues that they feel are relevant to them.
- Facilitators must find the balance between allowing clients to express their views and moving the discussion in such a way as to relate their views and experiences to HIV and treatment adherence.
- Sharing statistics is an engaging segue into discussing HIV complications. Statistics that show survival rates for individuals with a certain HIV viral load and/or CD4 count, on or off treatment, have been very successful in helping clients begin to consider HAART who have been reluctant to start medications previously.
- Some clients feel that it is not worth their effort to achieve an undetectable viral load because they have not planned what they are going to do with the rest of their lives. Some have admitted not wanting to take medications because they will no longer have a reason to take illicit drugs. An effective community-based client education program will have to provide supportive services to deal with these kinds of issues and address these concerns in an appropriate setting.

Even topics that may not seem relevant to HIV – like *The Implications of the Tuskegee Experiment* – are quite appropriate in this setting. The medical clinician who takes on the role of transmitting vital medical information to an audience who may feel disempowered to change the course of their destiny needs to bring all their experiences, talents, medical knowledge, and compassion to the table and see what unfolds.

Carlos Santiago Treatment Educator, ACRIA, New York, New York

I began learning about HIV and AIDS in memory of a friend who died from this deadly virus. His death left me confused, sad and angry, pensively wondering for days what could have been done to help him stay alive. As a result, I am now a community-based HIV treatment educator. I started to do this work a year ago with ACRIA. My focus is to educate people living with HIV and AIDS in New York City's underserved communities. I do workshops about current HIV medications, how to manage drug side effects, opportunistic infections, and hepatitis C.

Among other things, I make hundreds of calls a month to community-based organizations in an effort to schedule free group workshops, individual treatment counseling, and offer up-to-date literature about treatment issues and resource listings. Unfortunately, not every organization accepts the offer even when their clients want the information.

The people I educate are from low-income neighborhoods similar to the one I grew up in. Many are caught up in, or recovering from, the vicious cycle of poverty, crime, and substance abuse, which usually also means having a difficult time meeting basic needs like food, clothing, shelter – and medical care. They often experience little communal life, struggle with a lack of direction, face discrimination, and, not surprisingly, have a difficult time trusting people.

Trying to educate people about HIV treatment issues and hepatitis C has been challenging for me. My main obstacle during this first year has been trying to rid myself of rigid presentation habits, focusing more on my audience instead of the information, and setting realistic expectations for myself.

When I encounter these challenges, I often think of Sherlock. He died while we were together in prison. I recall both of us being 23 years old, talking about Puerto Rican history and politics in an effort to make up for the loss of college programs within the New York State prison system. Our efforts symbolized our conscious willingness to

survive within the “belly of the beast.” Over a short period of time, this struggle created a bond between us. A couple of days later, Sherlock died from PCP. All I can think of is how young he was, how strong he was, and where he died.

One of my new ways to survive inside was to learn about HIV and AIDS. Eventually, I began giving basic presentations on HIV treatments and the immune system as a member of the Prisoners for AIDS Counseling & Education (P.A.C.E) program at Sing Sing until I was released. Ridding myself of the presentation habits that I had developed with P.A.C.E was my first challenge when I began working with

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ACRIA. My audience changed, so I had to change. When I was with P.A.C.E., I gave basic lecture presentations to an audience that was consistently present, attentive, and had time to deal with personal issues. So when I lectured about the immune system, my dry talk about T-cells, B-cells & antibodies ruled. There were almost never any disruptions or questions.

When I did my first ACRIA workshop, I immediately knew that the simple presentation style had to go. There was too much going on in the lives of my audience. I saw anger, sadness, depression, and fear on people's faces, which made me feel obligated to learn and understand ACRIA's approach to being interactive with the audience. I began to meet the participants' level of interest and knowledge and allow the discussion to develop

at their pace. I tried to engage them with questions and hoped to motivate them to consult with their doctors about beginning, changing, or stopping HIV medications. For the most part, I accomplished this, but I found it hard to accept that some of my audience did not want to deal with doctors at all. I literally wanted to push them into a doctor's office, but I realized that was beyond my control.

After a few months of doing workshops, I thought that I was doing a good job because I was developing an understanding of some of the best approaches to the work. I was so wrong. Yeah, the information I shared was clear, accurate, engaging and more practical, but there were plenty of times I enjoyed listening to myself speak. It felt good because I was developing a better grasp of the information. I would talk about the prognosis of untreated HCV while proudly drawing a pie chart. I would talk about wild-type virus, get into DNA and RNA, and try out newly learned analogies because it was interesting to me. That's when I lost my audience. Eventually, interjected questions stopped me dead in my tracks. “Where do I fit into what you're saying, Carlos?” I felt so irresponsible when I first heard something like this. That's when I realized that I can lose an audience without intending to.

Rebounding from my missteps while conducting workshops is easier than rebounding from missteps while providing individual counseling. Lately I've noticed that I feel as though I am not doing enough for those clients who have a hard time learning and applying HIV treatment information. I'm also not giving myself enough credit for the work I've done with the clients who make it easy for me to assist them. For example, Jane (not her real name) always calls me just before every doctor's appointment to review her situation, informs me about new medications she is taking, change of diet, and inquires about any new information related to her situation. Since the work with her is a breeze and I haven't felt my efforts, I feel as though I've done nothing. On the other hand, here is Mr. John whose hoarse voice

(continued on page 11)

Yukihiro Ippei Yasuda Treatment Advocate, Asian & Pacific Islander Wellness Center, San Francisco, California

The popular image of Asian & Pacific Islanders (APIs) is that of the “model minority,” well educated and well off. When it comes to HIV care, however, their educational and economic status doesn’t guarantee access. Their rich cultural diversity poses its own set of challenges and perplexities in utilizing the HIV care system and in delivering HIV care.

Like other ethnic minorities, APIs are not just one cluster of people. In the United States, APIs consist of 49 ethnic groups speaking more than 100 languages. Although there are some basic cultural similarities, APIs, with their different cultural and linguistic backgrounds, don’t possess one common identity. Comprised of different generations and classes and shaped by such factors as being American born versus being a recent immigrant, each API group has established its own unique society and culture.

Since APIs comprise only four percent of the U.S. population, however, they have historically been perceived and categorized as a single population. Government funding for HIV care is usually allocated to the API community as a whole. Tailoring a program to a specific target population in the API community and providing culturally and linguistically sensitive and comprehensive HIV care service is time consuming and expensive.

