



WE'RE HAVIN' A PARTY!

by John Hatchett

Well, not exactly... but we are having a "get together" —in fact, a series of get togethers all around the state for LTI Core graduates and other PLWHA. We're calling these events Community Orientations, for reasons that I hope will be clearer as you read on, and they're all being co-hosted with local advocacy groups, such as Ryan White Title II HIV Care Networks and Ryan White Title I Planning Councils.

The purpose of these events is three-fold: first, they offer LTI Core graduates a chance to have a sort of reunion, a small-scale version of the statewide graduate meetings we held some years ago. Second, they allow the LTI to get feedback from our grads about what they've been up to in their regions and to update them about LTI training opportunities. And third, they're a way for local PLWHA groups to speak directly with LTI graduates and other PLWHA about the groups' work and the many ways "consumers" can participate in local advocacy.

For some time now we've been hearing from graduates that they'd like to get

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SCOURGE PREYS ON CITY'S POOR

African Americans bearing brunt of virus' sting in ever-widening problem

We are proud to present this article, reprinted from the Rochester Democrat and Chronicle, about HIV/AIDS in the Rochester region of New York State. Many of LTI's own graduates are profiled here, most prominent among them is our former LTI CAB member Karen Johnson-Murray, who currently lives in Greece, NY.

October 30, 2005

Lauren Stanforth, Staff writer

Karen Murray had tried to escape everything in life that was bad for her.

She left the two fathers of her four children because she says they were abusers.

She tried to move away from drug-infested neighborhoods to tame her addiction to crack cocaine.

She got tested for HIV every year.

But like so many people struggling in Rochester's poorer neighborhoods, there was only so far Murray could run.

Around 1996, she got a call from an old boyfriend who was in prison. He called to tell her he had tested positive for the HIV virus. One test later, Murray would learn she had it, too.

"I was the type of person who felt like it could never happen to me," said Murray, 48, who now lives in Greece. "I was devastated."

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The PWA LTI is a program of Cicatelli Associates Inc., supported by a unique collaboration between the New York City Department of Health and the New York State Department of Health, AIDS Institute.

This newsletter was supported by Grants Nos. 2 H89 HA 00015 11 and 2 X07 HA 00025 11 from the U.S. Health Resources Services Administration (HRSA). These grants are funded through Title I and Title II of the Ryan White Comprehensive AIDS Resources Emergency Act of 1990, as amended by the Ryan White CARE Act Amendments of 1996 & 2000 through the New York State Department of Health, AIDS Institute. Its contents are solely the responsibility of Cicatelli Associates Inc. and do not necessarily represent the official views of the funders.

SCOURGE PREYS ON CITY'S POOR

(continued from front)

At the end of 2003, 701 people in the Rochester region were living with HIV, the virus that causes AIDS. And the majority of those people—like Murray—are African American.

First found in the white gay male community in the United States, the human immunodeficiency virus has become a plague of the poor and of both gay and straight people of color—particularly African Americans. And at no time did this become more apparent than earlier this year, when the federal government announced that HIV infection rates doubled among African Americans between the 1980s and 2002, while rates held steady in white people.

HIV and AIDS experts here say our numbers mirror national trends. But the percentage of people in the Rochester region newly diagnosed with HIV who are African American hit 61 percent in 2003—11 percent more than the previous year. African Americans make up 11 percent of people in the Rochester region.

Some say the higher numbers might just reflect the vigilance of agencies to test more African Americans. But others see it as a clear sign that disadvantaged African Americans, predominantly those living in Rochester's poverty-stricken neighborhoods, have one more scourge to deal with—on top of the battle already being waged there against drugs and violence. Outreach workers are desperately trying to reach those most at risk, one person at a time.

"If we're not successful (in fighting this disease), we're going to lose whole generations," said Bishop Willie Davis, coordinator for the Faith Community Alliance, a group of more than 50 congregations, mostly in Rochester.

Why African Americans?

