

Survival



## SURVIVING AND THRIVING

by John Hatchett

As we prepare this issue of *The Circle*, some signs of spring are beginning to surface. No, I don't mean the weather—winter seems determined to get its full due this year. The signs I'm referring to are activities in the HIV advocacy community, which is gearing up for a strong push around reauthorization of the Ryan White CARE Act (RWCA). Between now and this fall, Congress will decide not *if* to reauthorize the CARE Act, but *how* it will look when it's reauthorized. For many of us, it's enough to know that no one seriously expects the Act not to be reauthorized, and we feel like delving into the details is not worth the sometimes considerable effort it takes to understand them. As long as the Act won't be done away with completely, we assume things will be ok. But as with many things in life, the devil is in the details.

Every time reauthorization comes around (in 1996 and 2000, and again this year) Congress has the opportuni-

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## RECOMMENDATIONS TO GUIDE REAUTHORIZATION OF THE CARE ACT

### Executive Summary

The National Alliance of State and Territorial AIDS Directors (NASTAD) strongly supports the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act—a critical component in the nation's HIV/AIDS prevention, education, and treatment efforts. The CARE Act is a federal-state partnership to provide comprehensive care and treatment to low income, uninsured and underinsured people living with HIV/AIDS.

State and territorial HIV/AIDS programs administer the Title II programs of the CARE Act, including the state AIDS Drug Assistance Program (ADAP). Title II provides funds to all states, the District of Columbia, Puerto Rico, the Virgin Islands and U.S. Territories to improve the quality, availability and organization of care services for people living with HIV.

Title II is designed to assure that people living with HIV have access to quality HIV care, regardless of whether they live in rural, suburban or urban areas. \$1.1 billion in federal funds were appropriated to Title II in FY2005, including \$797 million in dedicated funds for ADAP. In 2004, over 136,000 individuals received ADAP services.

There continue to be low-income persons living with HIV/AIDS that are unable to access Title II services due to funding limitations of the program. NASTAD supports full funding for the CARE Act to ensure that all low-income HIV-positive individuals have access to primary care, life-saving therapy, and support services that are

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credits

## CARE ACT

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essential to keeping persons in care and adherent to their treatment regimen. NASTAD supports the inclusion of an authorizing level for Title II that addresses these unmet needs, at a minimum of \$1.4 billion for FY2006.

NASTAD has extensively examined the effectiveness of the CARE Act over the past two years. Further, NASTAD has developed five structural and financing proposals and 30 issue-specific profiles, which inform this position paper.

NASTAD supports the existing structure of the law. NASTAD has two major financing proposals to provide additional resources to states in need—one through the ADAP Supplemental Grants and one through the Title II Base Emerging Communities Supplemental Grants.

NASTAD has identified six major themes that should frame the 2005 CARE Act Reauthorization. They include: strengthening state program capacity; maintaining program infrastructure; CARE Act simplification and flexibility; enhancing state's ability to coordinate HIV/AIDS health systems; CARE Act mandates; and CARE Act accountability.

The number of people living with HIV/AIDS is growing, therefore, increasing the number of individuals expected to be served by CARE Act programs. The epidemic continues to grow disproportionately among people of color, women and young people. State AIDS directors believe that we need to reexamine our programs and our approaches to ensure that the CARE Act provides funding in an equitable manner to assure that individuals throughout the United States, regardless of state or jurisdiction of residence, have access to

*The National Alliance of State and Territorial AIDS Directors (NASTAD) represents the nation's chief state health agency staff who have programmatic responsibility for administering AIDS health care, prevention, education and supportive service programs funded by state and federal governments. NASTAD is dedicated to reducing the incidence of HIV infection in the United States and territories, providing comprehensive, compassionate, and quality care to all persons living with HIV/AIDS, and the development of responsible and compassionate public policies.*

*This article presents excerpts from NASTAD's recently released document, "Recommendations to Guide Reauthorization of the CARE Act", the full version of which can be found on NASTAD's web site at <http://www.nastad.org/>*

comprehensive HIV/AIDS health and medical care of the highest quality.

