

Towards an HIV/AIDS Health Education Movement

By Julie Davids

Time for Treatment Education to Evolve It's about more than adherence	1
Project TEACH One community's response to treatment education	4
Paisan Tan-Ud Interview with a leading Thai HIV/AIDS activist	8
Boundary Issues Education and treatment in San Diego	11
Treatment Ed Daybook A week in the life of a frontline educator	12
Short Course Notes on drugs in development	14
Global Treatment Update Gates is all over the map	15
Opinion James Learned on reclaiming HIV/AIDS empowerment	16

What is treatment education, really? Seminars, peer education, workshops, "one-on-ones," adherence counseling, training programs? Pamphlets, articles, interactive exercises, pens with drug company logos, occasional trips and free lunches? Military metaphors, biology lessons, tearful confessions, and cultural clashes? Struggling rural programs, industry-sponsored inspirational speakers, small armies of underpaid urban peer educators? Certainly it involves health, hope, fear, controversy, elephants-in-the-room, conflict, doubt, and lest we forget, illness, disability and death.

What we now call treatment education began to bloom when life-and-death AIDS activism born in the 1980s collided with the downpour of Federal and pharmaceutical funding that opened up after truly effective therapies became available in the mid-90s. To me, activism means working together to question conventional wisdom, and working to change systems, as well as individual situations, through strategic analysis and action. Treatment education started out as, and often remains, an offshoot of activism. At a time when there were no good options, people with HIV and their loved ones fought for scraps of information on any promising therapy. And when they saw promise, they fought for access to those options.

These days, treatment educators may be self-trained people with or without HIV, community organizers and activists, people with social work degrees, street-smart current or former drug users, church folks, and occasionally, people with scientific or medical backgrounds.

So we're a mixed bag using mixed resources, but we're almost always overworked and overwhelmed by the challenges. On the one hand, we need to know our content cold—from drug interactions to how to get through to stubborn doctors. On the other hand, we need the skills to swim and not sink in the world of people's real lives, where lack of information can pale in comparison to the lack of food, safe housing, emotional stability, or even, in the case of an increasing number of incarcerated people with HIV fighting for their lives behind bars, lack of freedom.

With all these demands, there's little time or room to take a step back and look at both hands at once, to grapple with the multiplicity of issues, to learn from other educators' experiences, and check-in on the many emotional, logistical, financial and ethical challenges of dispensing unbiased information that may prove to be wrong a few years later. Throw in the need to deal with the structure, funding,

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and politics of our programs, and the race to keep up with an ever-changing, complicated realm of scientific and social data that can save or change lives, and our stress is understandable. Treatment educators may not always agree on methods or even message, but there is one commonality: we all seem to share a passion for the work—maybe because it's just too difficult to do without being driven by passion.

Why Treatment?

The Fall 2002 issue of *ACRIA Update* is admirably dedicated to telling the stories and strategies of a diverse group of 14 treatment educators (www.acria.org). The issue is prefaced by a moving analysis written by editor and long-time treatment educator and activist James Learned, on the troubling transformation of treatment education from an initiative carried out by a community for itself, to a client-focused service that is performed for patients. He writes:

"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 [people with AIDS] 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."

What does it mean as treatment education becomes increasingly professionalized and formalized? What does it mean as the work is carried forward by a new generation of people who may be very capable but did not live through the early years when information and education were inextricably intertwined with advocacy and activism? For one, it may make us particularly vulnerable to fetishizing antiretroviral therapy as the core concern around which all other educational topics must orbit. Learned continues:

"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 combination 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 Treat-

ment 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 because healthcare providers and public health officials couldn't imagine that patients could understand Highly Active Anti-Retroviral Therapy (HAART) and the attendant diagnostics.... 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."

I wonder if we should ask, does our definition of ourselves—treatment educators doing the treatment education thing—help prioritize treatment as the be-all and end-all of decision-making and living with HIV? Could we adopt something more neutral? A friend recently suggested the bold move of reframing what we do as simply "HIV/AIDS education."

At a time when a list of potential drug side effects or toxicities can look strikingly similar to the risk factors for heart disease, it seems unwise to not invest in combating the other risk factors—like smoking—that have not necessarily been within our area of expertise but have a profound effect on the health of people living with HIV. But treatment education is too often disconnected from mental health education and care, and we are rarely trained to understand our role in working with people with moderate or severe mental health conditions. I have yet to hear of an HIV/AIDS organization with a systematic plan or resources to address the very high prevalence of smoking among people with HIV.

Hard Core Curricula

We have all seen industry-produced materials that offer easy-to-grasp explanations of antiretroviral resistance or handy tips for adherence—and sometimes they are very good. But they almost always come with subtle or not-so-subtle biases and omissions. Not surprisingly, the basic message is often to "start consuming drugs and don't stop."

So here's a challenge: where is the community's stylish kit of reality-based information for treatment educators working with groups and individuals? There are many great resources out there at varying reading levels and formats, like some of the fact sheet series that are rigorously reviewed and frequently updated, or articles from treatment activist journals such as this one. But these are not the same as a set of sexy materials with a teaching guide ready for use by an overworked "adherence counselor" in a busy

urban hospital. Or by a community volunteer running a support group in a rural area who can't quite figure out how to lead a useful discussion on the contradictory information floating around about structured treatment interruptions or lipodystrophy.

Lately, I have been talking to just about anyone who would listen about my desire to see a core curriculum developed that's been shaped by treatment activists and designed by the kind of cool people who know how to make educational materials interactive and fun. The curricula would offer treatment educators a starting point that could be adapted for our many and varied efforts. Imagine bringing together a group of treatment activists and educators to brainstorm a set of core curricula that is absolutely accurate, doesn't gloss over the real contradictions and controversies, and offers engaging ways for individuals and groups to struggle with this information rather than passively receive a lecture. Of course, a good set of core curricula would cover the basics in a way that is not overly reductive and would remain infused with a spirit of community activism and history (and, I'd hope, is not too dependent on military metaphors). The writ-

ers would also recognize that many people do not read at a high level of literacy or may not be accustomed to relying on written information when making major life decisions.

I also think it's time we talked about the working conditions endured by members of the "profession" of treatment education. I have met with dozens, if not hundreds, of peer educators throughout the years who are doing the Lord's work for a stipend or maybe just public transit tokens—with no sick time or vacation pay, no chance of switching to the agency's benefits rather than relying on Medicaid, no emotional or professional support given the intensity of the work, and no possibility of advancement to full-time. And it's no picnic either for the folks with full-time jobs, who do hundreds of presentations a year to people with often overwhelming needs for additional information, support and interventions with medical providers.