In San Francisco, for example, where APIs comprise 35 percent of the population, they speak more than 14 languages. HIV care service agencies, faced with limited funds and human resources, are forced to prioritize ethnic groups within this population depending on the HIV/AIDS prevalence and incident rate in each ethnic group. It is a challenge for service providers to deliver comprehensive HIV services to all of the API ethnic groups.

People with HIV often face multiple issues, such as mental health problems, substance use, low income and lack of housing. These issues interfere with both their opportunity and their willingness to access HIV care. In order to maximize

service delivery and to help them opt for positive life changes, referrals need to be made to appropriate service providers, but not all referral agencies have the language capacity and cultural sensitivity to deal with API clients. In such cases, clients may not be able to access medical care because of unsolved immediate problems. Especially for newcomers, marginal populations and multiple-diagnosed individuals among APIs, HIV treatment can still be unavailable or ineffective for this reason

**“It is a challenge...
to deliver
comprehensive
HIV services
to all of the Asian
& Pacific Islander
ethnic groups.”**

Recruiting community members to be HIV workers and/or peer leaders in order to deliver effective HIV care can be difficult in a particular community if its population is quite small. Misconceptions about and social stigma surrounding HIV/AIDS may also discourage community members from working in the field. The emergence of HIV/AIDS activism and leadership among APIs with HIV can be slow or stagnant for the same reason. In practice, however, peer-based HIV care, activism and strong leadership are crucial both for improving HIV care and for promoting behavioral changes which will allow people to improve their health and to reduce the risk of an AIDS diagnosis.

The Asian & Pacific Islander Wellness Center in San Francisco has established a team approach to HIV treatment advocacy including case managers, peer advo-

cates, treatment advocates, a psychotherapist and a psychiatrist. Providing services in seven Asian languages, team members accompany clients to their medical appointments in order to assist them in communicating with healthcare providers, in learning how to utilize medical facilities, and in improving their adherence to treatment protocols. To maximize language capacity and cultivate future leadership, the agency recruits and trains clients to be peer leaders who can help other clients with medical appointments and other chores. In order to provide primary HIV care for uninsured APIs and API newcomers, the agency has an on-site HIV clinic once a week in collaboration with the San Francisco Department of Public Health. This collaboration has enabled agency care staff to work with the clinic staff as a team in steering clients to learn about HIV treatment and increase their adherence to HIV medications and medical care.

In addition to one-on-one work with clients, the agency provides monthly support groups, a weekly psychotherapy group, an annual clients’ retreat, seasonal parties, bimonthly HIV agency field trips, bimonthly HIV treatment forums and a weekly weight training program in order to build an API HIV community to provide peer support and to recognize and develop future leaders. In the process of implementing these programs, care staff, peer leaders and clients participate in activities designed to create a community atmosphere.

Even with all of the agency’s efforts, there are still challenges in providing comprehensive HIV care services and building a sense of community. Finding ways to increase the participation of monolingual clients in agency activities and increase the degree of integration between immigrants and American born clients in such activities are challenges that the agency is facing. It remains a challenge to provide equal service across the different cultural and linguistic divides of the API community while operating under a limited budget. ■

Harry Dohnert Case Manager, Columbia University, Harlem Adherence to Treatment Study (HATS), Harlem Hospital Center, CPCRA Community Constituency Group, New York, NY

My involvement in the field of HIV/AIDS treatment is the result of a gradual personal evolution. Over time, I overcame mistrust of the medical establishment to accept information about HIV treatment. This ongoing process of accessing, personalizing, and acting on information enabled me to make healthy lifestyle changes and save my own life. In turn, I now pass on this process-oriented approach to empower others living with HIV/AIDS.

I had originally seen AIDS as a major conspiracy to get rid of minorities and swell the pockets of drug companies. I refused antiretroviral medications because I felt I was being used as a guinea pig. My first experience with overcoming my fear and mistrust came from a woman at a methadone treatment program I was attending. Her shared experiences about living with HIV/AIDS and overcoming battles with substance use gave me hope and allowed me to make some healthy decisions about my life. I was able to work through my fear of treatment and begin to trust in the medical establishment. Another valuable decision I made was to develop a relationship with my primary care physician, someone who was understanding, compassionate, giving of her time and who met me where I was at, not where she thought I should be. In 1996, I made a decision to stop using illicit drug and start treatment for HIV. To this day, I have the same primary care physician, and I have not looked back.

I also decided to educate myself about HIV and its treatments. I was diagnosed in 1988, so I had a lot of catching up to do. Even though I had started treatment and was beginning to trust my doctor, fear still lingered. Trials that had gone bad, such as Tuskegee, and the early treatments for HIV were still in my mind. Education was the answer. My search for information led me to attend HIV conferences, symposiums, lectures, peer training programs and community forums. I started to read everything I could get my hands on. Treatment newsletters like *NATAP Reports*, *ACRIA Update* and *POZ* magazine were

valuable sources of information for me and continue to be to this day.

I started getting involved in the HIV/AIDS community. In 1997, I became a member of the Community Advisory Board (CAB) at Harlem Hospital Center. It was here that I was able to learn and share about HIV/AIDS clinical trials. Soon I was nominated and elected chairperson of the CAB. Being a member of this body, I provided valuable input into the development of clinical trials. I learned about the Community Programs for Clinical Research on AIDS (CPCRA), a federally funded research network conducting HIV/AIDS clinical research at clinic-based hospitals. Harlem Hospital's infectious disease clinic was one of the

national CPCRA sites. I was asked to represent the CAB on the CPCRA's Community Constituency Group (CCG). My involvement as a CCG member empowered me to become a strong advocate for my community. Along the way, other programs and support groups at Harlem Hospital empowered me to seek out information and understand treatment options.

In 1998, I was asked to participate in an adherence study being conducted at Harlem Hospital

Center to evaluate the effectiveness of using peer health educators, case managers, social workers and health educators to help people adhere to antiretroviral medications. I was trained as an adherence peer worker with the Harlem Adherence to Treatment Study (HATS). I learned about all aspects of HIV, its treatments, clinical trials, and how to work effectively with clients living with HIV/AIDS. As a peer worker, I was able to share my personal experiences and knowledge. My commitment to treatment education grew as I learned about all aspects of treatment, from clinical research to adherence skills.