### Overview

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has had a tremendous impact on the lives of people with HIV/AIDS throughout the nation, improving the availability and quality of health care services for these individuals and their families. As the largest federal program for people living with HIV/AIDS, the CARE Act is an essential source of support for HIV/AIDS care and treatment services. As NASTAD's Principles for Reauthorization state, assuring that all persons with HIV/AIDS, regardless of geographic location, have equal access to appropriate and high-quality HIV/AIDS services is our highest priority.

Disparities in the availability of resources affect the accessibility and quality of HIV services, both within and between states. NASTAD recognizes that the structure of the Ryan White CARE Act contributes to the challenges faced by some states in effectively addressing the needs of persons living with HIV/AIDS. In many states, the current structure is a contributing factor to funding disparities that affects availability, accessibility and quality of services, both within and between states, as well as the coordination of HIV care

and the efficient delivery of essential services. While the Ryan White CARE Act cannot be viewed as the sole mechanism for equalizing these inherent differences, the current structure of the CARE Act leaves many states struggling with the delivery and coordination of HIV services, while trying to meet legislative mandates to provide for the public health of citizens within their respective jurisdictions.

NASTAD recognizes that alternative proposals for serving persons living with HIV/AIDS have been developed, including the Institute of Medicine's report *Securing the Legacy of Ryan White*. This report attempts to respond to these challenges. These proposals are worthy of and warrant further study, consideration and discussion.

At this time, NASTAD recommends retaining the current structure of the CARE Act. It does so while establishing the following two goals which are reflective of NASTAD's vision for improved HIV care services in the nation: (1) to enhance the availability of ADAP resources and services for persons living with HIV/AIDS in need in all areas of the nation, and (2) to address inequities in per-capita overall CARE Act funding among states.

NASTAD strongly supports further discussion and study of the structure of the CARE Act, and reserves the right

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to make recommendations regarding changing the structure of the Act in pursuit of improved HIV care services for all persons living with HIV disease. The Ryan White CARE Act must strive to provide funding in an equitable manner to assure that individuals throughout the United States, regardless of state or jurisdiction of residence, have access to comprehensive HIV health and medical care of the highest quality.

### Principles for Reauthorization

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was originally signed into law on August 18, 1990 as a federal program designed to improve the quality and availability of care for persons with HIV/AIDS and their families. The Act was subsequently amended and reauthorized in 1996 and again in 2000. The current Act is scheduled to expire and requires reauthorization at the end of September 2005. The CARE Act reaches over 500,000 individuals each year, making it the federal government's largest program specifically for people living with HIV disease.

Like many health problems, HIV disease disproportionately strikes people in poverty, racial/ethnic populations, and others who are underserved by healthcare and prevention systems. CARE Act funded programs are the "payer of last resort." They fill gaps in care not covered by other resources. The most likely users of CARE Act services include low income, uninsured or underinsured individuals who have no other source of healthcare. In order to fill these gaps in care while maximizing limited available CARE Act resources, states are entrusted with ensuring collaboration among other

CARE Act grantees and programs within the state to reduce duplication of services. States are the only CARE Act grantees that have this legal responsibility within the United States public health system to ensure the delivery of effective public health programs in their respective jurisdictions. The role of states, therefore, is unique among CARE Act grantees and must be affirmed in CARE Act legislation to reflect this responsibility.

Scheduled reauthorization of the CARE Act presents NASTAD and its member states and jurisdictions a timely opportunity to re-evaluate the extent to which the goals and objectives of the CARE Act continue to be met. The goal in 2005, as it was in 1990, is to assure all persons living with HIV/AIDS equitable access to state-of-the-art care and treatment by eliminating barriers to care imposed by income, age, race, ethnicity, place of residence, or gender and sexual orientation. The epidemic today can be characterized somewhat differently than the epidemic 20 years ago. Today's infected population is more likely to include persons of color, women, and youth. The U.S. Centers for Disease Control and Prevention (CDC) estimates that over 40,000 new HIV infections occur each year; of these new infections, over half are among persons from communities of color, about 70% are among men and 30% are among women. Between 1985 and 2003, the proportion of adult/adolescents AIDS cases reported in the U.S. among women increased from 8-27%. Furthermore, in February of 2005, 592 persons were on waiting lists for the AIDS Drug Assistance Program (ADAP), a figure which will likely continue to increase as funding levels fall behind demand and need for the program. Those in need should

not have to wait for medical care or medications. Access to medications, as well as to other essential health care and supportive services, varies from one state to another throughout the nation.