So let's keep writing and talking and educating ourselves and those we work for, not worrying if we are getting it perfect, but striving to get a little further along in the constant struggle with this lousy epidemic in our less-than-perfect world.

Curricular Picks

My top picks for curricula—either because I have sought in vain for something that fits the needs of our work at Project TEACH in Philadelphia, or because I feel that Project TEACH has insights to offer—are:

- Structured Treatment Interruptions: Understanding the data from chronic vs. acute infection; analyzing what is known and not known in terms of different goals, from taking a break from meds to self-immunization to recovery of wild-type virus.
- The Tricky Matters of Drug Resistance, including: Why would someone stay on meds to which they are "resistant" when other treatments are not available? Is there such a thing as "wimpy virus" due to drug-resistant mutations? What is the difference between low-level and high-level resistance and are there implications for cross resistance?
- "Re-infection" and "Superinfection": What is really known? What are critiques of the data? What makes this one of the most popular topics discussed by many peer educators and AIDS service professionals, despite confusing and contradictory data? How can we be responsible to the challenges of prevention, including the prevention of STDs, while respecting the individual struggles and choices of people with HIV?
- AIDS Activism: What is the history of AIDS community activism that has brought us to this point and won greater access to meds and resources? How has AIDS activism, and treatment activism, changed in the last 15 years? What are the basics of community organizing and mobilization that impact treatment issues like research and access to therapies? How do activists strategize and choose tactics? What does it mean to be an organizer or community leader, and how can you take a further step as an activist, even if you live in an isolated area?
- HIV Treatment in Prisons: What is the structure of corrections systems and what is the provision of care behind bars like for people with HIV who are locked up? What are methods of advocating for yourself or a loved one who is incarcerated and not receiving proper care? Why are the hours and days after arrest often the most dangerous times for people with chronic illnesses? What are successful examples of discharge planning for the transition out of jail to ensure continuity of care, housing, and support? What are examples of advocacy models that have changed systems of care in individual jails or at the county, state or federal level that we can learn from?
- Street Drugs and HIV: What is really known and unknown about the impact of street drugs on the progression of HIV, on concurrent illnesses, and on antiretroviral therapy? What about legal drugs like alcohol or diet pills? What are the challenges of talking about these issues or being a supportive person if you have a history of drug use and recovery?

—JD

Project TEACH Instructors' Handbook

By Julie Davids and Val Sowell,
Project TEACH, Philadelphia FIGHT

History of Project TEACH

Project TEACH stands for Treatment Education Activists Combatting HIV. TEACH was initiated in Philadelphia in 1995 by Julie Davids and Jeff Maskovsky, two members of ACT UP Philadelphia, working in collaboration with two local organizations, *Philadelphia FIGHT* and *We the People Living with HIV/AIDS, Inc.*

Philadelphia FIGHT brought together people living with HIV and other AIDS activists, clinicians, and researchers to sustain a community research initiative and bring cutting-edge treatment and research information to the impacted communities of Philadelphia. Today it is the largest provider of HIV/AIDS medical care in the region. We the People, a groundbreaking PWA coalition primarily led by people of color, was a central force for effective community mobilization in struggles for housing, benefits and inclusion of people with HIV in decision-making processes.

As treatment activists and organizations rooted in the day-to-day experiences of people with HIV in Philadelphia, the initiators of Project TEACH designed the program to move towards the stated goals of people most impacted by HIV in the mid-1990s—current and former drug users, people of color, and women. They felt that crucial medical and HIV-specific information was not reaching their communities, and that they did not have meaningful participation in debates and decisions that impacted their communities. They felt that people were dying because they did not have information that would have saved or prolonged their lives.

Thus, the initial goals of Project TEACH were to ensure that people living with HIV had adequate information to make informed decisions about their health care, had continuing access to information as standards-of-care changed, and could participate in the community advocacy and mobilizations that have shaped the development of HIV/AIDS treatment and care. In order to meet these goals, TEACH has developed a hybrid model of training and support rooted in HIV/AIDS activism, harm reduction, and community building.

Since its inception, Project TEACH has recognized that the potential impact of HIV/AIDS treatment education in hard-hit and underserved communities can be best realized through a

process of community building and interactive learning. The initial curriculum was determined by local HIV+ leaders, the majority of whom were African American people of all sexual orientations who were current or former drug users.

What is Project TEACH?

Project TEACH began as a 30-hour, 10-session training. Today, the course has expanded to 17 sessions over a two-month period, meeting twice a week, with two semesters each year offering a choice of day or night classes. In general, these are secondary prevention trainings, focusing on how people living with HIV can stay as healthy as possible for as long as possible by preventing opportunistic infections or other complications of HIV as well as preventing the transmission of HIV to others.

The focus of this instructors' handbook is on the basic principles and beliefs of our program, and how we actualize them in the planning, implementation and follow-up of our trainings. For those outside of our region, it may provide an interesting document for comparison with local programs or spark conversation on new initiatives. If so, we would love to hear your thoughts and ideas.

Overview of Project TEACH Curriculum

Of course, there is no way we could cover all the information someone needs for an optimal life with HIV. Our curriculum is designed to provide:

- An encouraging environment in which everyone learns something and learns that they can continue to learn more once the class is over;
- A link between community health beliefs and common misperceptions about HIV and its treatment that values community experiences while providing absolutely accurate information at our current level of knowledge;
- A variety of levels of sophistication of information in key areas, so that people who know very little will not be lost while those who enter class knowing more will not be bored;
- Teaching strategies and interactive exercises to decrease competition between individuals and to emphasize the importance of people with HIV supporting one another as a community;
- An analysis of subjects such as prisoners with HIV, needle exchange, and pain management as issues rather than problems. Issues, when used in the context of community organiz-

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ing, refers to the potential solutions to problems, in which ordinary people play a role in campaigns large and small to change the conditions that impact their lives.

In order to achieve these goals while shoe-horning everything into the hours available, we structure our curriculum around four main subject areas: Treatment, Living with HIV, Communication Skills, and Issues and Resources. It should be recognized that in each of these areas, participants learn as much or more from fellow class members as from the lead instructor or guest speaker; each area includes interactive times, work in small groups and pairs, and time for discussion.

