

# the circle

Summer 2005, N° 16

leading lines advocacy outreach community

seattle summer



## A NEW AIDS CRISIS?

by John Hatchett

If we PLWHA want real national leadership to slow or end the crisis in this country, we'd better get off our duffs and start making some noise. What brought this reality home (yet again!) most recently was the late-July release of the federal government's proposals for reauthorizing the Ryan White CARE Act. Although there's lots of language about addressing unmet need, you'll notice there's no suggestion of actually *increasing total CARE Act funding to the levels required to adequately meet that need*. Instead, what we get are questionable policy ideas that would remove some of the most innovative and effective elements of the Act and a financial bait-and-switch, penalizing states like New York that have worked hard to respond to HIV/AIDS in a more comprehensive way by committing state and local funds to the fight. One proposal in the administration's plan would reduce CARE Act funding for most states that have Title I EMAs and redistribute those funds to states with fewer cases. Now, nobody wants to deny historically underfunded states the

(continued on page 3)

## THE CAMPAIGN TO END AIDS - WHAT YOU NEED TO KNOW

excerpted and adapted from [www.C2EA.org](http://www.C2EA.org) by Gregory Huang-Cruz

### The VISION

The Campaign to End AIDS (C2EA) is a diverse, exciting new coalition of people living with HIV/AIDS, their advocates and their loved ones—uniting to demand that our leaders exert the political will to stop the epidemic, in the U.S. and abroad, once and for all. In small towns and big cities across America, C2EA is mobilizing to ensure the best treatment and care for all HIV-positive people...and HIV prevention methods backed by good science. Best of all? This October, they're taking their message to Washington, D.C...by the thousands! And YOU can be a part of it!



### WE HAVE WHAT IT TAKES TO BEAT AIDS. SO HOW CAN WE LET IT BEAT US?

You may have heard: AIDS isn't over. Not only that—it's poised for a major comeback. While the epidemic's devastation in the developing world has embroiled activists in a desperate fight for the funds and political will to turn around the global crisis, the epidemic has quietly made new inroads into vulnerable

(continued on page 2)



#### LTl Community Advisory Board

Rafael Abadia	Mark Novak
Steve Hemraj	Jairo Pedraza*
Bill Kress	Daphane Sanders
Michelle Lopez*	Bruce Soskind
Victor Martinez	Charles Thomas
Jack Miller	Michael Wade
Kim Nichols*	Ayo Wells
	*charter member

#### AIDS Institute Staff

Sallie Perryman  
Dan Tietz

#### NYC Office of AIDS Policy Coordination

Stephen Bailous

#### Program Staff

John Hatchett *Director*  
Petra Berrios *Deputy Director*  
Greg Huang-Cruz *Trainer*  
Jenny O'Brian *Program Assistant*

credits

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.

## THE CAMPAIGN TO END AIDS

(continued from front)

communities right here at home: a new generation of young gay men; women who never thought that their boyfriends or husbands could be infected; and African Americans, many of whom have so many other challenges they're not even diagnosed until they're sick. Yet while the epidemic has been establishing deadly new roots, our leaders have repeatedly failed to fully fund the programs we need to keep people with HIV/AIDS alive and well—and the science-based prevention methods to keep those most at risk from contracting the virus.

### THAT'S WHERE WE COME IN: THE CAMPAIGN TO END AIDS

We're a diverse, new coalition of people living with HIV/AIDS (PLWHAs) and the advocates, organizations and loved ones who stand behind them. After years of watching our friends and family die, we're ecstatic that we finally have the tools to stop the epidemic—treatments that work, however imperfectly, and prevention methods like abstinence and condoms, as well as needle-exchange programs, which keep injection-drug users HIV-free. But we're infuriated that some of our most powerful leaders, including our president, have withheld these tools from those who need them most. That's why we're organizing on the local, state and national level to demand that those in power:

1. Fully fund quality treatment and support services for all people living with HIV everywhere in the world.
2. Ramp up HIV prevention at home and abroad, guided by the best science.
3. Increase research to find a cure, more effective treatments and better prevention tools.
4. Fight AIDS stigma and protect the civil rights of all people with HIV and AIDS everywhere.