Dr. Amneris Luque, director of the AIDS Center at Strong Memorial Hospital, said

HIV rates in African Americans have been disproportionate for years. But what's concerning her now is how fast the rates are going up. Disparities in health care between white people and African Americans are well documented. African Americans might not be getting health insurance or the preventive messages from clinicians that they need to protect themselves against HIV infection, Luque said.

In addition, Hispanics in New York state represent 28 percent of new HIV cases in 2003, compared with 50 percent African American and 19 percent white. In the Rochester region, the numbers are much lower for Hispanics—14 percent. Some suspect it's more difficult to get that community in for testing, said Letty Padilla, lead case manager at McCree McCuller Wellness Center on the old St. Mary's Hospital campus.

There are people of color living with HIV and AIDS in the suburbs and in small cities in surrounding counties. But many HIV and AIDS counselors and advocates interviewed said the disease here is of particular concern in the Crescent, the diverse C-shaped area surrounding downtown Rochester that struggles with high rates of poverty, drug abuse and crime. A high concentration of people living with AIDS in the Rochester region reside there, according to 2001 statistics provided by the Finger Lakes Health Systems Agency. And it is there that many agencies focus their outreach efforts.

Drug abuse in these poverty-stricken areas is part of the problem, said Annie Piazza, director of client services at AIDS Rochester, where about 75 percent of its 800 clients are African American. The stereotype is that people mainly contract HIV by sharing needles to inject heroin. But abuse of other drugs, such as marijuana and crack cocaine, can cause people to make poor decisions about their sexual partners, Piazza said.

"Some people can break out if it. But

it's so depressing. It's easy to see how people can fall into these circumstances," she said.

Kraig Pannell, program director of the nonprofit group Men of Color Health Awareness Project in Rochester, didn't agree that one could blame African-American HIV rates on drug abuse. "(Drug) abuse is across the board for all demographics. To say that's why it's disproportionately affecting one community is difficult to say," he said.

But poverty can force people to make bad choices in other ways, such as when women choose to stay with men because they support them financially, said Steven Price, director of prevention at AIDS Rochester. The majority of people with HIV are men, but experts say infection in women of color is increasing. Women made up 30 percent of new HIV cases in 2003 in the Rochester region, compared with 25 percent in 2001.

"I went to a forum for people of color, and one of the questions that came up was—how do you impress upon people the importance of knowing their (HIV) status and taking the precautions, when their main concern is, 'How do I feed my children?'" said Michael Lee, an outreach educator at Huther-Doyle (an agency that offers risk-reduction services), who was diagnosed with HIV in 1986.

Dr. Nayef El-Daher, Unity Health System's chief of infectious disease, said current anti-viral medications allow HIV patients to live for decades without contracting AIDS.

Medicaid and Medicare often pay for the medicine, which can cost thousands of dollars a month. But it's often difficult to get high-risk patients to stick to monthly doctor visits and take the daily pill regimen, El-Daher said.

Shame, and secrets

The spread of HIV in the African-American community might also be the result of complex social trends.

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SCOURGE PREYS ON CITY'S POOR

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There is a theory that African-American men are more unwilling than white people to divulge their sexual preference. That can result in the “down low” phenomenon, a topic written about nationally, in which a man has relationships with women while having secret relationships with men.

Also, it's still difficult for many African Americans to disclose their HIV status—even to their closest relatives—because of perceived prejudice in that community against those infected, said Priscilla Hardy, an outreach worker at AIDS Community Health Center on North Clinton Avenue.

“People might not even know their family member is positive because of the shame involved,” she said.

Patrick Trevor, program director of the prevention and primary care program at Anthony Jordan Health Center, said he recently came in contact with a young African-American woman who grew up near Anthony Jordan on Holland Street and is now attending a local college. She was in a relationship with a man 20 years older than her, who gave her HIV.

“It's getting these kids to realize they're not invincible,” Trevor said. “All they want is to be in a relationship. Everyone wants to be loved.”

In the family

Murray said her path to an HIV diagnosis likely started during her childhood in College Station, Texas. She did not know her biological father and said she dealt with incest and other abuses in her family. While in her 20s she attended college, but never finished after the birth of her first child. She eventually had two other children with the man, who introduced her to marijuana and eventually, cocaine. She said she left him because he was physically and mentally abusive, only to marry another man who had the same traits.