Goals within each subject area include:

Treatment

- To gain or share the basic knowledge base on the medical aspects of HIV/AIDS and current standards of care that are needed to participate effectively in decisions about your own treatment.
- To recognize that different people have different priorities about treating HIV and will choose from a range of treatment options or strategies, and to recognize the need for people with HIV to support peers whose decisions are different than theirs may be.
- To gain or share perspectives on progression of HIV, including monitoring, lab tests and clinical symptoms, while dealing with the frustration of not being able to fully predict what may happen to yourself or other people over time.
- To discuss current controversies and debates about HIV treatment—such as superinfection, when to start treatment, or structured treatment interruption—in order to participate in discussions, understand the range of perspectives of care providers, and to gain information for making your own decisions.
- To understand the history of AIDS treatment activism, how it has influenced current treatment options and strategies, and how to participate in ongoing treatment activist issues and campaigns.

Living with HIV

- Learning and sharing the balance between living life fully and being cautious in order to preserve or prolong health.
- Understanding key symptoms or indications that call for immediate care or going to the hospital.
- Discussing the benefits and challenges of disclosure, including the recognition that it is each individual's right to determine the level of disclosure that works best.

- Managing the anxiety and stress of dealing with the ins-and-outs of this disease.

- Managing the stress of this curriculum—learning new information about “what could go wrong” or “what we’re not really sure about” is stressful.

- Coping with the often confusing or frustrating information obtained from doctors and other service providers, including learning from people who have handled similar situations.

- Discussing the advantages of working together as a community rather than as isolated individuals.

- Exploring next steps as an activist, recognizing that everyone has qualities that are useful and can develop new skills to help change conditions that impact yourself and your communities.

- To continue learning and developing as individuals and communities by identifying future directions to explore after the course ends.

Communication Skills

- To learn how to communicate your needs effectively.
- To learn and improve skills for communicating with care providers and gatekeepers that can stand between you and what you want or need.
- To strategize how to enhance and/or change your relationships with doctors, health professionals, service providers, family members, other people with HIV and community members you might come into contact with.
- To learn how to hear people who make us uncomfortable and to find ways to respectfully discuss topics that bring up strong feelings.
- To learn, practice and improve listening, understanding and responding skills.
- To recognize the potential problems with giving advice or assuming that other people with HIV will benefit if they do exactly what you did.

Issues and Resources

- To expand understanding of HIV/AIDS as not just a medical condition but something that is political, social, and economic in its personal, community and societal implications.
- To review key moments in AIDS activism and community mobilization, often integrated into the curricula based on the gains of these movements (such as the expansion of the definition of HIV/AIDS to include conditions prevalent in women or injection drug users.)
- To learn when and how to access area services, by learning key resources and strategies for accessing services, rather than simply

Different people have different priorities about treating HIV and will choose from a range of treatment options and strategies.

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reviewing long lists of AIDS and support organizations.

- To recognize that people may not respond in the same ways to controversial issues as you do, and to deal with that respectfully.

- To agitate for your needs if you are not getting the health care or services you deserve, and how to advocate for people with HIV in the hospital, prison, or other controlled settings.

Priorities of our curriculum are:

Self-determination: People have a right to know what's going on with their bodies, and to understand what their doctors are recommending and why. Each person should be able to make decisions about their health care that take into account their health beliefs, priorities, and goals.

Social and political realities: HIV/AIDS is a political condition—people with HIV in the United States are often from politically marginalized groups, such as people of color, drug users and queer people, that have not controlled major resources in our society. Thus, individual, community and societal opinions and treatment of HIV/AIDS is affected by the racism, sexism, homophobia and class bias that is pervasive in our nation.

Our curriculum and standards reflect the lived experiences of people impacted by HIV—we do not gloss over the impact of bias, stereotypes and neglect that have shaped our society's response/lack-of-response to the epidemic. In addition, we talk explicitly about the possibility of bias, the impact of stereotypes, and horizontal hostility (when people act more aggressively towards members of their own peer or racial group) in the classroom, and ask people to actively resist these pervasive ways of relating to one another.

Power: Power is the ability to make things happen, and is present in all levels of dealing with HIV. People who go through Project TEACH are encouraged to use their power to participate in their health care and have a voice in decisions that impact themselves and their communities. If their doctor does not want them to participate in their health care, we ensure that they have the skills to access a better provider. We also take people through a process of recognizing that the skills they have developed in their daily lives—as a church member, a mother, or if they are “out there” using—can be potent tools for increasing the

collective power of people with HIV and their communities and to win meaningful change in their lives.

Community Solidarity and Mobilization:

People living with HIV are not victims, and the course of this epidemic has been actively altered by the mobilization of people living with HIV and their loved ones. We seek to embody in our curriculum, pedagogy and policies a spirit of collaboration rather than competition, and encourage people to participate in community mobilization on issues they care about.

Learnable materials: The activists who became experts in HIV treatment were self-taught. Although many well-known leaders in treatment education and activism had the benefit of advanced education that has not been within reach of most TEACH members, we have seen that TEACH members can, and wish, to learn sophisticated treatment information. We emphasize concepts and philosophies of treatment, rather than going through the dosages, side effects and details of each drug, in order to help members develop a framework of understanding into which they can add new information from fact sheets, articles and workshops as our knowledge base extends.

In addition, we work to make information understandable without “dumbing it down,” by trying to use accurate, clear, non-technical language and by repeating key concepts and information at multiple points in the course. Homework readings and interactive exercises give additional opportunities to learn essential information.

Spreading the word: On the first day of class, each Project TEACH student is given the goal: “Each 1 TEACH 10.” People need to take this lifesaving information back to their communities, their families and friends and to their networks. They can reach people that TEACH or Philadelphia FIGHT never will.

Themes Articulated by Project TEACH Instructors

The curriculum of Project TEACH was developed over the years by people rooted in the experiences of living with HIV and/or participation in AIDS activist struggles. Thus, our materials and approach show the results of a dynamic process that is not based in traditional education methods. We have found it useful to analyze our curriculum based on what we have ended up with, rather than

methodically working to develop materials to meet well-defined goals and objectives. We have found that we tend to emphasize several overarching themes throughout the term. Some of these themes find their way into formal curricula; others exist more as oral histories of the matters that have been most important to hundreds of class participants.

Living Well with HIV

- Unnecessary suffering is unnecessary. You should have a good life. You can't pay back past behavior that you are not proud of through suffering today.

- Honor people who've had deep health challenges.