During this year, the C2EA organization will conduct aggressive advocacy



to our Federal legislators. Issues that will be addressed include:

1. Reauthorizing and fully funding the Ryan White CARE Act;
2. Keeping Medicaid strong for people with HIV/AIDS and all other beneficiaries;
3. Strengthening the global fight against AIDS by fully funding the Global Fund and backing 100% debt cancellation; and
4. Restoring and reviving effective HIV prevention worldwide based on the best science.

### WE HAVE THE TOOLS TO STOP AIDS. LET'S DEMAND THAT OUR LEADERS USE THEM.

When it comes to the global devastation of AIDS, we're at an exciting—and crucial—juncture. [W]e have the treatment and prevention tools to halt the epidemic's deadly toll and then go on to find a cure for those infected and a vaccine for those at risk.

The only thing stopping us is lack of political will. So let's insist that our governments and private institutions take the following steps to contain the pandemic, once and for all.

C2EA has developed a 21 point plan for domestic and global issues surrounding Health Care, HIV Prevention, Racial Disparities, HIV Stigma, Research and Science, Corrections, Harm Reduction, Public Benefits, Immigrant Populations,

and Housing. The platform will be used as a 'living document.'

(To view the complete description of the 21 point plan, visit their website at [www.c2ea.org](http://www.c2ea.org). or email them at [platform@endAIDSnow.org](mailto:platform@endAIDSnow.org))

### HOW WILL WE MAKE THIS HAPPEN?

In lots of fun, exciting ways. We're building strong local, state and regional networks of people with HIV/AIDS and the groups that serve them. We're mobilizing the veterans of legendary activist groups like ACT UP, which played a major role in securing PLWHAs their first wave of treatment and legislation, to train a feisty new generation of fighters. And from October 8-12, 2005, we're bringing it all home—to the nation's capital, that is, where caravans from around the nation will converge for five lively days of meetings, prayer groups and lawmaker visits. It all culminates with a massive march that will show the world we're united, strong...and ready to make a mighty ruckus until our leaders do the right thing to halt the epidemic.

### HOW CAN YOU BE A PART OF IT ALL?

In so many ways! You can do everything from getting involved in your area to joining a national C2EA workgroup to joining a caravan traveling to D.C.! Beginning September 30 and ending in

(continued on page 3)

## THE CAMPAIGN TO END AIDS

(continued from page 2)

Washington, DC on October 8, caravans will trek from across the nation in solidarity, before enmassing on the front steps of the Capitol. Caravans will begin their treks from the states of Washington, California, Oregon, Texas, Florida, Vermont and of course, NEW YORK! The Nor'easter caravan will trek through Vermont, Maine, Massachusetts, Rhode Island, Connecticut, New York, and Pennsylvania before arriving in Washington, DC. This caravan will make stops in Albany, Rochester, Buffalo and Erie. To get on the caravan contact: [sonny@champnetwork.org](mailto:sonny@champnetwork.org). For those of you in the New York City area, visit the C2EA website for updated caravan information.

*Greg adds:*

*As PWHAs, we have many opportunities to become involved. By being a graduate of the PWA LTI, you have already begun your journey to becoming a community leader. Imagine if all our PWA LTI graduates collectively agreed to become involved in this effort. Our caravan would stretch out for miles!! Now, this doesn't mean we are setting up a caravan ourselves, but nothing should stop you! And if you are not able to actively join the effort, there are still other ways to be supportive. For more information visit the Campaign to End AIDS website at [www.C2EA.org](http://www.C2EA.org). or call 1-877-End-AIDS to get involved.*

*The C2EA offers just one (important!) venue for community participation. Throughout New York, many activities are planned for different levels of involvement. For the most up-to-date information about how you can get involved in your own area, be sure to visit your region's HIV Care Network, HIV Planning Council (if you live in one of New York State's Ryan White Title I EMAs), or check out the New York State and/or New York City Prevention Planning Group (PPG). A full list of all these groups and their contact information can be found on page 7. ●*

## A NEW AIDS CRISIS?

(continued from front)

resources they need to address the HIV crisis, but taking resources away from states with large urban centers (still the hardest hit areas in the nation) makes no sense at all. After all, New York City remains the epicenter of the AIDS epidemic in the United States, and redirecting funds away from cities like New York would be counterproductive, to say the least, not to mention the impact on PLWHA in rural areas in those same states—areas that do not receive Title I funds at all. One step forward, (at least) two steps back.