Murray moved to Rochester when her husband moved here. She thought she

could kick her drug habit in a new hometown. But when the family moved next to a drug house on Campbell Street, the temptation was too great.

Murray would eventually leave her husband and continue using drugs for years, most of the time while working and hiding it from her four children. Her eldest son, 16-year-old George Johnson, was murdered in 1994—robbed on Hudson Avenue because he was dealing drugs.

“I felt responsible for some of the things that happened because of my drug use,” Murray said.

About a year later, she got a call from an on-again, off-again boyfriend she had been seeing for seven years. She said he called from prison to tell her he had tested positive for HIV. Murray had been taking the test for the virus about once a year. This time, the test was positive.

“I felt like it was a death sentence,” Murray said. “I thought, ‘I really did it this time.’” But she kept the diagnosis to herself.

A year later, Murray got word that her stepfather, a computer teacher, had suddenly died. The rumor among her five siblings, she said, was that he died of AIDS after contracting it from someone he had an affair with. Murray confronted her mother on the day of his funeral.

“I asked, ‘Are you HIV positive, because I am,’” Murray recalled. “And my mother said, ‘So am I.’”

Murray has been drug-free for eight years, and now works occasionally as a bathroom attendant in a local club to supplement her disability income. She also married an HIV-positive man whom she met through a local support group. In her attendant job, she gives out condoms and offers advice to young people.

“I don't know what it will take for people to wake up and realize that if you don't use protection all the time, you could be putting yourself at risk,” Murray said.

“My mother was a homemaker. She was a woman who stayed at home—and she ended up with HIV.”

Stopping the trend

The University of Rochester has tested possible HIV vaccines since 1988. No vaccine has been found. But it's difficult to get African Americans enrolled because of incidents like the Tuskegee experiment, in which the federal government secretly studied African-American men for syphilis for 40 years, said Dr. Michael Keefer, principal investigator of the UR HIV vaccine trials unit.

Many HIV prevention advocates are working hard on the route they think is best to stop HIV's spread—education.

Organizations are doing this on a very personal level, sending people out into Rochester's highest-risk neighborhoods to hand out condoms and talk to people about HIV.

One night in September, several local agencies—AIDS Community Health Center, Huther-Doyle, Ibero-American Action League, Men of Color Health Awareness Project and AIDS Rochester—banded together to walk around Troup and Reynolds streets. Most everyone they talked to listened patiently and took condoms. Two young teenagers rode up on bikes and asked for condoms. One said he was 14.

“I wish I had seen someone out there when I was out there,” said outreach worker Annie Dixon, 54, of Rochester, a former crack cocaine addict who learned she had AIDS 10 years ago. She walks the streets often with the workers, using a cane because she needs knee surgery.

AIDS Rochester also holds classes for women in group homes or who are coming out of prison, Price said. The focus is on communicating with men and negotiating condom use. Both McCree McCuller Wellness Center and AIDS Rochester also have vans they take into the Crescent to offer HIV testing.

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MY GIFT OF LIFE...

My name is Patricia Steen (a.k.a., "Trish"). I am a 41-year-old Caucasian woman, born and raised in the Gerritsen Beach section of Brooklyn, NY. I have been living with HIV for the past 16 years. My diagnosis came in November 1989, after burying my husband, who died at the age of 28 from the complications of AIDS on October 28, 1989.

After learning of my HIV status, I was devastated. I didn't know where to turn or who to speak to about my diagnosis. I felt alone, embarrassed, and most of all, very frightened. My only belief was that I was going to die at the young age of 25. Having watched my husband deteriorate over a short 2-year span of his diagnosis, and with AZT being the only medication available at that time, I swore I would never seek treatment until it was necessary. My fear of dying led me to a life of alcohol, drugs and depression. I had quit my job as a legal secretary and let my life spin out of control for a number of years. If only someone had told me I would be alive today writing this article, I would have lived my life differently. Had I only known of the many resources available for people infected with HIV, and kept abreast of the many drugs that became available throughout the years, I would have lived my life with HIV, and not in denial for 11 stressful years.