- Really early, address the tyranny of the healthy. There will be people who've been HIV+ for years and are healthy now, and sometimes they have a tendency to castigate people who are sicker, saying, "You just need to take care of yourself and you'll be okay." Don't let it happen in the class.

- Everybody's body is different. Find new ways to say that.

Activism and Empowerment

You should stick up for yourself (in the doc's office, in the community, within ACT UP), and there are many skills you can learn to help you do that. It's up to you to decide what works best for you.

But it's important to recognize that what you face is not simply a struggle to get what you need in a confusing but basically fair system. Often the system is not fair. Sometimes, those in

power make bad policies intentionally, either because they would rather hurt people with HIV and their communities than alienate their campaign funders, or because they have personal beliefs that further stigmatize or discriminate against people with HIV, people who are gay/lesbian/bi/queer and/or transgendered, and against poor people or people of color.

HIV is political, and often there are political decisions that impact people's health. We need to fight for what people need as individuals, but remember that we have also successfully fought to change the larger systems that create these barriers to individuals getting what they need—and that is why we continue to need activism and organizing and education.

This is not a complete set of curricula. We have not produced a stand-alone training manual for use as curricula, although we have included several interactive exercises as examples in a longer document. In fact, we support the proposal for treatment activists and treatment educators to produce an independent set of core treatment curricula in the public domain, and would eagerly participate in that process. However, our existing curricula is available if you contact us—in general, we prefer to have technical assistance agreements with organizations when we share our full set of curricula.

For more information, contact Val Sowell,
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Health Emergency 2003

The Dogwood Center and the Harm Reduction Coalition have jointly released a new report, *Health Emergency 2003: The spread of drug-related AIDS and hepatitis C among African Americans and Latinos*.

Here is the foreword by Dr. Joycelyn Elders, former U.S. Surgeon General:

This powerful report brings home the severity of the problem of AIDS spread through dirty needles. It makes me angry!

We have got to be about preventing disease! We have better drugs, but we still don't have a vaccine or a cure for this disease. We have watched people die from this disease; now they must learn how to live with HIV/AIDS. But why can't we help prevent this disease by providing clean needles? We do not allow people to get the clean needles that would reduce the spread of HIV disease, yet we spend thousands of dollars to treat each person who develops AIDS, to take care of them, to watch them die. That makes no sense! We have got to be about preventing problems, not fixing things after they are broken.

Our best scientific research shows that needle exchange programs do not increase drug use, but do reduce the spread of HIV. We need to speak out. Silence about the importance of needle exchange programs is causing the deaths of thousands of our bright young black and Latino men and women. Time is slipping away. Our bright young people are slipping away.

We must recognize the spread of AIDS through dirty needles as the public health problem that it is. We must accept the scientific data and stand up for needle exchange programs and begin to save precious lives!

Copies of the report and information about harm reduction, AIDS prevention and drug use are available at: www.dogwoodcenter.org or www.harmreduction.org

Interview with Paisan Tan-Ud

By Karyn Kaplan

Paisan Tan-Ud is the Founding Chairman of the Thai Network of People Living with HIV/AIDS (TNP+), Bangkok, Thailand.

How did you become an AIDS activist/treatment access leader? And how did Thai people living with HIV/AIDS (PLWHA) coalesce into a movement and put treatment access on the top of its agenda?

Around the time I learned my HIV status about 12 years ago, we started Thailand's first group of PLWHAs, Wednesday Friends Club (WFC) at Chulalongkorn University Hospital. At first I just participated in their social activities and group support, recreational stuff and seminars. I got there through the encouragement of social workers at a therapeutic community (TC) for drug users where I was staying, and I and my other friends there who were positive got involved because we thought this was the only way we could survive—it was the only thing out there for us. Our TC took us and I soon felt this is what we needed.

No one understood us at that time, and everyone was scared. PLWHAs used to come to the medical clinics and hold newspapers up in front of their faces, so as not to be recognized. No one would look at each other. So, I joined a group of HIV+ people in my TC and we went to WFC every month, whenever we went to that hospital to get care. There were about 12 of us. We weren't that involved at first, mainly because we had the TC, but I was still interested in their activities because I felt it was a very good place for PLWHA.

Then, I left the TC and started working at Alden House, an NGO that works with HIV+ drug users. I also became the Wednesday Friends Club Assistant Manager. At that time, I was talking to my other PLWHA friends and we were seeing many of our friends dying or living their lives under such duress, so we started to discuss making our group more active, beyond just support. At the same time, in the Upper North of Thailand, many groups were also forming because it was the hardest-hit region. I started working with people in the northeast, and met more friends through the NGOs who were inviting us to speak about our lives to the public.

We ultimately established a central PLWHA network, starting soon after the 1995 Asia Pacific Islands regional AIDS conference in Chiang Mai, where we had held a special session for the first

time for all Thai PLWHA to come together and talk and strategize. At that time, we wanted to strengthen our own regions before taking the step to build a national group. But the following year we formed a national network, TNP+, and I was elected its Chairman.

Our mission at that time focused on improving the quality of life of PLWHA and all who are affected by HIV/AIDS. Our objectives included: 1) supporting and strengthening PLWHA groups; 2) campaigning for human rights and social welfare for all PLWHA; and, 3) cooperating with NGOs and government entities to move toward resolving the epidemic. At that time, the climate was full of discrimination and misunderstanding, combined with a total lack of treatment. The basics of HIV transmission were hardly understood by people in general. Doctors had no ability to treat us and had a terrible attitude toward us. The prevailing thought was that we were bad for having done this to ourselves. We did have a government AIDS Division in the Ministry of Public Health and a National AIDS Committee early on. We did not have a TNP+ budget. We came together at meetings funded, initially, by the Thai NGO Coalition against AIDS, and would meet in Bangkok about every three months. We had no funding for activities and just went to meetings we were invited to on our own money. We used those opportunities to share our experiences but we really couldn't move forward. We were determining our strengths and potential. In our second year, we focused on a long-term plan and made treatment our banner issue. We started working with NGOs who were dedicated to the right to health and treatment for PLWHA, such as MSF and AIDS Access Foundation, a Thai NGO. At our second annual TNP+ conference, we all agreed to take up a Treatment Access Campaign and chose to focus on opportunistic infections (OI), getting 100% treatment coverage for OI as a goal. We focused on cotrimoxazole, a cheap PCP prophylaxis.