Another proposal put forward by the administration would effectively gut local control of spending decisions and impose a list of federally mandated services, an odd approach considering the administration's preference for moving power away from the federal government and toward communities. In fact, local planning and flexibility has always been a unique feature of the CARE Act and one of its greatest strengths. Reducing Title I EMAs' Planning Councils to an "advisory" role would remove that flexibility, failing to recognize that HIV/AIDS is lived differently in different places.

Other provisions of the plan move dangerously toward a complete medicalization of CARE Act funding without regard for the essential role support services play in enabling low-income PLWHA to access and remain in care. Housing, transportation and nutrition services come immediately to mind, yet it's not at all clear that they would be included in a federally determined list of "core medical services."

Well, folks, now's the time. You've taken LTI's workshops to strengthen your leadership and advocacy skills, and you've shared with us your dedication and determination to help our communities fight the spread of HIV/AIDS and improve the quality of life for those of us already infected. The reauthorization of the CARE Act is our chance to get involved as never before. If you're not already part of a local advocacy group – a Care Network, a Planning Council or an agency advisory board – we need you to join; that's where you can get and share up-to-date information about how to protect life-saving services. Also, this issue of *The Circle* contains articles about the Campaign to End AIDS ([www.C2EA.org](http://www.C2EA.org)); go online or call them to learn how you can join in this important national effort to strengthen the country's response to the crisis. We've previously published contact information for advocacy groups like the National Association of People With AIDS (NAPWA—[www.napwa.org](http://www.napwa.org)) and the CAEAR Coalition ([www.caear.org](http://www.caear.org)), among others, and there are a number of other groups hard at work as well—they ALL need our support. (For further discussion of CARE Act reauthorization, see Robert Cordero's article on the following page.)

Take your pick, but please, pick *someplace* to get connected to these critical efforts in our community to ensure that the Ryan White CARE Act retains its integrity as it is reauthorized for the next five years. What we do—or *don't* do—today will make enormous differences for all of us for a long time to come. ●

## 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@cicatelli.org](mailto:jenny@cicatelli.org)



## THE RYAN WHITE CARE ACT AND BEYOND...

by Robert Cordero

During his State of the Union address in early 2005, President Bush declared support for reauthorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (authorization of legislation expands and creates federal programs). He also pointed out the dire impact of the AIDS epidemic on African Americans. What exactly does all of this mean, considering the CARE Act is due to expire on September 30, 2005? Let's examine the key issues related to the CARE Act, and how this critical public health legislation may change in 2005 and beyond.

Since 1990, the Ryan White CARE Act has been America's most important response to the AIDS epidemic. The CARE Act currently funds treatment and supportive services for individuals living with HIV who lack health insurance and financial resources for their care. CARE Act programs serve approximately 533,000 individuals in the United States and its territories each year (for more detailed information on the Ryan White CARE Act go to <http://hab.hrsa.gov/history.htm>).

### Funding Does Not Keep Pace with the Epidemic

Funding allocated for the CARE Act in fiscal year 2005 was slightly over \$2 billion. Despite increasing caseloads and rising costs of treatment and care, the President and Congress have once again proposed a fiscal year 2006 budget with no increases of any significance for the Ryan White CARE Act, despite the fact that there are now an estimated 100,000 more people living with HIV than there were in 2000. The Centers for Disease Control and Prevention recently revised the estimate of

Americans living with HIV to slightly over 1 million. Health care costs, including the cost of medications, have risen dramatically. AIDS care funding is not keeping pace with the need.

Treatment for people living with AIDS and HIV has changed. With the advent of more effective antiretroviral therapies in the mid-1990s, we all know that many people are living longer. The drugs are not a panacea though, especially for our most vulnerable and poor communities. We know that the epidemic disproportionately impacts women, young gay men and people of color. Other communities, including people living with HIV/AIDS over 50, are growing in number. Rural America and our inner cities are still suffering from lack of access to quality HIV care.

### 2005 CARE Act Must Focus on Treatment Access for all PLWHAs

The Ryan White CARE Act of 1990, as well as the amended CARE Act of 1996 and 2000, attempted to be responsive to the needs of Americans living with HIV for those times in history. Advocates, government officials and elected officials have been working for more than two years on crafting policy recommendations for what the CARE Act of 2005 might look like, given shifts in the epidemic and allocation of resources to areas of highest need around the country. **The CARE Act of 2005 needs to be responsive to these shifts in the epidemic while ensuring that all uninsured and underinsured people with AIDS and HIV have access to life saving medications, treatment and supportive services, whether they live in Jackson, Mississippi or in East New York, Brooklyn.** This issue of access for all PLWHAs wherever they live in the country will be a key reauthorization issue for 2005.