Ongoing principles for CARE Act programs include:

- Assuring that all persons with HIV/AIDS have access to appropriate and high-quality health, medical care, and other related and required support services.
- Coordinating CARE Act services with other health care delivery systems, thus ensuring that available resources are expended in a manner such that efficiency, effectiveness, and accountability are optimized, both within the CARE Act and across other delivery systems.
- Revising care systems as needed to meet emerging needs.
- Evaluating the impact of CARE Act funds and making improvements as needed.

These principles must guide current reevaluation in light of the changes noted. Evaluation is particularly pertinent in the face of fiscal constraints in states throughout the nation that relate to medical assistance programs and the ability of the states to provide care and services for populations at risk. For those who have no other source of or access to health care, the role and responsibility of CARE Act programs is paramount.

NASTAD proposes that the CARE Act be evaluated in a manner that seeks to achieve the following goals and objectives through subsequent proposals for change:

- Assure equitable access to state of the art care and treatment for all persons with HIV/AIDS.

## JOSE MEDELLIN INTERVIEW

by Gregory Huang-Cruz

Jose Maria Medellin. Now there's a name that sounds like a discoverer of continents, perhaps a great political figure, maybe even the creator of Spanish culinary delights like paella. But as Jose himself puts it, "My name has been passed down through generations from my great-grandfather to my grandfather, to my father, myself and all the way down to my nephew." It's been in his family for generations. The "Maria" in his name comes from his mother, thereby maintaining a family tradition held in Spanish-speaking families for centuries.

For Jose the tradition of continuing a family legacy by the handing down of your name is significant. Because of this Jose, an LTI graduate, contributed an article entitled "My Journey of Transformation: Reflections on Vision Impairment Caused by HIV" in Body Positive's monthly magazine in February 2003. In that self-written article, Jose spoke eloquently of the day blindness set in, no longer being able to see life as he enjoyed it and the challenges he encountered in order to advocate for himself.

In that article Jose writes: "*Autumn was setting in and a last visual impression—my blurred reflection on the glass doors—was engraved in my mind. Like me, other patients sat in the waiting room of the HIV clinic. Isolated voices around me made conversation with a neighbor, but most of us pensively waited our turn.*"

As I sat down and began my interview with him, the first thing I noticed was his easy confidence and striking good looks. Then, as I started to ask some initial questions, something profound happened. He looked at me as though

he could see me and remarked, "I call myself blind; being visually blind is very challenging. I only see darkness. The challenge for me is to show people, to persuade them, that it is not a big deal to be blind and challenged. I don't need to define myself. I think that blindness happened to me for a reason. Reinventing has become a process for me, sort of an evolution." Indeed, Jose's experience is a strong reminder of the power each of us has to reinvent ourselves, to continue evolving, whatever twists and turns our paths may take.

I opened my interview with Jose by referring to a line he wrote in "My Journey..." which said, "*Although sunsets occurred for me at four in those days, too early for any New York City season, I secretly hoped to regain healthy eyesight. It was not to happen. Soon I would be totally blind.*"

With that I paused briefly, sighed and asked, "Can we just talk, have a conversation, that sort of interview"? He laughed, then smiled and looked at me and said, "Go ahead". Here are some highlights of that very enjoyable conversation:

**Question:** "So, what was it like writing that article for Body Positive?"

**Jose:** "There were some challenges, basically I wanted to find a partner and secondly I wanted to get a job."

**Question:** "And how is the job hunting going?"

**Jose:** "In my search for jobs, I have found HIV/AIDS agencies have been very discouraging in that they are not willing to employ me because of my impairment. But, they want me to volunteer my services, especially around development."