This strategy showed that people with HIV/AIDS are the core of the infrastructure. We are critical in any plan to scale up treatment, because it is we who provide peer support day in and day out, who help each other adhere better to our meds, who take each other to the hospital and do patient advocacy and have the direct experience with these drugs and interventions. Especially now that Thailand will receive one of the largest grants (US \$133 million) from the

Doctors had no ability to treat us and had a terrible attitude toward us. The prevailing thought was that we were bad for having done this to ourselves.

Global Fund for HIV/AIDS, TB, and Malaria, PLWHA will be a critical component of a successful strategy of expanded treatment access and care.

After five years as the Chairman of TNP+, I have stepped down but continue to work closely with them in an advisory capacity. Having seen the need for stronger PLWHA leadership, for more clear information and skills to build capacity in the grassroots, and wanting to bridge the gap between us and our regional PLWHA partners and international AIDS activist allies, I have formed my own treatment advocacy group, the Thai AIDS Treatment Action Group (TTAG). It recognizes the need to support the advocacy capacity of people living with HIV/AIDS on the local, national, and international policy level. I am very excited to start the activities and start raising the voice and strength of PLWHA in holding our government accountable to its obligations and promises in terms of treating people living with HIV/AIDS in Thailand.

Recently, people living with HIV/AIDS and some NGO allies made history in Thailand's Intellectual Property court. Can you tell me about that victory against Bristol-Myers Squibb (BMS) and its significance for treatment access in Thailand?

We are fighting to produce generic ddI tablets, a fight we started about three years ago. At first, we demanded our government to order a compulsory license. They were afraid of U.S. trade sanctions, a very real threat to our country, so we were forced to produce only powder form ddI, which as you know is very difficult to tolerate. The ddI issue emerged because there was a working group of academics and lawyers looking at the problems of drugs in terms of patent issues and drug company monopolies, and we joined with them as the Thai national network of people living with HIV/AIDS (TNP+) began to focus more on treatment access issues and to do something about deadly restrictions on our country's ability to provide lifesaving medication to PLWHA. Out of that collaboration, between the consumer rights people, intellectual property and pharmaceutical experts, and PLWHA and NGO allies, came the court case that was won by two people living with HIV/AIDS and an AIDS advocacy group, AIDS Access Foundation, against Bristol-Myers Squibb, the patent holder, and our Department of Intellectual Property on October 1, 2002, in the Intellectual Property Court.

Winning in the court is significant for us because patents are killing our people and people with AIDS around the world. In fact, there

were going to be a few more PLWHA plaintiffs on the case but, in the year it took for the first case to be decided and to submit papers for the second case, they died. We must let people know that it is not just the product patent that is bad, but that even the process patent is bad. BMS claimed they used an "innovation" that gave them the right to keep the ownership of buffered ddI tablets, but adding a buffer is common knowledge to pharmacists. Clearly their motive was greed and exploitation of our system. The court did rule their application was illegal, and now we are moving into a second court case against BMS, demanding they revoke the patent altogether.

In fact, the first time people living with HIV/AIDS in Thailand held a public demonstration, it was about a treatment access issue. We were expanding access to medication for opportunistic infections and came up against the reason that ARV could not be made as available as OI drugs—it was because of patents. We immediately put treatment access at the top of the TNP+ agenda, started to become familiar with the issues such as TRIPS (Agreement on Trade-Related Aspects of Intellectual Property), and demanded our government invoke a compulsory license for ddI because, according to TRIPS, we had the right to address our public health crisis.

Two hundred people stood in front of the Ministry of Public Health, for three days. As I mentioned, the government would not do it, citing fear of trade repercussions. Even though I got a personal letter from Charlene Barshefsky, then U.S. Trade Representative, promising there would not be action taken against our government, Thailand remained reluctant. But here we are today, victorious in the courts; people with HIV/AIDS beat Big Pharma. I hope now our Government Pharmaceutical Organization will immediately start producing generic ddI according to its legal right.

How do you see the international AIDS treatment access movement impacting on or useful to your movement?

We can see many barriers for people with HIV/AIDS to access treatment. Mainly trade regulations like the TRIPS agreement, and other negative impacts of globalization that have increased rather than decreased poverty, as its promoters promised. Resources are scarcer now. The promises made about the benefits of free trade are not true. Poor countries are taken advantage of. Capitalist concepts like this have been detrimental to our cultures and economies.

The first time people living with HIV/AIDS in Thailand held a public demonstration, it was about a treatment access issue.

We have a voice, we know what we want, and we have the capacity to work effectively toward realizing our right to health and life.

In relation to AIDS, patents that give long monopolies on drugs that we need today to stay alive are deadly to people with HIV/AIDS. When we became conscious of this in Thailand, when we learned about the drug company monopolies that were holding back our own capacity to make affordable drugs, we saw that strategically we needed to work together. But in Thailand we have many pressing issues nationally, and working internationally, until more recently, was not a priority. And of course the language barrier is a major impediment. But it is helpful to have help in watching our government and it is helpful to have help in addressing the corrupt drug company influence on our government. It is also necessary to challenge new and powerful entities like the World Trade Organization and of course the U.S., which needs to stop waging a war on poor people around the world.

Since we have started working with international partners on treatment access issues, you can see many things have moved forward. There was the court case in South Africa, dropped by the 39 drug companies in the face of international public pressure, and there was Thailand's activist cooperation with S.A.'s TAC when they came here to buy cheap fluconazole to take back home in defiance of high drug company pricing and international trade restrictions on exports of generics. Thailand, too, had a lot of international support when we demanded coverage of antiretroviral therapy under our universal health care plan last year. AIDS was one of two diseases whose treatments were excluded; after our demonstration we received a commitment from the Ministry of Public Health to cover ARV. Also more recently in our court case battle against the BMS patent on ddI, we worked together with international groups like Medecins Sans Frontieres/Doctors without Borders, who often are our allies on the ground here in Thailand, and with the International Gay and Lesbian Human Rights Commission (IGLHRC) and Health GAP to let people know about the case and ask for advocacy support including press coverage and a letter writing campaign. International pressure on our government, or on the U.S. government, and on multinational corporations has been effective sometimes, but the truth is we need more. As I said, there are barriers to working cross-culturally but we will move forward.

The next International AIDS Conference will be held in Bangkok in the summer of 2004. What are the Thai people living with HIV/AIDS focusing on in terms of treatment advocacy? Describe your expecta-

tions from international partners. How do you envision working toward these goals?