*AIDS care funding is not keeping pace with the need.*

Reauthorization of the CARE Act seems to be a priority for the President and Congress, and advocates wholeheartedly agree. The CARE Act must be reauthorized and fully funded, but we need to begin looking beyond the CARE Act if we really want to end the AIDS epidemic in this country.

### From the Ryan White CARE Act to Ending AIDS

In Washington this year, our elected officials will not only determine the

future of the Ryan White CARE Act, but also Medicaid and Medicare (which fund over half of HIV care for Americans), HIV prevention, Social Security and the Global

AIDS Fund. They're going to make decisions that will determine the future of America's response to the AIDS pandemic above and beyond the Ryan White CARE Act.

Congress needs to demonstrate its seriousness about addressing the AIDS epidemic in this country by swiftly reauthorizing and fully funding the CARE Act, because the CARE Act works. More importantly, government must develop a real plan to end AIDS that includes:

- Fully funding high-quality treatment and support services for all people living with HIV everywhere in the world;
- Ramping up HIV prevention at home and abroad, guided by science rather than ideology;
- Increasing research to find a cure, more effective treatments and better prevention tools;
- Fighting AIDS stigma and protecting the civil rights of all people with HIV and AIDS everywhere.

(continued on page 6)

## MEET THE CAB, GREET THE CAB

This summer, the LTI experienced a tremendous amount of turnover.

A number of our Community Advisory Board (CAB) representatives completed their second two-year term or stepped down due to personal reasons. After an extensive application and selection process, nine new members were selected to represent the different regions of New York State. Outgoing members and new members, along with LTI staff, spent time together in early June getting to know one another and the issues they will face as LTI CAB members. Now that we've had the opportunity to get to know the CAB, we'd like to give our graduates that opportunity as well. We'll be featuring new and old members of the CAB and their answers to our five simple questions in each newsletter.



**Name:** Jack R. Miller (LTI Core graduate—January 2004)

**Region:** New York City Regional Area (Brooklyn)

**Work Affiliation:** Bedford Stuyvesant/Crown Heights HIV Care Network

**Advocacy and Volunteer Involvement:** Peer Mentor 2 years, New York City Planning Council Consumer Committee & PWHA Advisory Group

**Hobbies:** Teddy Bear collecting, map

collecting, refrigerator magnets, and shot-glass collecting. I also enjoy traveling, going to casinos in Atlantic City and Connecticut. I like to relax on the beaches of Riis and Sandy Hook, NJ. I like to party with the NYC MetroBears and indulge in BrotherHood with my Leather Brothers of ONYX NYC M.C. I am still fighting for equality within the current face and fight of HIV/AIDS, and I'm on the battlegrounds with local planning bodies. I am single with hopes to find that soul mate someday again (smiling) LOL...and I enjoy a good novel.



**Name:** Ayo Wells (LTI Core graduate—May 1998)

**Region you represent:** Mid-Hudson region (Orange, Dutchess, Ulster and Sullivan Counties)

**Work Affiliation:** Outreach Resident Counselor for Stephen Saunders Residence for homeless HIV+ adults (Newburgh, NY)

**Advocacy and Volunteer Involvement:** NYSDOH/AIDS Institute Consumer Advisory Committee; Ryan White Title II Care Network PLWHA Advisory Committee

**Hobbies:** I enjoy traveling (so far just the States), and I'm a movie watcher, from old black-and-white to new computer animation; also a music lover, mostly oldies, soul and R&B. I also

enjoy educating about HIV/AIDS policy issues - if you want talk shop just email me at jabari\_12500@yahoo.com



**Name:** Mark Nowak (LTI Core graduate – October 1997)

**Region you represent:** The 8 Counties of Western NY (WNY) - Erie, Niagara, Chatauqua, Cattarrugus, Gennesse, Orleans, Wyoming, Allegany

**Work Affiliation, if any:** None, professional volunteer!

**Advocacy and Volunteer Involvement:** It reads like a phone book, but shows active participation at many levels:

Vice-president of the Executive Board of the AIDS Network of WNY (a Ryan White Title II Care Consortium), 6 yrs; member of PLWHA committee, 9 yrs; chair for PLWHA Survey, 9 yrs; Service Delivery Plan, 5 yrs; National HIV Testing Day, 4 yrs; openly HIV+ member of the Board of Trustees at AIDS Community Services, the largest HIV/AIDS service provider in WNY

**Hobbies:** I am a Disney fanatic, roller coaster junkie, and beach bum. My favorite holiday is Halloween. Without this sounding like a dating service, I do enjoy traveling, theater, fine dining and as much safe sex as possible. (I think that it should fall under the category of hobby...)