It wasn't until April 2000 that I sought the medical attention I needed. I was depressed all the time, felt sick to my stomach, fought fatigue on a constant basis, suffered night sweats, insomnia, oral thrush, yeast infections, gastrointestinal problems and esophageal difficulties. My general practitioner suggested I see a



specialist in HIV care and referred me to an infectious disease doctor. He told me I had to start HIV therapy immediately or risk dying by the end of the year, so my decision was easy. I decided to live, because I was too young to die and I had much to offer the world.

I began taking medication shortly thereafter, and though now I've been adhering to my regimen for the past 2 years, my first three years on meds came with many difficulties. The side effects of the meds, such as nausea, diarrhea and so on, were difficult, but worst of all was the deep depression that consumed my life. Although my health improved significantly after about 6 months on treatment, I still battled depression, as well as the stigma of being HIV-positive. Not only was I afraid of being rejected by people, I held a tremendous stigma within myself. I was not comfortable living with HIV. I still felt alone and powerless. HIV controlled nearly every aspect of my life. It was the only thing holding me back from being who I truly am. I was allowing it to take over my entire existence.

After about a year on meds, I slowly began disclosing my status to some of my closest friends. My family was aware of my status from day one, and through all these years, they believed I was handling my problem with "flying colors." I kept my family, as well as my friends, fooled by keeping a stiff upper lip. I never confessed to them that I was scared, lonely, depressed and sometimes thought of suicide. My thoughts of suicide pushed me to seek psychotherapy. I have been in therapy, on and off, for the past five years.

Having disclosed my status to my friends and family, I suddenly realized how different I had become. My outlook on life had changed drastically. Thankfully, my family and friends have been supportive, but I still don't think they understand where I come from as a person living with HIV, or the fears and loneliness that people with HIV sometimes experience. Realizing this for the first time, I decided I needed to get involved in the HIV community. My therapist and doctor reinforced my decision, urging me to overcome my fears and start being around others who are HIV-positive.

In the summer of 2004, I began volunteer work with Turning Point/Discipleship Outreach Ministries in Sunset Park, Brooklyn. There I met other HIV-positive people and was able to relate with them on some levels. I began doing outreach with

Turning Point, and although I was only with them a short time, they considered me a peer educator. But I still felt out of place, never really feeling comfortable with myself. I took advantage of a one-day training course

dealing with ADAP, and upon completion, I asked the instructor about additional training courses for people with HIV. He directed me toward Ciatelli Associates.

After doing a search online for Ciatelli, I found the LTI. I sent an email to Jenny O'Brian expressing my desire to attend their courses, and she wasted no time in answering my plea. She sent me the application for the Core Training, which I filled out and mailed back to her. Within days, I received notice that I would be in the next Core Training in September 2004.

Upon completing the LTI Core, I felt empowered, gaining the confidence I needed to take myself one step fur-

"[LTI] has given me the tools I needed to continue my life in a productive and fearless way."

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MY GIFT OF LIFE...

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ther. I felt I had finally found a place where I belonged and most of my fears ceased to exist. Shortly thereafter, I signed up for a couple of the advanced topic trainings. I attended some of them but unfortunately, I fell back into my depression for some reason or another and suddenly disappeared on LTI in mid-March of this year. I still harbored the stigma and fear of being HIV-positive.

Not knowing where to go next, other than the local "gin mill," I decided to seek help on the internet. I did a Google search on "HIV/AIDS" and came across "AIDSmeds.com." AIDSmeds.com is a wonderful networking resource for people living with HIV, and I highly recommend it for information, lessons, and support from people who are living with HIV. Having found AIDSmeds.com, I began to see that I was not alone and I was able to relate with people just like me. I have been a regular contributor to AIDSmeds.com since mid-March, and I am grateful for having found them.

At AIDSmeds.com, many of us decided to meet in person for the first time. We dubbed this meet as "AMG2005 Gathering." We chose Toronto, Canada as our venue through a majority vote. We wanted to hold this gathering in the United States, but our government does not allow HIV-positive people in the U.S. because HIV is considered a "communicable disease," comparable to TB and other air-borne diseases. Having learned this fact for the first time, I was appalled and disgusted with our government. However, this is another issue, which I will not go into at this time.