Today, through my education efforts and my commitment to treatment, I am able to give back to my community. As a trained case manager for HATS, I have new skills with which to advocate for better quality of care, more effective treatment, and better management of long-term side effects.

"I had originally seen AIDS as a conspiracy to get rid of minorities and swell the pockets of drug companies."

Last night a particular client crept into my mind. Her doctor had just prescribed her first combination therapy and recommended that she talk to me before actually starting the regimen. We talked for about two hours, covering everything from dosing schedules and food restrictions to potential side effects and – in my opinion, she wanted to know – how long this regimen would work before she would have to change medications. But our conversation started with her question, “Why do I have to take these medications?” Her doctor had not taken the time to explain the *Whens* and *Hows* to her, so it should have come as no surprise that he did not explain the *Whys* either.

This morning when I got into the office, the phone rang and I had a call from a former client. He abruptly began, “You probably don’t remember me, but I talked to you about a year ago after a presentation you did.” I vaguely remembered the conversation, but I really did not remember him. I could not put a face to the name or recall the particulars of our conversation except his complaints about how his doctor did not take his side effects as seriously as he thought he should. According to him, however, I *did* take them seriously and spent quite a bit of time talking with him about how to manage the side effects he was experiencing. He informed me that all of my side effect management tips had worked and that he was doing great. Without the side effects, he was now perfectly adherent to his medications and, as a result, his labs were the best they had ever been.

As I reflected on these two very different individuals with very different treatment education needs, one common thread connected them: they both received inadequate treatment information from their physicians. The woman’s doctor did not spend the necessary time with her to prepare her for taking HIV medications. Being emotionally ready to take medications – in this case, having all of her questions answered and understanding the impact of starting medications – is crucial to successful compliance. The

man’s doctor did not really listen to his concerns or take him seriously, an all-too-familiar criticism of physicians. Side effects are real, and quality of life and lifestyle issues must be addressed as clinically significant.

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The revelation that some physicians provide insufficient treatment information is not new. Were physicians always capable of providing comprehensive treatment information, community-based treatment educators would not be necessary. This is not, however, a blanket indictment against physicians. There are three reasons why doctors cannot fully educate their patients and, as a result, properly serve as treatment educators.

First, many physicians do not have – or possibly make – the time to fully inform their patients about treatment issues. Large numbers of patients and increasing pressure by healthcare administrators to see patients as expediently as possible make it difficult, if not impossible, to give each patient the time and attention she or he deserves. Treatment educators, on the other hand, make the time to

inform clients and answer their questions. At AIDS Treatment Initiatives, for example, it is not uncommon to spend two to three hours with a client who is either newly diagnosed or has multiple treatment issues that need to be addressed.

Second, some physicians are incapable of explaining treatment issues in language that patients are able to understand. Treatment educators, however, strive to discover the most effective ways to explain treatment issues in consumer-friendly terms. Using illustrations, analogies, examples, and other devices, treatment educators “translate” complex medical data into easily understood information.

Third, physicians approach health from a philosophy of “treat the symptom.” Specialization training (infectious disease, oncology, etc.) creates insular expertise in a particular field, often at the expense of a broader, more comprehensive approach to care. Physicians are not trained or educated, for example, in nutrition, exercise, or integrative therapies and, as a result, either do not lend credibility to these disciplines or are not willing to make recommendations or referrals for such complementary care. Treatment educators are usually more open to integrative approaches to healthcare. They are often better versed in offering balanced information about complementary therapies or more amenable to providing referrals to dietitians, fitness trainers, or acupuncturists.

In general, treatment educators approach education opportunities – either one-on-one counseling sessions or group educational programs – from a wider, more diverse standpoint. This outlook allows the treatment educator not only to propose a wider range of treatment options but also to view the client’s health status from a more holistic perspective. Treatment educators are good at looking beyond the symptom itself to addressing the cause of the problem. This involves an understanding of the client’s

James Learned *(continued from page 3)*

treatment decisions. Treatment education isn't about specific treatment courses that a person *should* follow. We can't know what's best for a specific individual. We offer information and support shaped directly by the needs of the individual, not those of the healthcare system. The ideal goal of treatment education is an empowered, informed individual.

Providing community-based treatment education is, by its very nature, a somewhat subversive act. Historically, discussions of medical information have been the province of doctors and other healthcare providers. When lay people – those of us without formal medical training – offer information about biology, disease progression, medications, treatment strategies, even nutrition and alternative therapies, it threatens many healthcare providers, public health officials, and even some of our peers. Although many clinicians welcome and understand community-based treatment education as an integral part of healthcare, others are uncomfortable with what they feel is a usurpation of their authority. After all, ignorant patients are easy patients. You tell them what to do and they don't ask pesky questions or make demands.

Community-based organizations are supposed to serve people with HIV, not the interests of the pharmaceutical industry, the healthcare system or any other authoritative body. Yet sadly, many organizations increasingly infantilize positive clients, treating them like dangerous children who need protection from medical information that could be upsetting or confusing. At some infectious disease clinics, medical providers on staff provide all treatment education – community educators are no

longer welcome. While agency employees at some AIDS service organizations meet in comfortable conference rooms, client workshops are conducted in busy cafeterias, full of distractions, or in windowless rooms without chairs or circulation. The disrespect is astonishing. There's a pervasive and unsettling assumption that PWAs are not worthy of basic, human respect, incapable of understanding treatment information and making informed decisions. This may be purposeful. Ignorant clients are, after all, easy clients. Again, no pesky questions or demands.

This is where the committed treatment educator comes in. Clinicians and people working within traditional social services can be our partners in offering whole-person care. Effective treatment educators recognize the whole person. Those of us working and volunteering at the community level can offer true help to people who are confronted by the complexities of HIV treatment decision-making. Ideally, we allow people to acknowledge and discuss the complicated emotional issues that underlie treatment decisions. Our work is based on a firm belief in survival and deep respect for every individual's decision-making process. Through ongoing examination of available data, we offer individuals a supportive space where they can explore their fears, beliefs and understanding of HIV, medications, and the healthcare system.