## DREAMS

“Aliyah had a dream, Left Eye had a dream...” These lyrics from the rapper Game are profound for me. I have a dream, My dream is in the making... to be a voice and presence to be reckoned with in the battle against AIDS.

Having recently returned from the LTI’s two-day training, “Community Planning,” I am gathering the ammunition needed in this fight. My ammunition is knowledge. The knowledge that I received during this extensive training is power, the power to effect change where it is necessary.

My first training with the PWA LTI took place in April 2001. A friend had suggested that I apply to the Leadership Training Institute, and, not having heard of this before, I began seeking information as well as applying for the Core.

Asking around, I realized that this Cicutelli Associates program was crucial in empowering oneself with knowledge about all of the components that encompass dealing with this disease in a political world. And how to be effective in my community in ensuring that PWA’s special needs are met.

Although some time has passed since my first training in 2001, I am currently a member of the Women’s Prevention Program at AIDS Community Health Center (Rochester). The trainings offered by the PWA LTI have provided me with invaluable knowledge and allow me to now direct and align myself with the various planning councils and advisory groups where my advocacy will be maximized.

Last Friday, the first day after my training, I participated in the AIDS Community Health Center (ACHC)’s HIV testing day. Was I ever amped over this! It is so vital to our existence to ensure that our voices are heard by those individuals who determine our funding.

I realized this during the Community Planning training, with emphasis on the Ryan White CARE Act—without funding for ADAP (New York State’s AIDS Drug Assistance Program), I may not be here.

Having been officially inducted in 1997 into this “Hall of PWAs”, it took a while for me to commit to a pill regimen. The one I’m on now is my second attempt, through no fault of mine: my first regimen that I began in the fall of 2001 failed after about a year, due to some viral mutation difficulties (that is, “resistance”). Last June (2004), I somewhat reluctantly agreed to a combination of Norvir, Reyataz, Efavir and Viread once a day (5 pills) at lunchtime. I am happy to say, so far, so good! Without ADAP to pay for these costly medications it wouldn’t matter about treatment adherence, ‘cause I couldn’t afford these medications on my meager SSD income.

As a black middle-aged (51 year-old) woman who sees the epi-data statistics, it grieves me and saddens me to see just how disproportionately my sisters are being infected, and I’ve prayed to God to help me find my purpose. I don’t know that I would have taken this route on my own, but since I’m here I feel that I must make the best of what some might see as a horrible place— but I say, “Not so!” In the HIV community I have met nicer people than I’ve ever known in my life, and the kindness that has been exhibited to me as well as my passion for outreach are unlike anything that I’ve ever felt before.

As an LTI graduate, I encourage all those PWHA who have not had the opportunity to participate in the courses offered, not to hesitate to sign up. Not only will your own life be changed, you can then help to change the lives of others!

This is my dream...

**LaDawn Williams** ●

## THE RYAN WHITE CARE ACT...

(continued from page 4)

## Get Involved in Putting an End to AIDS

In the spirit of Ryan White - who endured horrible stigma and discrimination because of his HIV status - advocate for the Ryan White CARE Act and beyond. WE HAVE THE TOOLS TO END AIDS. LET’S DEMAND THAT OUR LEADERS USE THEM. Join the Campaign to End AIDS (C2EA), a national grassroots coalition of people living with HIV/AIDS and individuals and organizations united in action to demand a far more urgent response by our government to end the AIDS epidemic at [www.C2EA.org](http://www.C2EA.org) or call 1-877-End-AIDS to get involved. (editor’s note: see Gregory Huang-Cruz’s companion piece about the Campaign to End AIDS on p. 1)