Although I was extremely nervous and scared to death about meeting people from the internet, I felt drawn to this gathering. I knew I needed to do this

for myself. I needed to see the people I corresponded with for many months from behind a computer screen. Approximately 30 people from all over the world attended. I met a woman from New Zealand, a man from Belgium, and others from all over the U.S. (Arizona, California, Tennessee, Florida, Washington State and many other states.) We were a very diverse group, with some of us living with HIV for 20 years or more, others with 15, 16, 17 years under their belts, as well as others who had only been diagnosed a year or two ago.

Being in Toronto has given me more stamina, knowledge, confidence and power to believe in myself. The bonds I made in Toronto have enriched my life so much. I was not alone and I didn't have any fears. I felt comfortable from the moment I met one of the other members in the hotel lobby for the first time. The feeling of being alone was suddenly a fog. I found a "home" in Toronto.

Toronto was an experience I find hard to put into the right words. All of us there experienced something so powerful and surreal no words could explain. I went to Toronto with no expectations and with a completely open mind, and I have no regrets about my bold decision to go. The only regret I do have is that more people were not there to witness the most empowering experience of a lifetime. I will cherish the bonds I made there forever.

(F.Y.I. there will be another gathering next year called "AMG06." Simply go to www.AIDSmeds.com, click on "Forums" and go to the "Forums Gathering" link. There you will find all the information needed about next year's bigger event. An event that could change your life forever.)

Upon my return from Toronto, I turned to LTI again with much enthu-

siasm. Because of my experience in Toronto, I am ready to get involved in the HIV community. I am proud to say I have made my way back to LTI. I attended the CAB Roles & Responsibilities training this past September, and will be attending future trainings as they become available. I have set my sights on advocacy and activism. I recently joined the PLWHA Advisory Group of the HIV Health & Human Services Planning Council of New York; I also hope to join the LTI CAB in the near future. I am better prepared and confident that I can be a voice in the fight to end HIV/AIDS. I am ready for the challenges of what it means to be an HIV positive individual and I want to be a part of the solution to eradicate HIV/AIDS in my lifetime. I am comfortable with who I've become, and I no longer fear disclosing my status. Relinquishing my silence has proven to be a lifesaver.

At this time, I would like to thank the LTI, which I credit with contributing to saving my life. LTI gave me the power and knowledge I needed to network in a way I never thought possible. It has given me the tools I needed to continue my life in a productive and fearless way. My life has changed drastically in the past year, and it is all for the better. My fear of being discriminated against has dissipated. The stigma I felt within myself has completely disappeared. My loneliness has diminished, and after 16 difficult years, I feel complete again.

In closing, I have come to the realization that HIV is a part of me. I embrace it, and I accept it. I realize I can no longer live in denial, or in a lie. I have learned to be comfortable with myself. I am proud to say, "I am living strongly and happily with HIV, but most importantly without barriers." This is my gift of life. ●

MEET THE CAB, GREET THE CAB

We'd like to take this opportunity to continue our introductions of LTI's Community Advisory Board members by letting Victor, Bill, and Lynn tell you more about themselves. These three CAB members are part of the greater board and have a variety of responsibilities to fulfill in this role. CAB members are essential to the LTI program for their role in outreach. They contact local HIV/AIDS service providers to request assistance in promoting the LTI to their clients. They also serve as liaison between the LTI and Ryan White Care Networks, HIV Planning Councils, HIV Prevention Planning Groups and Community Based Organizations, sharing information about LTI with consumers through these groups.



Victor Martinez
(LTI Core graduate—October 1999)

Region: Lower Westchester Tri-County

Work affiliation: Grace Church Community Center HOPWA/Housing C2/Manager

Advocacy and Volunteer Involvement:

Yonkers Task Force—Mental Health Substance Abuse Committee, Living Together—Member, Ryan White Title II Steering Committee.