PWA self-empowerment has become an overused and appropriated phrase. But the power to regain its original, bold meaning is ours. True commitment to community-based treatment education is part of that power. ■

Carlos Santiago *(continued from page 7)*

makes it hard for him to speak. He never remembers his T-cell and viral load counts, he is always difficult to contact, and misses most of his medical appointments. What do I do? I become emotionally involved and feel as though I haven't done anything for him no matter how

many times I call or write to him. Meanwhile, the truth is that there is no way for me to know the exact reasons Mr. John is having problems taking his medications.

The other truth I have to accept more often is that some things are beyond my

control. This, of course, means that I have to move forward with my work as an educator. It's not always easy to notice unless someone else points it out to me. But once I do recognize this problem, I can move forward. I am quite sure if Sherlock were here, he would agree. ■

(continued from previous page)

medical history as well as getting to know some of the client's personal history and understanding the psycho-social dynamics involved in her or his treatment issues.

When the first client popped into my thoughts, I wondered how she was

doing. Was she taking her medications? Had she moved back to Chicago to live with her sister like she wanted to do? Was her eleven-year-old son living with her again? For her, these family dynamics would play a role in her adherence and were factors that would need to be addressed. For the thankful client on

the phone, essential side effect management was all that had been required. Both situations had their unique complexities, but the ability to give each client the time, attention, and fundamental respect she or he deserved allowed me as a treatment educator to meet their particular needs. ■

Anthony Salandra CSW, Treatment Advocate/Educator, Hyacinth AIDS Foundation, Fort Lee, New Jersey

My interest in treatment for HIV started in 1986, when I decided to do something about this thing called AIDS that was ravaging my life. My friends and my community were being hit hard. I got involved with the Gay Men's Health Crisis and quickly became co-captain of the New Jersey Team. HIV devastated me, causing me to throw myself into the work of advocacy. So much was not available in those early years. It was a fight to get even the most basic service. We've come a long way since then, and it has been personally fulfilling to see what one person can do to make change happen.

From the beginning of my personal journey in this work, my interest was always in how to get people treatment. Like many others, I was desperate, looking for anything that could even remotely help. I researched alternative healing, visualizations, nutrition, herbs, and vitamins. I involved myself with underground meetings with advocates and a few scientists to discuss treatments that were being used in Europe and how to get those drugs here in the US. I attended the first meeting of the newly formed ACT UP. I looked for anything to get help regarding treatment.

Today, I work for the Hyacinth AIDS Foundation in New Jersey as a treatment advocate/educator. I include the word advocate along with education because I have found the combination necessary to see clients achieve their goals of understanding their options and receiving better treatment. I hold educational forums, have small group interventions and do one-on-one counseling with clients – all aimed at informing them about HIV and treatment options so that they can achieve overall better health.

I am a person with AIDS. This has proved to be valuable in this work. It instills a sense of confidence when clients know that I've been where they are and can relate to their lives. With that comes the responsibility to offer clients current information and not my own personal experience. Many people come to me because they know I'm a long-term survivor. Thinking I have the magic formula, they often ask, "What are

you taking?" I let them know that my particular success was in taking the medications as prescribed and having a good partnership with my doctor, which allowed me to discuss what was happening to my body and adjust my treatment. I tell them that this is also possible for them.

What I find works most effectively is providing information in a way that is easily understood and meeting a client where they are – their language, their life situation, their needs first, not mine. An example: A client is referred to me because he needs to begin new medications and wants information about side effects. When I meet with him, I learn that he has just gone through a break-up with his life partner. He's crying and totally distraught. My goal was to talk about side effects, but if I were to do that and not address his immediate need to talk about the break-up, what will I have gained? I will have accomplished nothing. I will have lost his trust, and the client will have walked away with nothing. Handling the immediate problem first allows learning to happen.

Another important tool is repeat visits. A one-time intervention is

just that. What really works is follow-up calls or sessions that continually reinforce treatment goals. Treatment is constantly evolving over time. Clients need to be able to discuss these issues with us – and we need to be available.

HIV treatment works and it is complex. People need to understand what is or may be happening to their bodies. Only then can they make informed decisions that lead to long-term treatment success.

When clients "get it" you know your work is good. The feeling that you get is so positive. Giving people what they need to better their lives and live well is entirely rewarding to me. Seeing people go from being very sick to health or never getting sick from HIV – wow! I was around when that was not the case. We have the tools to see people live with HIV. It is our duty - our joy - to do this important work.

"...their language, their life situation, their needs first, not mine."

Debra Johnson MPAS, NP, PA-C, Adjunct Faculty, Keck School of Medicine, Los Angeles, California

The importance of adherence to HAART and its correlation with virologic rebound and resistance is well documented. Unfortunately, behavioral interventions to improve adherence are only occasionally successful. As a medical provider delivering healthcare to people with HIV, I welcome and include treatment advocates in my interactions with patients. I also work as a clinical instructor at several community-based organizations, in conjunction with the AIDS Education & Training Center (AETC). These programs provide a unique opportunity to observe doctor-patient interactions.

In a time when we finally have effective HIV therapies, especially with once-a-day regimens moving slowly toward the forefront, we still have a tremendous number of virologic failures (some reports are as high as 50% at 48 weeks). We need all the help available to deal with the complexity of adherence. It is time for the medical community to recognize that we need help from those individuals who have the most experience in dealing with the barriers of getting well. We are not doing a fabulous job alone in our efforts to improve adherence. We need to increase patients' support systems and better understand the barriers to healthcare for each patient, and to then personally tailor our interventions. To do this effectively, WE NEED TREATMENT ADVOCATES.

Many well-educated investigators and healthcare professionals believe that they can develop adherence programs on their own. But treatment advocates already have many of the tools needed to assist not only the patient but also the healthcare team in addressing the life problems that can make adherence difficult. Many advocates are themselves living with HIV and may face the same issues that impact patients, such as drug addiction, homelessness, transportation issues and, especially for women, being the primary caregiver for the family. Treatment advocates can help healthcare providers understand what it's like to live with this disease – that the very medications prescribed to

maintain health can sometimes make patients feel worse than the disease itself.

Treatment advocates are trained to provide support to those who do not process new information easily, or who lack the strength to advocate for themselves. This can apply to all of us who face a difficult medical decision. AIDS activism began when gay men and lesbians demanded attention to a disease that directly affected their loved ones, but their activism has benefited other illnesses, such as cancer.

“Working with treatment advocates as an integral part of the healthcare team has definitely helped our patients...”