For Jose, self-advocating for a job, even with a Masters Degree in Hospitality from the University of Houston in Texas, drew repeated comments on volunteer opportunities, but no job offers.

**Question:** "How else are you self-advocating and further preparing for a possible career offer?"

**Jose:** "I am participating in a 10 week study at CUNY in which I am learning Braille. And I have until recently volunteered as a Board member at God's Love We Deliver."

At the moment his community advocacy work is in transition, due to his current focus on employment. Jose also says that his medications can sometimes hinder him; on certain days the side effects can limit his energy and mobility. But he believes strongly that involvement in advocacy is for the good of *everyone*—the whole community—not just for himself or people with visual impairments. He also believes that everyone should get involved in community work at some level. Once his work life settles in somewhat, Jose would like to do more advocacy around the state as well as at the national level.

In his spare time his daily regimen continues to include yoga, going to the gym, watching his nutrition and generally keeping healthy. And with that smile he ends by saying, "I am always in a state of self-advocating, and appreciate it when others advocate for me."

**Question:** You wrote, "*In April 1994, after just turning 32, moving to 'The City'—as Manhattanites dub their river-bound isle—my life seemed packed with myriad opportunities.*" So, how much of that has changed, or has it?

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**JOSE MEDELLIN INTERVIEW**

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**Jose:** “While some opportunities, like finding a boyfriend, have become somewhat limiting, and finding my dream job more difficult, I have found ways to build my skills and use updated technology to help me function routinely.” In fact, listening to Jose describe his activities of the last several years, it’s hard to imagine him “limited” in any way other than by the challenges of managing the often conflicting goals of full-time employment and maintaining his involvement in community work.

Thanking Jose for his time, I returned and listened to our taped conversation and reflected on his remarks about his family name and tradition. In the world of HIV/AIDS, one can see, as Jose puts it, a life full of “myriad opportunities.” Among these opportunities, as he sees it, is the ability to self-advocate, to become empowered, and to develop skills for self-sufficiency.

In “My Journey...” Jose wrote, *“What is important is the awareness of my power to create my reality. I realized the importance of being self-sufficient. I would also acquire skills and engage in activities ranging from the basic to the complex.”*

All I can add to that is, “Way to go, Jose Maria Medellin!” A new tradition begins...

*Note: If you would like to exercise or develop your advocacy skills, refer to page 7 of this newsletter for some available opportunities in your area.* ●

**SURVIVING & THRIVING**

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ty to make changes—changes to what services RWCA funds may be used to pay for, to rules governing how various grantees plan, allocate and evaluate the use of their awards, as well as changes to the formulas used to calculate award amounts for cities and counties (Title I) and for the states and territories (Title II). It’s not enough that we let our representatives know that we want them to support reauthorization; that’s not the tricky part. We need to let them know how RWCA funded programs allow many of us to access essential care and how essential support services enable us to stay in care. We need to make sure they understand that RWCA planning processes at every level are strengthened and enhanced by meaningful representation and participation of PWHA. And those are just two items on a much longer list.

As the season begins to unfold, advocacy groups representing a wide range of interests and perspectives are beginning to release various documents—statements, recommendations, sets of principles—that articulate each group’s priorities and concerns in the reauthorization process. In our last issue we featured an overview of the epidemic in the United States released jointly by the CAEAR

Coalition and AIDS Action, but that is only a piece of those groups’ full statements on the CARE Act. (Once again, the full statements can be found on the organizations’ web sites: <http://www.caear.org> or [http://www.aidsaction.org/.](http://www.aidsaction.org/)) We also distributed a survey that the National Association of People With AIDS (NAPWA) is using to refine its own position statements on the CARE Act (there’s still time to complete and return the survey, but hurry!).

In this issue we offer a summary of recommendations from NASTAD, the National Association of State and Territorial AIDS Directors, which is comprised of the individuals and offices charged with coordinating HIV/AIDS programs in every state and U.S. territory. NASTAD’s focus is understandably Title II of the Act, the title that provides the funds for which its members are responsible. In the summer issue of The Circle we will highlight positions from groups that focus on other parts of the CARE Act.