Hobbies: Listening to music (all kinds); Salsa dancing; reading biographies, history, etc. (good novels too!). Last book read was *An Unquiet Mind* by Kay R. Jamison, collect unusual toys (cars and bears).



Bill Kress
(LTI Core graduate—September 2003)

Region: Rochester region

Work Affiliation: Huther-Doyle, alcohol/chemical addiction treatment center

Advocacy and Volunteer Involvement:

Member, Board of Directors of AIDS Community Health Center (ACHC); Co-Chair, ACHC Patient Advisory Committee; Rochester Area Task Force on AIDS (RATFA) General Committee member, Prevention Committee member, and Nomination Committee; Member-Patient Advisory Committee at DePaul HART Program.

Hobbies: I love travel and photography; I collect airline memorabilia and dictionaries; I enjoy caring for my potted flowers and then sitting beside them with a good book—or the Sunday *New York Times*.



Robin Bronner
(LTI Core graduate—November 2003)

Region: Southern Tier (Binghamton)

Advocacy and Volunteer

Involvement:

Binghamton Tri-County HIV Care Network: Steering Committee, Co-Chair of Community Awareness Committee, Nomination Committee, Planning Committee; Southern Tier AIDS Program Speakers Panel; Statewide Coordinated Care Committee; New York State Statewide AIDS Service Delivery Consortium (SASDC); Consumer Advisory Committee in New York City for New York State Department of Health AIDS Institute; United Medical CAB; very active in faith community

Hobbies: I like to go to movies, and I'm on a cooking kick now. I like bowling. I travel a lot, I've been to the Caribbean 8 times. I especially enjoy Bermuda and Paradise Island.

SCOURGE PREYS ON CITY'S POOR

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"As long as these people aren't getting tested, (the disease) is going to grow," Padilla said.

Others believe the only way to reach African-American communities is through churches—some of which are still too conservative to take up the topic.

"If it doesn't come from the church, I don't know where it would possibly come from," said Rodney Wilkinson, an HIV case manager at Baden Street Settlement.

The message is being delivered to more congregations. Aeon Baptist Church on Genesee Street hosted an HIV awareness

event in May, which also was to have included a talk by NBA legend Earvin "Magic" Johnson, who himself is HIV-positive. Johnson had to cancel, but the talk has been rescheduled for Nov. 9.

Bishop Willie Davis, who helped found McCree McCuller, said the Baptist Ministers Alliance has developed a curriculum whereby pastors teach other pastors about the disease and how to talk to their congregations about it.

"If we as a community can get to those kids with a sincere message about how to protect oneself, I believe we can put a dent in this," Davis said.

Pannell, from Men of Color Health

Awareness Project, said he would like to see the state embark on a major advertising campaign targeting African Americans and HIV prevention.

Anthony Jordan Health Center received a \$160,000 federal grant seven years ago to conduct a public awareness campaign that ended in 2004. Its "down low" initiative—with bus ads and billboards depicting an African-American man sneaking a look at another man behind his woman's back—got a lot of attention, Trevor said. "There's a community responsibility to help us grow, to help all of us to form," he said.

"We just need to keep it in people's faces." ●

Now, with community planning activities more important than ever, your local HIV Care Network is the place to be... to be heard, to be seen, to be involved, to be a leader! Below is an updated list of the networks, their coordinators and basic contact information. Give them a call and ask when their next PWA Advisory Committee meeting is, and/or how you can help.

Albany Region HIV Care Network

JILL FARNHAM
Tel: 518-434-9194, ext. 116
Web: www.ccsnys.org/rwnet
Email: jfarnham@ccsnys.org

Bedford Stuyvesant/Crown Heights HIV Care Network

EVE AMMONS-JOHNSON
Tel: 718-613-6595
Email: bschhivcare@earthlink.net

Binghamton Tri-County Region HIV Care Network

SANDRA KOSTY
Tel: 607-778-3066
Email: skosty@co.broome.ny.us
Web: gobroomecounty.com