This past June, I was diagnosed with breast cancer and decided that I deserved a treatment advocate during surgery, to ensure that breast conservation would be the goal of the procedure and that a modified radical mastectomy would be done only as a last resort. I ended up having the mastectomy (removal of the entire breast), but I know that the correct decision was made because my surgeon had discussed his findings with my advocate, who protected my wishes and rights. This may not be an option for everyone, but I would like to think that it might become a standardized approach to managing illness.

Working with treatment advocates as an integral part of the healthcare team has definitely helped our patients decide if they're ready to start HAART and to overcome problems that may be impact-

ing their quality of life. Changes in the future should be made to improve the training of treatment advocates so that standardization can define common goals and data can be collected for future validity studies.

It can be very frustrating to attempt to advocate for a client who doesn't want to accept your intervention or to work with a healthcare team that feels you are interfering with their medical practice or that you may be providing misinformation. Hang in there; change always takes time. You provide a very important role, so try another approach. Schedule a face-to-face meeting between you, your client and the medical team, since this may be the only way to handle confidentiality concerns. You may want to include a social worker to improve communications and make the meeting less confrontational. Be persistent. Learn from each encounter. Educate the healthcare team about your role as a treatment advocate, and share your common goal of improving not only your clients' viral load, but also their quality of life.

Treatment advocates provide a very important and essential service – your clients need your expertise, as does the medical community. Some of us just don't know it yet. ■

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Larry Diaz

AIDS Treatment Advocate, Alamo Area Resource Center, San Antonio, Texas

I like to think of myself as an AIDS treatment advocate. To me that means I wear several hats. I try to stay focused on the treatment aspects of living with HIV when wearing my peer treatment educator hat, and sometimes wearing this hat can be rewarding.

I remember one client coming to me complaining about stomach trouble along with trouble with his eyes. He had talked to his doctor about this several times, but they couldn't find the cause. I know that patients often might not feel comfortable talking with their doctor, no matter how good the doctor. That can mean that the doctor may not get all the details and information needed to figure out the problem. Because I work as a volunteer and don't have to generate units of service, we could talk all day. We were able to list a couple of symptoms that he hadn't shared with his doctor. Then we got on the Internet and were able to find a couple of reasons he might be feeling this way. Together we learned that many antiretrovirals have been known to cause gastrointestinal problems. The choices were his; I just helped him look for the information. After all, he knows his body better than anyone else. Weeks later he came to see me again. He was happy to say that, because of the information he had taken to his doctor, they changed one of his meds and within a few days he felt better. His eye problems turned out to be that he needed glasses!

This is one example of what I do. I don't diagnose, I don't contradict, and I don't make the choices. I just help find out what's what.

Then there was the time I was sitting in a doctor's waiting room and started talking to one of the other patients. She told me she had heard about people in New York using mercury to treat HIV. She was planning to inject herself with mercury from a thermometer to try to cure herself of HIV. Having been an IV drug user for years,

using a needle was no biggie. She wanted to know how many times she would have to do it for it to work. I was stunned. I spent the next three hours gently talking about how that might not be the best idea and that she might not want to do something like that without having a little more information than "a friend of a friend said that he read something somewhere." A few months later I ran into her. She was still walking around so I guess she choose not to treat herself with mercury. Did my

"I know that patients often might not feel comfortable talking with their doctor, no matter how good the doctor."

talking to her make a difference? I don't know. Would she have used such a dangerous, deadly home remedy if I hadn't talked with her? I don't know. Weeks, sometimes months, can go by and I'll never know if all the work I do trying to help others is making a difference. It can be hard. But I've seen the good it can do, so I just keep on trucking.

Recently I had a call from someone referred to me by a case manager. He was newly diagnosed and scared. He was afraid that the people he worked with would find out. He was afraid to tell his parents because of how he thought he had gotten infected. He was afraid of the way he thought it would be to die from AIDS. We spent like six hours talking. I tried to

give him some hope, talking about how we now have a whole bunch of drugs for fighting HIV. I explained that I had been positive for several years and was doing fine. I told him about a few people that I had met over the years that had been living with our friend HIV for 15 plus years and were doing great. He wanted to know more about the drugs and how they worked. I gave him a short history of how we got from AZT monotherapy to using our friend "the HIV drug cocktail." After several hours we split. When I got home I could barely talk, my throat was so hoarse. My girlfriend and I had to communicate by pointing.

I haven't seen this client since, but I hope he's doing well. I try not to think about the possibility that he's not doing well. I've had to learn to shut off that part of my feelings or else I'd be helpless. I know that no matter what I try to do, some of the people I talk to are going to get sick and some will die. I suffer when I hear of someone that we lost. I know it's not all on me, but if I think about it too much I'll end up in the "what if I had..." place that goes nowhere. If I invest too much in the outcome, think too much about the losses or make it too personal, I wouldn't be able to move forward.

I try to walk a safe line when talking to clients. I try to keep to the most solid opinions out there. I never contradict a doctor's or other professional's opinion or advice. Every one of my encounters will have the question "Have you talked to your doctor about this?" or "Can I help you talk to you doctor about this?" I think part of the value of what I do is that I am also HIV-positive. I can offer some personal experience. There is always one thing each client and I have in common. We are both trying to live with HIV.

I do this as a volunteer, most of the time not knowing if I'm doing the right thing or if I'm helping. But someone has to do it, and if I don't, who will? ■

Philip Gardiepy-Hefner

HIV/AIDS Service Coordinator, Superior AIDS Prevention Project, Upper Peninsula, Michigan

Ten years ago, I left the bright lights and the big city of Los Angeles and settled in Iron Mountain, Michigan. Iron Mountain is in the Upper Peninsula (U.P.) of the state, and is very rural. The state of Michigan is comprised of two peninsulas, upper and lower. The U.P. is surrounded by Lake Superior to the north, Lake Michigan to the south, and Lake Huron to the east, and it's bordered by the state of Wisconsin to the west. The two peninsulas are connected by the Mackinac Bridge, with one interstate that runs north and south and two highways that run east and west, neither of which are four-lane freeways. Although Michigan has a population of roughly nine million, the U.P., which comprises a third of the state's total landmass, has only 300,000 residents. Weather may be a factor in this equation, since residents here endure five or more months of winter every year.