Thailand could be the next Brazil. We have excellent capacity to produce generic drugs and in fact 70% of our AIDS treatment budget goes to Thai-produced generics. We produce a combination drug called GPO-vir (3Tc, d4T, NVP). Yet, our national AIDS treatment budget, which is 250 million Thai Baht (US \$5.8 million), has hardly increased in five years. Antiretroviral therapy is still excluded from coverage under our universal health care plan, despite government promises almost one year old now. We need our government to stand for us, to stand with us as PLWHA in particular in their position toward the WTO and the U.S. The Doha Declaration upheld the precedence of health over trade and profit. What more should our countries need to fulfill their obligations to improve the health of all without discrimination? Yes, we got a huge Global Fund grant, but that should not be an excuse for the government to not continue putting additional funds toward its national AIDS treatment budget. PLWHA must be included meaningfully in the government's plan to improve the quality of life of people living with HIV/AIDS—many people have jobs because of AIDS, many people get funding for themselves because of AIDS, but how many of those people are people living with HIV/AIDS?

We PLWHA have the right to self-determination and the right to have a voice, not just a seat, at the table where decisions that affect our lives are made. We hope to gain regional and international solidarity for our advocacy goals and objectives. The government in its Global Fund proposal laid out benchmarks for the provision of AIDS treatment and comprehensive care. Yet it has a weak policy and no strong commitment for rolling it out immediately. We will hold them accountable to those stated goals, and at the same time build our PLWHA capacity to be leaders, to better advocate for our positions, and to ensure a real partnership with NGOs and government through our strong and indispensable participation in the plan to scale up treatment. We are starting now to build coalitions and to strengthen our own movement—by the International AIDS Conference in Bangkok, we hope to be another model for the world, like Treatment Action Campaign was in Durban; to show that we have a voice, we know what we want, and we have the capacity to work effectively toward realizing our right to health and life. We are going to use that opportunity for visibility.

HIV Education: Crossing Borders

By Tito Ramirez

Reprinted from *ACRIA Update*, Fall 2002 (www.acria.org)

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 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 this 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 or often unavailable in Mexico. Only individuals with a significant employment history and membership in the Social Security 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 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 beginning 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.

Also important 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.

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. 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 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.

Tito Ramirez is a Case Manager and Treatment Advocate at Comprehensive Health Center, San Diego.

Diary of a Treatment Educator

By Anonymous

Note: All names of individuals and programs have been changed and identifying details have been altered.

Monday:

Inland Tri-County Agency

The woman who led me into the group room said, "There aren't going to be many people here today" and then left. There were four people, two of whom had chronic HBV, and they had lots of questions. I know I'm needed when people ask which hepatitis virus is airborne. I offered to meet with each of the participants individually after the group and one agreed. It was a major hassle to get a private room there—first they led me into a case management den, which was a series of cubicles with other people working nearby. I insisted on getting space with some privacy. I'm glad I went up there, and feel like I could continue to do some good work, but they are making it an ordeal.

In the office

My Monday staff training group was more engaged this time and I thought it was pretty exciting because I had a chance to address lots of questions that indicated misinformation—people tended to attribute ART resistance solely to poor adherence rather than considering serial monotherapy, improper dosing/absorption, etc. I mentioned that certain side effects may or may not be directly caused by the drugs, HIV itself, or another underlying or developing condition. Participants were extremely interested in the Guidelines. I promised to bring copies to the next workshop. We discussed the pros and cons of starting "early" or "later" and of taking STIs/drug holidays in a real-world sense, i.e. asking clients what they are doing in terms of monitoring their VL/CD4 cell counts.

Went upstairs to do two intakes. Both people were excited and happy to have a chance to sit down with someone who had time to speak with them. The first client is someone it will be great to work with—he is invested in getting good care, asking questions and learning as much as possible. The second client has a lot of issues (with anger and stress management, recovery from 13 years of heroin addiction) and really needs what ever support and information he can get as his health care appears to be very sketchy.

Tuesday

Women's Drop In

The workshop went very well, although I didn't stay strictly on topic—the women had questions about the relative risk of oral sex (this was

introduced initially by some questions about reinfection when two positive people have unprotected sex—and could a person make "antibodies to protease inhibitors from someone's semen who is taking them?") Anyway, the group was aware that we'd strayed and it was easy to get back on topic. One woman said that it was really, really helpful—she had never understood what her HIV meds were doing—having an understanding made her feel much more invested in adherence. There were a lot of comments about the various side effects people had experienced with different medications, and resistance came up a lot. I covered a little bit of that and said I'd be happy to come back and do another workshop just on resistance.

There was one person who had a pretty detailed question about stopping HIV medication. She was told by her doctor that no one should ever stop taking their medications because the virus could get too strong for the medication to kill—but she knew people who had stopped taking them. So what was happening, who was right, why would someone stop taking meds, did everyone need to stay on them? I encouraged her to stay and talk if she could but she said that she had another appointment and that she would try to come back next Tuesday.

Suburban Center

This staff training went well—people were really interested and asked lots of questions, including things like "How can we work with medical providers?" and "How can we educate clients?" and "Does Medicaid pay for peg-interferon?" Of course, it wouldn't be a workshop without some characters, like the staff member who kept nodding out.

Although the person who had arranged the group wasn't there, things went pretty smoothly until 20 minutes before it ended, when a supervisor interrupted us and suggested we quit so they would have time to clean up. The group told her that we still had 20 minutes left, and they remained invested for the whole time. This was especially amazing because the group ended at 7:30 P.M. A couple of the participants had additional questions that we answered individually after the group was over. We encouraged people to contact us directly anytime they had a question.

Wednesday—Rain

Decent but not fabulous workshop at Long Station Cares. Got lost in the rain and arrived soaked. The directions were completely misleading. There

were a couple of talkers who sure had a lot to say! Most of it was very interesting, although not pertinent to the topic of the workshop, which was resistance and cross-resistance. I fielded questions about sperm washing, why teenagers have such a high rate of HIV infection, why some people who are long-term drug users seem to live a lot longer than those who take ART and take good care of themselves (one person said, “just because someone gets clean doesn’t mean that they have not already really damaged their body”).

I was confronted by the director who expected me to offer bus passes to people who showed up 25 minutes late. I gave out the bus passes and nicely explained (again) what our policy is about paying for transportation.

Fairlawn Village

There was a delay with lunch and the next group started 25 minutes late. Almost everyone was engaged in the workshop—“HIV Meds and How they Work.” People had a lot of comments about side effects and depression. One woman said that her HIV meds make her feel tired all of the time. I responded by letting the group know:

1. There may be another reason why a person is not feeling well, and talking to a doctor to figure out what is causing symptoms/side effects is a good idea.