Bronx HIV Care Network

SOCRATES CABA
Tel: 718-231-3296
Email: scaba@montefiore.org

Buffalo Region HIV Care Network

ANDREW KIENER
Tel: 716-882-7840
Email: aidsnet@pce.net
Web: www.aidsnetwork.net

Central Harlem HIV Care Network

LEATRICE WACTOR
Tel: 212-531-0049
Email: lwactor@hdg.org

East Harlem HIV Care Network

JOSE MARTIN GARCIA ORDUNA
Tel: 212-828-6143
Email: jorduna@unionsett.org
Website: www.aidsnyc.org/network

East New York Brownsville HIV Care Network

GWENDOLYN EDWARDS
Tel: 718-483-3099
Email: enybhcn@aol.com

Lower Hudson Region HIV Care Network

KELLI EVERETT
Tel: 914-428-2114, ext. 230
Email: lhrcairenetwork@gmail.com

Mid-Hudson Region HIV Care Network

CARLOS RECINOS
Tel: 845-563-8058
Email: carecinos@aol.com
Web: www.mid-hudsonhivcare.org

Nassau Suffolk Region HIV Care Network

DEBRA ROSS
Tel: 631-940-3700, ext. 3736
Email: dross@unitedwayLI.org

Queens HIV Care Network

MARITZA VILLACIS
Tel: 718-389-5100, ext. 188
Email: mvillacis@steinway.org

Rochester Region HIV Care Network

LYNN VARRICCHIO
Tel: 585-461-3520, ext. 106
Email: lynn@flhsa.org

Community Health Action of Staten Island

LILLIAN AGBEYEGBE
Tel: 718-448-8789
Email: lillian.a@sihealthaction.org
Website: www.sihealthaction.org

Syracuse Region HIV Care Network

STEVE WALDRON, Ph.D.
Tel: 315-472-8099, ext. 105
Email: sewaldron@cnyhsa.com

Williamsburg/Greenpoint/Bushwick HIV Care Network

TROILOYE SANON
Tel: 718-455-6010, ext. 138
Email: troysanon66@yahoo.com

ALL TRAINED UP AND NOWHERE TO GO?

There are many chances to use your LTI experience to assist our communities in planning, strategizing and priority setting for services and interventions for PWHA. Every region of the state has a Ryan White Title II **HIV Care Network** (see list on p.5), and several regions are also Ryan White Title I designated EMAs, with their own **Planning Councils** and **PWHA Advisory Groups**. If prevention is your passion, check out the city or state **Prevention Planning Groups**.

In other words, there are lots of opportunities for our involvement in different kinds of groups all around New York State. All of these groups depend on our contributions and expertise as PWHA, and some are actively recruiting members right now!

Please directly contact any of the groups below for more information or for schedules of their open public meetings.

DUTCHESS COUNTY HIV SERVICES PLANNING COUNCIL

Call: (845) 452-8805
 Contact: Amy Wen

NASSAU/SUFFOLK COUNTY HIV PLANNING COUNCIL

United Way of Long Island
 Call: (631) 940-3716
 Contact: Myra Alston

NEW YORK CITY HIV HEALTH AND HUMAN SERVICES PLANNING COUNCIL

Call: (212) 442-3929
 Staff Liaison: Stephen Bailous
www.nyhiv.org

TRI-COUNTY RYAN WHITE TITLE I PLANNING COUNCIL

Westchester County Department of Health (also includes Rockland & Putnam Counties)
 Call: (914) 637-4752 or 2453

NEW YORK STATE HIV PREVENTION PLANNING GROUP (PPG)

General Number: (518) 473-8484
 Staff Liaison: Barry Watson

NEW YORK CITY DOH HIV PREVENTION PLANNING GROUP (PPG)

Call: (212) 788-4180
 Staff Liaison: Yevgeniy Breger
 Email: dohmhppg@health.nyc.gov

FROM THE ROOTS OF ADVOCACY

by Gregory Huang-Cruz

It's always rewarding to see advocacy take root. Okay, sounds familiar, but then it should. Why, you ask? Let's go back in history.