Having worked with and cared for many people with AIDS over the years, I planned to continue my work as a prevention and treatment educator in my new home. To my dismay and surprise there were no services available in the Tri County area – no support groups, no doctors that actually had HIV-positive people as patients, no prevention efforts or treatment education. The attitude in this rural community was that AIDS was a big city problem.

Knowing that there were people in the community who were HIV-positive and living with AIDS, I started a support group, recorded public service announcements, and developed prevention and treatment presentations.

The support group was one of the first challenges. Fearful of confidentiality issues, we had to meet in various locations. Getting people to the table was something that made little sense to the people of the support group – why would you, a total stranger, care about us? Each individual viewed him or herself as “the only one” because no one talked about these issues. People suffered in silence, not even wanting to admit their diagnosis to themselves, let alone family or friends for fear of becoming a total outcast, or fearing that their families would be outcasts if word reached the community that their son, daughter, brother, uncle – whoever – was positive.

Through the years, the support group has looked into many different areas of treatment, engaging in long conversations about available medications and alternative therapies, such as herbology, nutrition, vitamins, massage therapy, acupuncture and mental healing (crystals). People were grasping for anything that might

work. I encourage them to find out about different therapies and ask questions of each other, myself, and, more importantly, their doctors. Be informed, ask questions, keep up the fight and do not give up in the face of adversity.

Community presentations posed another obstacle. People in the support group did not go to local physicians. They traveled to the major cities for care and treatment, with the closest city an hour and a half away. They even refused to have their prescriptions filled at our local pharmacies, in case the pharmacist recognized the drug and its purpose.

Meetings with local physicians resulted in a lot of negative feedback. I wanted to talk with them about the new treatments that were becoming available. One physician said, “I know nothing about the virus and its treatments and I do not want to know. I – and I think I speak for all concerned in this room – have to worry about our livelihoods. We could lose our patients if word got out that we were seeing this population.”

Though it could have been a total disaster, I managed to meet with a few doctors who did come forward and at least agreed to be the general practitioners for people in our group. I meet with them occasionally to share treatment information.

Bringing the Names AIDS Project Memorial Quilt to our area was an accomplishment that, in my opinion, opened the eyes of our community. Through continuous community education presentations and

radio spots, a group of community members was formed to bring the AIDS quilt to the U.P. Two years of hard work reaped many rewards. Though we still had many obstacles to overcome – getting funding to bring the quilt to the community, finding a location large enough to display the panels, not to mention threats – the community came forward and learned about the disease. Some even talked for the first time about family members, friends, or acquaintances who were infected or affected by HIV.

Now people are asking questions about different treatments, the effectiveness of certain therapies, the pros and cons of one drug compared to another, and different drug studies.

It has been a long journey to meet the needs of the community in regards to prevention and treatment issues. Coming from Los Angeles, where the subject of AIDS was very open and talked about, to one where HIV/AIDS 101 never existed was and continues to be a difficult but welcome challenge. ■

“ I know nothing about the virus ...and I do not want to know... we could lose our patients if word got out that we were seeing this population. ’ ”

Charles E. Clifton

Executive Director, Test Positive Aware Network; Editor, *Positively Aware*; Chicago, Illinois

It was sixteen years ago that I first learned my HIV status. My partner, Antonio, had been sick off and on for months and, as a result, had lost a lot of weight. In April of 1986 he was hospitalized with pneumonia. I remember the exact afternoon, when the doctor came out from examining Tony and told me that Tony had AIDS. He asked about our relationship. I told him that we had been together for eight years. Then the doctor informed me that Tony was going to die from AIDS. And so would I.

Following several bouts of PCP, and after developing Kaposi's sarcoma and dementia, Antonio died at 11:23 am on October 8, 1986. AIDS. There was no mono, dual or triple combination therapy. No poverty or malnutrition. No substance use, illegal drugs or "hedonistic" lifestyle. No alternative therapy. But more importantly, there was no knowledge, an absence of information on the disease and how to treat it. Straight up AIDS. And there we were – alone, confused and scared. What did we know? Zero. Zip. Nada.

But I'm still here. Healthy. Drug-free. Take that, doctor know-it-all.

It wasn't an easy process. I had to take ownership of this disease and educate myself. That took time, energy, and most of all a commitment on my part. I have been involved as a volunteer with several community-based HIV organizations over the years. Five years ago, I joined the staff of Test Positive Aware Network as the Men of Color HIV/AIDS (MOCHA) Director. Two years later, I became editor of the agency's two HIV treatment journals, *Positively Aware* and *Positively Aware en Espanol*. And as of July 1, 2002, I was appointed Executive Director of the organization. Yet I still consider myself a treatment educator and advocate, because you can't survive if you aren't informed.

Throughout my self-education about HIV disease over the last sixteen years, I have noticed that the sense of helplessness that I, and others like me, experienced back in the 1980s has not completely vanished. While the 1980s slowly gave way to a generation of AIDS activists and advocates, there are still too many people living with HIV in the year 2002. Many of these people are too afraid to test for HIV, too par-

alyzed to come to terms with their HIV-positive selves, and too fearful to disclose their status to even their closest friends.

And that's why I keep on keepin' on.

I've watched the bodies of friends slowly shut down for any number of reasons related to HIV. The silver bullet that we hoped HAART was a few short years back looks a bit tarnished today. When should you start treatment? When should you stop treatment, if ever? We're not quite as sure as we thought we were just a few years ago. The shine may have worn off somewhat, but that's no excuse to surrender.

In response to an editorial I wrote in *Positively Aware* earlier this year, a reader wrote, "I'm grateful that you all are doing what it is you know how to do best. I'm sure you're tired, stressed, depressed and overwhelmed. But remember that there are thousands of people like me who gain experience, strength and hope from what you're doing and for that I'm not tired. I, AM, GRATEFUL!"

I, too, am grateful. I'm grateful that I've been given these last sixteen years to grow as a human being and to achieve goals that I once thought were impossible. I'm grateful that I didn't waste the opportunities afforded me over these many years. I'm grateful that I've been granted the chance to make a difference in at least one person's life. If I can help one person not to be afraid, to let go of the fear which can paralyze, then I've made good on the opportunity granted me. Because that is what it is really all about.

God knows it's not about the money. Oh, hell no!