2. There may be other options for a person’s ART selection.

3. It’s important to look at and treat the whole person.

The group really liked this last point. Two members shared their experiences with stress and depression and said that coming to the group had been a huge help and that they had gained weight and felt less tired after participating.

I’ve scheduled two more workshops there. There was, of course, a bus pass squabble. I outlined our policy to the Director clearly so that participants would be aware that they must attend the entire workshop to get the passes, but of course, one person was pretty indignant. I hate this—it feels really gross to squabble with someone over \$4.00—especially when it’s pouring outside.

Thursday

Today I did two workshops at Southside Drop-In. The first one, a staff training on HCV, went well. The staff was very engaged, and had really good questions and comments. One person stated that it was impossible for homeless people to take HAART. So I asked the group to suggest some possible interventions and the best they came up with was to “get housing for the person.” So I said,

“what about a regimen with fewer pills—what about finding out where they could get meals? These may be easier and quicker to achieve than finding housing, which of course is also very important.” They did not have any solutions for active users—I suggested asking the person about their patterns of using to see if they could incorporate their HIV medications into these patterns. All in all, I was happy about how it went.

The workshop for the peer educators at Southside was great! Somehow, it seemed to arrive at the perfect balance of content and process and the group was really engaged. The topic was HIV pathogenesis and while discussing transmission, we really got to explore how harm reduction could be integrated into the delivery of prevention services. It got really exciting when I said that next week we’d talk about how the drugs work. One participant said, “I’ve never asked how the drugs work—I’ve only asked about side effects.” I said, “once you get an idea of how they work, the side effects certainly won’t become less of a problem, but having more information about the other things drugs are doing can be helpful.” Anyway, his eyes lit up. He said he’d never thought about it that way and that he really wanted that information—and the rest of the group was really excited about learning more and said they can’t wait for me to come back. They also asked if the group could go more than one-and-a-half hours, so I suggested 2 hours with a 10 minute break next week.

I went to the graduation at the LifeGoals Program—an incredibly moving experience. I would have been crying anyway, but finding out that the program was de-funded and hearing the graduates speak, many of them saying that this was the first time they had ever been able to complete anything and having gotten to know them and watch them open up, become less angry, more trusting and open, really made it all the more emotional. The thought and hard work that’s gone into the LifeGoals program is amazing—and it was so wonderful to go somewhere where people actually care so much about the work they are doing and the people they provide services to. It is very disturbing that this wonderful program is coming to an end.

Friday

This morning’s workshop at River Group went well. I thought I did a decent but not a fabulous job. Things like “Do they still call it full-blown AIDS” and “ARC” came up, as did transmission stuff around oral sex and a lot of valid but difficult questions—i.e. “I have sever-

al clients who are mentally ill. They really need to be on HIV meds but they take them for a few days and stop because of side effects. Then the whole cycle starts up again a month later when they go back to their medical provider. What can we do about this?"

I'm going to go back and go over how anti-retrovirals work again. Towards the end of the workshop, one of the staff said "If you already have AIDS, why bother to take these drugs—it's too late for them to do any good, isn't it?"—a big red flag about addressing educational gaps. I addressed this in the few minutes that I had left, as did one of the peers, but I don't feel it was adequate. It's difficult, because when I have a group of peers who have life experience to share, the last thing I want to do is create the impression that my information is more valid than their life experiences. The only unpleasant thing that happened was a fight over a bus pass with a latecomer.

Challenge House

Another challenging workshop at Challenge House. A client who later did a one-on-one with

me was disruptive, and people kept joining the group and asking questions about themselves, so I had to stress again and again that I was happy to stay and do individual meetings after the workshop. It was extremely hard to stay focused on the topic. I'm not sure what all the situations are with people who go to this group are as far as mental health and active drug use go, but again, it was pretty challenging.

The things that really went over well with the groups were:

1. Mentioning that everyone's immune system is different, and although there's lots of information about HIV, not all of it may be as applicable to one individual as another.

2. Acknowledging that although we were going to be discussing medical information, there's so much more to a person than his or her medical issues.

Then, just as we were about to break, one of the peer educators loudly stated that neuropathy is just like arthritis and that you just have to tough it out. I was stunned, but then I got the signal to end the workshop so I didn't have time to really address this problem. I wish I'd handled it better.

Short Course Notes on HIV drugs in development

Setback for Validation of IL-2

Chiron Corporation has decided to stop funding its 2000-person SILCAAT trial of IL-2, a potential therapy for increasing CD4 counts in people with HIV. The SILCAAT trial has been costing Chiron \$20 million a year. With the company's patents beginning to expire in 2006, Chiron's president explained that stopping the trial was a business decision. Although the trial had been accumulating primary events (AIDS defining events) at the expected rate, its proposed conclusion in 2007 was no longer felt to be financially tenable.

During a planned interim analysis last spring, the trial's data and safety monitoring board observed CD4 count increases as expected. However, they saw no change in viral load, a secondary endpoint. Although no change in VL would be expected from the action of IL-2, apparently the company had suspended disbelief in a kind of a gamble. Evidence of an ability to reduce viral load would have greatly speeded FDA approval of IL-2, which will otherwise require the continued slow accumulation of clinical events to demonstrate a benefit.

Clifford Lane, of the National Institutes of Health, representing the SILCAAT Scientific Committee, is formulating an alternate plan to keep the trial going for about \$5M per year. This would involve fewer endpoint collections and sharing resources with another large IL-2 trial called ESPRIT. Chiron says they will consider this plan and make a final decision after consultation with the FDA.

How High the Sky?

Hoffmann-La Roche is set to launch two promising new treatments in the next few months for people living with HIV and/or hepatitis C (HCV). T-20 (Fuzeon) is the first of a new class of anti-HIV drugs called fusion inhibitors. The other new drug, called Pegasys, is an important improvement over the standard interferon used to treat HCV infection.

The price of Pegasys has already been announced at roughly \$14,000 per year. This drug must be used in combination with another antiviral drug, ribavirin, which may boost the cost an additional \$14,000 to \$21,000 per year depending on dosage. The price of Roche's T-20 is almost certain to be priced somewhere above \$10,000 per year with some estimates reaching a figure as high as \$17,000.

These prices will have a tremendous impact on public health programs facing fiscal problems, such as the AIDS Drug Assistance Program (ADAP) and Medicaid, which are already struggling to meet basic needs.