*Robert Cordero is the director of federal advocacy at Housing Works in Washington, DC ([www.housingworks.org](http://www.housingworks.org)), the largest community-based, minority controlled HIV/AIDS agency in the country. He serves as an officer on the board of the CAEAR Coalition ([www.caeear.org](http://www.caeear.org)), which advocates for Title I, Title II/ADAP and Title III of the CARE Act and he is also actively involved in the Campaign to End AIDS. ●*

**N**ow, 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](http://www.ccsnys.org/rwnet)  
**Email:** [jfarnham@ccsnys.org](mailto:jfarnham@ccsnys.org)

**Bedford Stuyvesant/Crown Heights HIV Care Network**

**EVE AMMONS-JOHNSON, COORDINATOR**

**Tel:** 718-622-8184, ext 101  
**Email:** [eve117@ptd.net](mailto:eve117@ptd.net)

**Binghamton Tri-County Region HIV Care Network**

**SANDRA KOSTY**

**Tel:** 607-778-3066  
**Email:** [skosty@co.broome.ny.us](mailto:skosty@co.broome.ny.us)  
**Web:** [gobroomecounty.com](http://gobroomecounty.com)

**Bronx HIV Care Network**

**SOCRATES CABA**

**Tel:** 718-231-3598  
**Email:** [scaba@montefiore.org](mailto:scaba@montefiore.org)

**Buffalo Region HIV Care Network**

**ANDREW KIENER**

**Tel:** 716-882-7840  
**Email:** [aidsnet@pce.net](mailto:aidsnet@pce.net)  
**Web:** [www.aidsnetwork.net](http://www.aidsnetwork.net)

**Central Harlem HIV Care Network**

**LEATRICE WACTOR**

**Tel:** 212-926-8000, ext. 15  
**Email:** [lwactor@hdg.org](mailto:lwactor@hdg.org)

**East Harlem HIV Care Network**

**JOSE MARTIN GARCIA ORDUNA**

**Tel:** 212-828-6143  
**Email:** [jorduna@unionsett.org](mailto:jorduna@unionsett.org)  
**Website:** [www.aidsnyc.org/network](http://www.aidsnyc.org/network)

**East New York Brownsville HIV Care Network**

**GWENDOLYN EDWARDS**

**Tel:** 718-907-3726, ext. 3725  
**Email:** [enybhcn@aol.com](mailto:enybhcn@aol.com)

**Lower Hudson Region HIV Care Network**

**KELLI EVERETT**

**Tel:** 914-428-2114, ext. 230  
**Email:** [ulwswd@aol.com](mailto:ulwswd@aol.com)

**Mid-Hudson Region HIV Care Network**

**ELLEN WAZ**

**Tel:** 845-563-8058  
**Email:** [ellenwaz@msn.com](mailto:ellenwaz@msn.com)  
**Web:** [www.mid-hudsonhivcare.org](http://www.mid-hudsonhivcare.org)

**Nassau Suffolk Region HIV Care Network**

**DEBRA ROSS**

**Tel:** 631-940-3700, ext.6480  
**Email:** [dross@unitedwayLL.org](mailto:dross@unitedwayLL.org)

**Queens HIV Care Network**

**MARITZA VILLACIS**

**Tel:** 718-389-5100, ext. 188

**Rochester Region HIV Care Network**

**LYNN VARRICCHIO**

**Tel:** 585-461-3520, ext. 106  
**Email:** [lynn@flhsa.org](mailto:lynn@flhsa.org)

**Staten Island HIV Care Network**

**REBECCA ORTIZ**

**Tel:** 718-448-8789  
**Email:** [rebecca.ortiz@siatf.org](mailto:rebecca.ortiz@siatf.org)  
**Website:** <http://community.silive.com/cc/hivcarenet>

**Syracuse Region HIV Care Network**

**STEVE WALDRON, Ph.D.**

**Tel:** 315-472-8099, ext. 105  
**Email:** [sewaldron@cnyhsa.com](mailto:sewaldron@cnyhsa.com)

**Williamsburg/Greenpoint/Bushwick HIV Care Network**

**SHAILA LOPEZ**

**Tel:** 718-455-6010, ext. 138  
**Email:** [mysticshai@aol.com](mailto:mysticshai@aol.com)

**ALL TRAINED UP AND NOWHERE TO GO?**

**T**here 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](http://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](mailto:dohmhppg@health.nyc.gov)

## RECRUIT PLWHA PARTICIPATION —WE NEED THEM

by Ayo Wells with support and input from Emily Boardman & Rena M. Meyer (This article is a follow-up to “You’ve Gotta Believe,” published in The Circle issue No. 11 in the Spring of 2004)

“The journey of a thousand miles always begins with one step...” And sometimes, that one step seems like a thousand miles in and of itself...