I'm grateful that my "work" not only makes a real difference in my day-to-day existence, but also in the lives of so many unknown people. The struggle against HIV/AIDS, like the civil rights, gay and women's movements, must continue as a collaborative effort. I'm grateful for the many HIV-positive people – from all over the world – who have collaborated on the direction my life has taken over the years.

"I had to take ownership of this disease and educate myself."

Tamil Kendall MA, Researcher, Centro de Investigación en Sistemas de Salud, Centro Colaborador ONUSIDA, Instituto Nacional de Salud Pública, Cuernavaca, Morelos, México

My experience providing community-based treatment information has come from working as a researcher and educator with persons with AIDS societies in Canada and in Mexico. I take a holistic approach to treatment education, one that aims to encompass the whole person and the whole treatment regime – conventional medicine (including antiretrovirals), nutrition, and complementary and alternative therapies. I have participated in treatment information workshops, written about treatment for community publications, trained people living with HIV/AIDS (PLWHAs) to offer treatment education, and done one-on-one treatment information counseling.

Perhaps because of my integrated approach to treatment, one-on-one treatment information counseling has been the richest learning experience for me. Face-to-face contact is important, because treatment counseling is more than an information exchange. For many people, beginning to consider and learn about treatment is an important step along the journey of accepting that they are infected and beginning to *live* with HIV. The empathy and depth of experience that people living with HIV/AIDS can share with each other increases the value of peer driven treatment information counseling.

Regardless of whether or not the treatment information counselor is a peer, talking about treatment should include the social, economic, cultural and psychological issues that surround living with the virus and taking treatment: how much money do you have?, where do you live?, what do you eat?, do you have a fridge to store your meds?, do you live with a partner or family?, do you have kids?, do they know you are infected?, do you work? etc. etc. etc.

Perhaps these “lifestyle” issues are particularly relevant for marginalized populations. In Canada, I worked mostly with current and former injection drug users living in the Downtown Eastside of Vancouver, known as “Canada’s poorest

postal code.” In Mexico, I work with HIV-positive women. These women are a diverse group, from rural subsistence farmers to business women living in the world’s largest metropolis. But they share some characteristics – almost all of them have children and most are AIDS widows. The majority of former and current injection drug users and Mexican women face challenges to accessing and understanding treatment because of literacy, poverty, and (real or feared) stigma and discrimination in their relationships with healthcare providers. Communicating treatment information can be difficult because of these challenges, but these difficulties only underline how urgent it is to develop and implement appropriate treatment education strategies within these communities.

“...people who haven’t completed elementary school can understand the mechanisms of pathogenesis and antiretroviral treatment.”

My philosophy is that everybody has the capacity to learn about treatment and to act in their own best interest. I want to be emphatic about this – people who haven’t completed elementary school can understand the mechanisms of pathogenesis and antiretroviral treatment. And, to give informed consent and make informed decisions, the individual must understand these issues. In addition to the ethics of informed treatment decision-making, knowledge is crucial for treatment success.

Adherence is a good example of why treatment information is important. People need to understand *why* taking their meds as prescribed is important. This is especially key for individuals who do not have open communication relationships with their treating physicians or other healthcare providers. Let’s imagine the case of a Canadian IDU whose physician makes participating in a methadone program a condition for receiving antiretroviral treatment or a Mexican woman without social security who is one of the few “lucky” people to receive free antiretrovirals at a public hospital. Each of these individuals is motivated to lie to healthcare providers in order to appear the “perfect patient” and maintain access to treatment. But even “perfect patients” have their off days, so when these people go on a binge and don’t take their meds, or if they discover that stopping the meds stops chronic diarrhea, and no one has explained (in a way they understand and accept) that stopping and starting can create resistance, they will not adhere, and they will not share this information with the treating physician.

Community-based treatment information programs, particularly programs in which HIV-positive individuals provide information to other positive individuals and the counselors and information seekers are members of the same “community” (as defined by race, class, gender, sexual orientation etc.), can explain concepts in a language that people really understand. Further, community treatment information counselors have more time and, often, more practical strategies for coping with treatment in the context of real life than is available in a clinic, doctor’s office, or hospital. The community-based treatment information counselor’s role is to be an instrument – not to play doctor or make decisions or predict that the other person’s disease process will be the same as theirs – but to use the tools, experience and knowledge that they have to support the individual PLWHA to make informed treatment decisions. ■

Hugo Mendez *Prison Services Coordinator, AIDS-Related Community Services (ARCS), Elmsford, New York*

HIV/AIDS is now the leading cause of death in New York State prisons, accounting for 66% of inmate deaths. In fact, New York State has more inmates living with HIV than any other state prison system in the United States.

Access to medical treatment can be difficult within the prison system. Prisons are already financially strapped without the additional stress of the expensive medical treatments sometimes necessary for people with HIV. Because of the overpopulation of New York State's prisons and the high demands placed upon prison doctors, it is difficult for even the most dedicated medical professionals to update their knowledge of the most cutting edge treatment strategies. Doctors rarely have the time to educate their patients even when they are up-to-date on current treatment options. The huge number of patients that need to be seen every day limits actual patient-doctor time. There just isn't the time to build healthy doctor-patient relationships. These factors make it hard for prisoners to access up-to-date and adequate treatment. Even if prisoners are able to get good medical treatment while in prison, they often face a gap in treatment upon being released.

Some prison administrative officials feel that educators are there to promote specific drugs instead of providing AIDS/HIV education. Because there is the potential for informed prisoners to advocate for specific (and often expensive) medications by name, administrators look at education as a hindrance in the system. One well-informed prisoner that I worked with was taking an anti-retroviral combination that he was comfortable with and felt worked well. His doctor wanted to change him to a combination that the prisoner did not feel comfortable with due to possible side effects. Soon after refusing to switch medications, he was moved to a higher security prison. Even if his transfer was a coincidence, this type of incident can heighten tensions between administrators, inmates, educators and medical professionals. The perception that this prisoner's self-advocacy led to negative consequences – accurate or not – can lead to other prisoners feeling apprehensive about speaking out about their own medical needs. The possibility of prisoner resentment and anger building up towards administration and medical providers is already high without the added stressor of perceived retaliation for simple medical advocacy.

Educators have to work hard first to dispel the belief of administrators, and even the occasional medical provider, that inmates in possession of information are dangerous before even being able to start the real job of providing education. The education of prisoners not only includes providing information on HIV/AIDS and available treatments, but also the importance of self-advocacy without furthering the rift between those in charge of the prisons and the prisoners.