Project Inform's Treatment Action Network is calling for individuals to contact Roche directly with personal letters: "If the proposed costs of these drugs will affect your ability to access either one, let Roche CEO, George Abercrombie, know it. It is important that he hear from those who will be impacted by his decision. Your letter will also let him know that people are paying attention and care enough about this issue to take action." Write to:

Mr. George Abercrombie, President and CEO
Hoffmann-La Roche
340 Kingsland Street, Building 85, 8th Floor
Nutley, NJ 07110

Global Treatment Update

By Gregg Gonsalves

Cold Feet and Timid Steps Forward

The World Health Organization announced a goal of treating three million people in the developing world with antiretroviral therapy by 2005. As 2002 comes to a close, plans for reaching this goal proceed at a snail's pace. Sometime in December the UN agencies and their partners will announce the formation of The International HIV Treatment Access Coalition (ITAC), which is supposed to be the vehicle for coordinating the effort to expand access to ART. GMHC and others have been pushing the UN agencies working on scaling-up ART to do more and come up with a "roadmap" for scale-up for World AIDS Day 2002. This roadmap would have several main features:

1) A discussion of the international infrastructures needed for scale-up and a commitment to fund and create these components. If we are to scale-up treatment, we cannot expect procurement, human resources development, resource mobilization, technical assistance, laboratory testing, monitoring and evaluation, to be done on a laissez-faire, country-by-country basis. The Goba Fund is realizing this fact for its own grantee countries and starting to think about some trans-national mechanisms to facilitate and coordinate some of these activities.

2) A discussion of some standardized planning, budgeting and implementation tools for national ART programs and a commitment to creating these tools. These could include training manuals, operational, technical, planning and budgeting guidelines, and templates for setting up recording and reporting systems.

3) A timeline and milestones for accomplishment of these international and national level components.

The establishment of ITAC is not a substitute for developing this roadmap as soon as possible. Right now, the main obstacle to hammering out a plan for scale-up is a failure of nerve and leadership by all involved, from the UN organizations, to development agencies and governments in the North, to the mainstream NGOs. Once there is a real plan for scale-up, these institutions will have no excuse but to move forward with expanding access to ART, with all its risks and challenges. It's as if they've been chased to the edge of a cliff and have suddenly frozen in fear of the leap they have to make to get safely to the other side. No one denies the true enormity of what is being proposed or the difficulties facing us, but the true risk here is for the millions of

people living with HIV around the world who face certain death unless action begins now.

\$100 Million for India

The Melinda and Bill Gates Foundation announced a new initiative to slow the transmission of HIV in India, raise awareness and fight stigma. In particular, the program will focus on mobile populations such as truck drivers and migrant laborers who are considered to be at higher risk of acquiring and spreading HIV/AIDS. The grant, however, makes no provision for treating the estimated 4 million people in India already infected.

Focusing on "containment" of HIV within targeted communities, some critics say, implies a lack of concern for the people of those communities. They fear that this persistent blind spot means that such prevention-only approaches are doomed to fail.

The proposals to address stigma in India have met a better reception. In a country where discrimination is a way of life, breaking through the fear and denial will be a major challenge.

Tenofovir? You're Soaking in it!

In a separate announcement, the Gates Foundation said it will fund a proposed multinational clinical trial to evaluate the use of tenofovir as a novel approach to HIV prevention in sexually active adults in resource-poor countries with high HIV incidence. The study will assess the acceptability of, and adherence to, a regimen of one tenofovir tablet taken once daily as prophylaxis. If shown to be safe and effective in this setting, tenofovir could be adopted as an HIV prevention method equally accessible by men or women.

The ethical implications of providing anti-retroviral drug to uninfected people while dying people go without and the impact of pre-exposure prophylaxis on the behavior of trial partici-

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Reclaiming Individual and Community Power

By James Learned

Long-time AIDS activists, advocates and educators have witnessed and often contributed to a subtle but significant shift in the way that people living with HIV/AIDS (PLWHAs) are viewed. In the early days of the epidemic, as a reaction to the term "victim," people with AIDS established a self-empowerment movement by fighting to be referred to as just that—people. These days, even the most sensitive service providers and clinicians are likely to refer to PLWHAs as 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 is allowed to participate in the course of his or her own care.

Providing community-based treatment education is, by its very nature, a somewhat subversive act. Historically, discussion of medical information has been in the domain of doctors and other healthcare providers. As lay people—those of us without formal medical training—became empowered to offer each other information about biology, disease progression, medication, treatment strategy, and even nutrition and alternative therapies, it has threatened many providers, public health officials, and even some of our peers. Although many clinicians welcomed and understood community-based treatment education as an integral part of healthcare—and healthcare as an integral part of life—others were uncomfortable with what they felt was an usurpation of their authority.

After about 1996, when combination therapy began to result in dramatic drops in opportunistic infections and deaths, many AIDS service organizations started to develop formal treatment education programs designed to help their 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 efforts turned into well-intentioned treatment adherence programs. Before long, the focus of many community-based programs became compliance, often at the expense of a respect for the person that had been central to the PLWHA self-empowerment movement. Helping people on treatment develop adherence strategies is important, of course, but an individual is more than the drugs he or she takes.

This reversal in the balance of power continues. Community-based organizations are supposed to serve people with HIV, not the interests of the pharmaceutical industry, the healthcare system or... Yet sadly,

utilize 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. Client workshops are often conducted in busy cafeterias, full of distractions, or in windowless rooms without chairs or fresh air. The disrespect is astonishing. There's a pervasive and unsettling assumption that PLWHAs are incapable of understanding treatment information and making informed decisions. This may be purposeful. Ignorant clients are, after all, easy clients.

This is where the committed treatment educator comes in. 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 by allowing people to acknowledge and discuss the complicated emotional issues that underlie treatment decisions. Through ongoing examination of available data, we offer individuals a supportive space where they can explore their fears, beliefs and understanding of HIV, the medications, and the healthcare system.

Many researchers, medical providers, and even some government officials understand and support the PLWHA self-empowerment movement. They understand there's plenty of power to go around. They recognize that 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 treatment decisions.

PLWHA self-empowerment has become an overused and much-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.

James Learned is Director of Treatment Education at ACRIA and Editor of ACRIA Update.

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NAME _____

ORGANIZATION _____

ADDRESS _____

CITY _____

STATE _____

ZIP _____

A copy of GMHC's latest financial report with the Department of State may be obtained by writing to NYS Department of State, Office of Charities Registration, Albany, NY 12231, or to GMHC.