Yes, it’s a lot of information to get through, but RWCA reauthorization is like a complicated machine, with lots of moving parts, and knowing what advocacy groups have to say about it can help us really understand just what all the fuss is about—the devil in the details.

See you in training! ●

**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)



## MY STORY: ACTIVIST, PERFORMER & MOTHER LOVE

by *Kim Watson*

During my journey in life, I've learned the most important thing for me is helping the minority community deal with discrimination and barriers to their health. I've learned that a person needs to own their identity and experiences, but that what is really important is to own it and then give it back to the community.

I was raised in three very different communities. My youth was divided between Barbados, Massachusetts and London. As a result, I think I have a unique understanding of culture and the role it plays in people's lives.

Within each culture, I've learned there can be a big difference between a policy and an issue. Policies are usually created *for* a particular culture, but issues come *from* a particular culture.

For me, an issue is something that comes from me, my beliefs, my opinions. But I sometimes have to go along with policies that are set by the city, the state or the country's government.

I know about this because of things I've experienced in my life. I found out I was HIV-positive in 1987. I'm an ex-offender; I've been homeless. As an African-American transgender woman, I've learned a lot about the places where issues and policies come face-to-face.

A real turning point in my understanding of this came when I went through the Exponents/Arrive training program (Cycle 56) in August through October of 1999. This experience helped me deal with my HIV status and learn how to relate effectively in the community with people who were either positive or negative.

I continued on this path as a client at Greyston Foundation and eventually

became a stipend worker for the intake and outreach department. It was here that I was introduced to the PWA Leadership Training Institute (LTI) and the possibility of doing the Core.

The Core was important to me because it helped me bring my trust wall down. I was able to open up to special people that I met there who have similar health issues to me. In fact there was a very special person I met there (Marcus), who continues to be a very important part of my life.

Basically the LTI Core training was like a pathway to a new adventure for me! Instead of keeping knowledge to myself, I wanted to share it by involving myself in doing outreach. I began to think that it was really important to talk to people who were still in the closet about their HIV status. I hoped it would mean something to them to talk to someone like me who is African American, born a genetic male and now living as a female. When I share with the community, it teaches me about myself and helps me deal with my own dark secrets, particularly understanding my "self," my mind, body and soul. And most definitely there are not too many African American trans women being role models, especially around HIV-related issues.

The PWA LTI helped me examine some of the discrimination and barriers that transgender folks deal with all the time, in the context of HIV/AIDS. The LTI helped me come to terms with that, to then help others do the same. I consider myself a mentor now.

I'd like to acknowledge a mentor of mine, Samuel Lurie, whose HIV Accessing Care syllabus had a big impact on me and which I've adapted for use with trans folk in the in-house sensitivity trainings I've run at Community HealthCare Network.

Currently, I attend support groups to relate to other people in the community. I have got back into the employment force. I work at Community HealthCare Network, in their Transgender Program, which is part of their primary care program, looking at hormone replacement therapy and other issues important to African American and Latino transgender people.

I just completed my final course with the LTI, having finished all the currently available advanced trainings! As I look back over the time since I took the Core, I've realized how much important work I've done. I've been a volunteer outreach worker for Harlem United and sit on their Community Advisory Board; I have led quit-smoking groups at the Lesbian, Gay, Bisexual & Transgender Community Center and Trans Kick Ash groups at the Bronx Lesbian & Gay Health Resource Consortium. I'm also a voting member of the New York State Prevention Planning Group.

Additionally, I've performed in many Gay Pride Month celebrations benefiting community-based organizations and recently took part in a gospel performance for a church in Harlem! Perhaps the achievement recently that I am most proud of was traveling to Tacoma, Washington to deliver a presentation on my anti-tobacco work in smoke-free Pierce County! I know that smoking is bad for everyone but particularly dangerous for people living with HIV!

If I had to sum up the change in me over the years—that the PWA LTI has been a large part of—I would have to say that I live my life now as a resource for other people.