Because of the high incidence of HIV in the system and the difficulties that those infected face while in prison, education is especially important. However, there are very few community agencies going into the prisons to provide education because of the difficulty in obtaining funding. There are very few grants available. Those that do obtain funding and go into the prisons face strict restrictions. Even providing condoms to encourage safer sex is impossible because they are considered contraband items! Educational materials are limited to literature/handouts because demonstration materials such as models for proper application of protective devices are also considered contraband.

Videos often need to be sent at least a month ahead of time so that they may be viewed and approved by administration before being used.

One of the most successful models to help prisoners combat these many obstacles is the P.A.C.E. program (Prisoners for AIDS Counseling and Education) at Eastern Correctional Facility in Ulster County. This group was founded in 1988 by a small group of HIV-positive inmates who felt the need for peer education and awareness. Prisoners are more receptive to peer education than presentations from outside educators. There is a feeling that peer educators understand the life of a

prisoner better than any visiting educator ever could. That said, those who do volunteer to become peer educators are often enthusiastic and very appreciative of any outside resources they may receive. Some prison administrators are also supportive of peer education efforts. In prisons where staffing is especially tight, officials often appreciate efforts to bring prisoners into meaningful activities that they might not otherwise be able to provide.

I work with eight different facilities in four separate counties, providing two trainings approved by the New York State Department of Health. The first is a four-day Peer Educator Training that offers the skills necessary to deliver peer education within the facility. The second is a two-day HIV Test Counselor Training, which provides the rules and regulations for providing HIV testing in New York State. I also present smaller workshops on topics like "Basic HIV Infection and Prevention" and "Domestic Violence." Providing HIV medication updates is also an important part of my job. The fact that I am able to provide these services to an underserved population with such a high rate of HIV infection is what motivates me to keep going back to these facilities. I am proud to be part of such a dedicated group of individuals. Hopefully, through the dedication of those working both outside and within the prison system, New York State will not continue to have the highest incidence of prisoners with HIV. ■

**“Educators have to
...dispel the belief
of administrators
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College Interns Enhance ACRIA's Research

Yasmeen Khan, a third year student from Brooklyn College, and Benjamin M. Brucker, a second year medical student at the University of Pennsylvania, recently completed internships at ACRIA. Benjamin was supported by a fellowship from the New York Academy of Medicine, and Yasmeen received a scholarship from the Jewish Foundation for Education of Women.

Under the supervision of ACRIA's Medical Director and Associate Director of Research, Benjamin has developed an assessment survey to determine how a patient's connection, or lack of connection, to their community correlates with adherence to the rigorous treatment regimens for HIV/AIDS. Does community support, such as friends and neighbors, assist them in adherence? Are people who are isolated less adherent in taking their medications? This on-going ACRIA research study is focusing on patients who attend the HIV/AIDS Harlem United Day Center.

Yasmeen's research project was to develop a compendium of statistics from the web that describe the incidence of HIV/AIDS in college-aged students (18-25 years of age). She also assembled a list of questions from the web that are used to assess HIV/AIDS knowledge levels. From that large inventory, questions have been selected that are appropriate for college-aged students. ACRIA plans to use this survey to study knowledge levels about HIV/AIDS in a number of ethnic groups of college students. Brooklyn College has one of the largest and most diverse number of ethnic student clubs making this research possible. How do levels of knowledge affect risk-taking behavior in college students with different cultural backgrounds? ACRIA is trying to assess whether there are varying levels of knowledge about HIV across different cultures and how this might affect risk-taking behaviors.

ACRIA Studies Integrase Inhibitor

ACRIA has initiated a Phase II clinical trial of a new class of anti-HIV drugs called integrase inhibitors. The agent we are studying is in development by Shionogi Pharmaceuticals and GlaxoSmithKline. Our protocol is designed to study the drug's safety, efficacy and pharmacokinetics.

This is an exciting project for ACRIA because integrase inhibitors represent a new opportunity to thwart HIV replication through a substantially different approach than that of existing antiretroviral medications. There are now very few entirely new drug treatment classes being considered for HIV. Integrase inhibitors are designed to block HIV's ability to replicate once it has entered a T-cell's nucleus. If these drugs are safe and effective, they offer a promise of helping the many people living with HIV/AIDS across the United States who have devel-

oped resistance to the current antiretroviral medications.

ACRIA Adds New Online Donation Capacity

ACRIA now has the ability to accept donations and payment for items from the ACRIA store directly online. We just introduced our new Internet donations/purchasing option in October to make it easier for people who want to provide their support via the computer. Eventually, ACRIA would like to conduct fundraising appeals online. Send your e-mail information to jaforde@acria.org if you would prefer to receive funding requests by computer rather than by regular mail. If you want to make a donation by credit card and have Internet access, please try out our new system. Of course, ACRIA will continue to warmly welcome any support through the mail.

Check out all of the fabulous art and note cards for sale in the ACRIA store.

Treatment Issues for Women

New free booklet available!

We are pleased to announce the availability of a new brochure written specifically for women with HIV. *Treatment Issues for Women* offers information about HIV-related conditions that can greatly affect a woman's health and quality of life.

Hormones • Anemia • Gut Health • Muscle Mass

Lipodystrophy • Bone Density • GYN Conditions

Free copies are available to women with HIV and community-based organizations serving women.

To order, call 212-924-3934, ext. 121
or email: treatmented@acria.org

Available soon in Spanish.

generous contributions

The following persons, corporations and organizations made major donations between June 13, 2002 and September 15, 2002 to support ACRIA's research and education efforts:

Ross Bleckner
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Lisa deKooning
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Katie Ford and Andre Balazs
The David Geffen Foundation
Neil Getnick
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Ortho Biotech
Philip Morris Companies, Inc.
Mr. and Mrs. William Rayner
Roche Laboratories
Louis & Rachel Rudin
Foundation

Thoughtful donations in memory of the following remind us of what is at stake in the fight against AIDS:

Barry Binkowitz, MD
Patrick Englese
Barbara Frey
Leslie Kaliades

Charles Lewis
Thomas Massot
Carl Parisi
Joseph Tamburo

Contributions in support of ACRIA's vital research initiatives were made in honor of the following individuals:

Fran & Jim Massot

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