When the four of us—Charles Gant, Ayo, Emily and Rena—first approached the HIV Care Network Steering Committee about developing an orientation process for new PLWHA members, we did not know what it would look like. What we did know was that we needed a tool we could use to educate them about the Ryan White CARE Act and our network, and to help them navigate the services in the Mid-Hudson area (Dutchess, Orange, Ulster and Sullivan counties).

So we started.

- We made a list of all of the information we wanted consumers to know about the Ryan White CARE Act and why they were important to the agencies that they were receiving services from.
- We reviewed the Ryan White CARE Act Manuals for Titles I and II, and we went to the CARE Act website: <http://hab.hrsa.gov/CATIE> and looked under “TA Topics: Consumer Involvement.”
- We made a list of all Consumer Advisory Boards and Support Groups as well as advisory groups for both the Ryan White Title I Planning Council & Title II, Consortia (HIV Care Network). The list had the names of agencies, their telephone numbers and a contact person at each one.
- We put this together into a PowerPoint presentation called “We Need Them—A Plan to Recruit PLWHA Participation.”
- We first introduced this new PowerPoint presentation to consumers at an LTI Core training held in Poughkeepsie, NY, and we had

consumers sign up who wanted to get involved.

To our amazement, we had twelve consumers show up at the next Ryan White Title II General Network meeting -- AND they were ready to learn and work!

As time went on, together we learned that a great beginning wasn’t enough. Continued efforts were needed to sustain the involvement.

- We decided that each new consumer would have a Buddy from the agency or county they were from. A Buddy is simply a person who is familiar with the consumer and the group they’re joining. We made some recommendations for the Buddy, like meet with the new person three times, tell them what is going on in the meeting process, answer any questions, and tell them of all the ways they could get involved.
- We developed a Membership Application. We had one for the Steering Committee but not for General Network. This was not hard. We copied it from the Ryan White Manual’s “Membership Commitment Statement” and application, and we adjusted it to our own network’s requirements. We even came up with a network slogan, “Be a Part of the Solution.”
- The chair of PLWHA Advisory Group, Ayo, and the Coordinator, Anita, developed a brochure for our Network that included descriptions of all Network committees, including their mission statements, organizational structures and contact information. The brochure first debuted on National HIV Testing Day, 2004.
- We looked for what we wanted to include in the Orientation packet with the help of John Hatchett (the Project Director of the PWA LTI) and Chuck Lobosco (our grant manager for the AIDS Institute). We included paperwork like “Roles and Responsibilities”, “The Denver Principles” and descriptions of the Ryan White Care Act Titles I and II.
- We did two more test runs with our Network members and the Orientation packet. At the PLWHA Committee

meeting with consumers, and at the General Network meeting with providers, we invited them to ask any and all questions about the groups’ purposes or processes. After working through the orientation, consumers seemed to have a better understanding of the work they had in front of them, and providers seemed to be more willing to work with consumers that they knew were empowered. The meetings were successful!

So after a year of continuous work we finally have it all: a Power Point presentation, a Buddy Program, a General Network Membership Application, our Network Brochure, a new Network Slogan and a General Network Orientation Packet. These tools have certainly made a difference, but that’s not to say it’s all smooth sailing.

Some of the challenges we have faced and continue to face are as follows:

- Charles Gant’s death (2-15-04) still hurts deeply. He was a friend and a hard-working and dedicated member of this team.
- The Ryan White Title II Network Coordinator changed at least three times during this process.
- Transportation for consumers to attend Network meetings is an issue for our area.
- Finding committed Buddies who understand their role is often difficult.
- Staying focused and making time with lives and jobs constantly changing made it hard for us to work toward our goal, but Ayo as PLWHA Co-Chair kept bringing the group back to focus. (Emily and Rena add: Thank you Ayo for this effort. It wouldn’t have happened without you.)

The process is complete, but it must be sustained with each new consumer who joins us. We continue to face challenges, but it has been worth the effort. If you are looking to do something similar in your area, you have some friends to lean on for suggestions and support! Just call us at 845-563-8059. ●