Just call me Mother Love! ●

**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

##### JUDITH BUTLER MCPHIEZ

**Tel:** 212-926-8000, ext. 15

#### 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:** [enybhcnaol@aol.com](mailto:enybhcnaol@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

##### ANITA WYATT

**Tel:** 845-563-8058  
**Email:** [anita8059@hotmail.com](mailto:anita8059@hotmail.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

##### RICHARD FERREIRA

**Tel:** 718-455-6010, ext. 138  
**Email:** [referreira@earthlink.com](mailto:referreira@earthlink.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: Wendy Shotsky

#### 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)

## THE LEADERSHIP TRAINING INSTITUTE

The value and importance of seeking knowledge and education revolving around HIV/AIDS is immeasurable. As the disease continues to run rampant in many sectors of the country and the world, miseducation, ignorance, and lack of information are to blame. Cicatelli Associates' PWA Leadership Training Institute provides individuals living with HIV and AIDS a purpose, a vision, and an education. The trainings have had an impact on me, helping me not only personally, but also allowing me to apply my experiences in my work as a Fundamental Education and Outreach Specialist.

The initial process began with Core training. Undoubtedly the most meaningful, purposeful, and powerful training given by the LTI, the Core gets the ball rolling. Through lectures, activities, and the sharing of personal experiences, members left the training with a new sense of identity and empowerment. My expectations were more than surpassed by the trainers. A fire of dedication was built, lit, and then spread within each of us. The journey had begun.

Interestingly enough, I was given a great gift... the gift of rebirth and life. In that, I mean I was learning things I never knew I never knew! After the completion of the trainings, I am able to apply and communicate what I have learned directly to my community. As a Fundamental Education and Outreach Specialist, I am required to provide services in the areas of education, empowerment, intervention, prevention and outreach. These tasks can sometimes prove to be impossible, for various reasons. But after the Core my sense of dedication and commitment was elevated to the extreme. I found that educating, engaging, and empowering the community wasn't as difficult as it had been previously. The results have improved, and my efforts are further noticed and commended. The interactions I have now are more in-depth and engaging, and serve a better purpose. My resources and networking capabilities have increased, and make it possible to interact with other communities in surrounding areas. I am making a difference.

On the personal level, I have gained confidence. The stigmas that I had placed on the issue were broken down, diminished, and removed from thought. Life in general has improved, and living is so much easier. My social, personal, and professional relationships are stronger, and I have built bridges that may not have been built otherwise. I find myself more focused and working harder to achieve success. The Leadership Training Institute re-instilled the drive and determination that was ripped from my fingers upon diagnosis.

As we search for a cure and research this epidemic, active consumer involvement is a necessity. Taking a stand, placing a face, and making a voice for all PLWHAs is not only a right - it is our obligation. One person can and does make a difference. Your voice, no matter how soft, must be heard. Growing up, we are taught that life is about choices. The choice is yours.

~ J.M. Angelo King, Fundamental Education and Outreach Specialist,  
Shades of PRIDE, Syracuse, PLWH ●

## CARE ACT

(continued from page 3)

- Assure that all individuals, regardless of income, racial or ethnic group, age, gender and sexual orientation, or place of residence have equitable access to care.
- Ensure that the role of the states is emphasized, and is meaningful and enforceable. As the only CARE Act grantees that have legal authority within the United States public health system to ensure the delivery of effective and coordinated public health programs in their respective jurisdictions, the role of states is important and unique to other grantees.
- Ensure coordination of all publicly financed health and medical care programs, including CARE Act programs, Medicare, Medicaid, Veterans Administration programs, State Children's Health Insurance Programs (SCHIP) and state Pharmacy Assistance Programs, as well as other federal, state and local programs.
- Maximize simplicity, minimize administrative requirements, and maintain maximum state flexibility in program design and implementation.
- Ensure little to no disruption in service delivery or major changes to infrastructure that impact service delivery.
- Emphasize the federal government's role and responsibility in assuring equitable access to care while incorporating, where possible, mechanisms to maximize utilization of state resources.

These goals and ongoing principles have guided the direction for all reauthorization analyses and NASTAD's subsequent program recommendations. ●