In November of 1994 a group of PWHAs lead by Jairo Pedraza approached the New York State Department of Health's AIDS Institute about creating a leadership training program for PWHA. AI thought it was a good idea, and asked that same group of PWHAs to propose what such a training program should look like. Focus groups were held around the state, and the results helped determine the program's focus: training PWHAs for community planning and involvement. A steering committee was created to develop this concept and to advocate for funding to pilot the project. This was the beginning of a successful advocacy effort that resulted in a collaboration between the AIDS Institute and the NYC HIV Planning Council to utilize Ryan White CARE Act funds from both Titles I and II to create a single statewide program. A program model was developed and the first trainings piloted at Exponents/ARRIVE in 1997. Eventually, in July 1999, the LTI program came to Cikatelli Associates, Inc. Well, history has repeated itself. And I am happy to say that through PWHAs' own advocacy efforts we'll once again reap the benefits.

Earlier this year, the LTI staff began conversations with Stephen Bailous, Office of AIDS Policy Coordination, Assistant Commissioner Jan Carl Park from the NYC Department of Health and Mental Hygiene, and other key stakeholders from the NYC Health and Human Services PWA Advisory Group to discuss the PWA Advisory Group's

direction. The intent of this initial meeting was to focus attention on the training needs of the Advisory Group and to design trainings that would enhance PWHA abilities and skills for the group's members.

After several months of meetings, information gathering and group discussions, combined with the AG's leadership under Frank Oldham and LTI graduate Felicia Carroll (Co-Chairs of the AG), the LTI will be offering free skills building trainings at the upcoming PWA Advisory Group meetings.

The training sessions will be held immediately after each AG meeting in December, January and February and will help participants with effective participation, building both leadership and advocacy skills. The sessions will be approximately 2 hours, and a certificate will be given for completion of each training session. Training will be conducted by LTI training staff: John Hatchett, Petra Berrios and Gregory Huang-Cruz.

The LTI is extremely excited about this opportunity to work with the AG. And we look forward to seeing our LTI graduates once again. We encourage you to attend the monthly meetings of the NYC PWA Advisory Group and stay for the training sessions afterwards. Not only will you have the chance to work on valuable skills, but you will at the same time have an opportunity to actively participate on your local PWA Advisory Group.

For more information on this exciting venture, please contact the LTI Staff at 212.594.7741. And if you would like more information on the NYC PWA Advisory Group, you can visit the New York City Planning Council web site at www.nyhiv.org and head to the link titled "PLWHA Advisory Group." ●

WE'RE HAVIN' A PARTY!

(continued from front)

together and see each other—to catch up, to swap stories about what they've been doing since they took the Core as well as to share information about advocacy strategies and issues; in short, to strengthen the support networks that are so crucial to community leadership. Well, the good news and the bad news is that there are too many graduates at this point to bring everyone together at one time; the logistics and costs involved in a meeting for over 1,000 NYS PLWHA would be too much.

These Community Orientations are a compromise, a regionally-based way to respond to our graduates' desire to stay connected with each other, with the LTI itself and to get or stay connected with local advocacy opportunities. In mid-November we worked with the PLWHA Consumer Advisory Committee of the Western New York AIDS Network to hold our first Orientation in Buffalo, and in spite of a major snowstorm in parts of the region, nearly 1/3 of our Western NY graduates managed to make it. They also brought along five friends who have not taken the Core, and all of those folks took applications with them.

By the time The Circle goes to print we'll have held two more: December 6th in Fishkill for the Mid-Hudson region and December 21st in the Bronx. Planning is continuing for Central NY/Southern Tier, Rochester, Northeastern NY, Lower Hudson and Long Island, and there will be at least two more held in New York City. If you haven't yet heard anything about an Orientation in your area, contact your LTI CAB member and/or Network PLWHA group and see about helping with planning or with spreading the word. And keep an eye out for the invitation letters, mailed from our office here at Cikatelli.

We hope to see all of our Core graduates at an Orientation near you! ●

WE DON'T WANT TO LOSE YOU!

We want to be able to send you the most up-to-date information about LTI programs and related HIV/AIDS events. Please call us if your contact information has recently changed, and remember to let us know if you move or change your phone number in the future! 866/PWA-LEAD (866/792-5323) x231; jenny@cikatelli.org

