

SURVIVING & THRIVING

by John Hatchett

Welcome back to *The Circle*, and to a new year of trainings, information gathering and networking with the LTI! This winter



has seemed colder and snowier than most recent years (at least for us here in New York City, at whom the upstate folks tend to smile and nod indulgently as if to say, "Yeah, yeah, and you call that snow?"). There's been some limited heat provided by celebrity scandals and the Democratic party primaries, but most of us have our attention focused on concerns for the HIV community itself: CDC's Prevention for Positives initiative, the alarming and growing number of states with waiting lists for their ADAP programs and on down the list. Our involvement as people living with HIV in any and all of these issues is needed now more than ever before.

In this issue of *The Circle*, LTI CAB member Julian Bain writes about his return to South Africa last summer, and LTI grads Charles Gant (please see In memoriam, p. 6) and Ayo Wells describe some things their region is doing to increase PWHA training and participation in its Ryan White Care Network. We've listed some conferences coming up in the year ahead that we thought LTI grads would be interested in. (Note: if you want program and/or scholarship information about any of these, please contact the sponsoring organizations directly. The LTI has no connection with any of these conferences.)

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"YOU'VE GOTTA BELIEVE"

by Charles Gant, Ayo Wells, Rena Meyer and Emily Boardman

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. Several years ago, the PLWH/A and Community Awareness Committees of the Mid-Hudson Title II HIV Care Network held a meeting regarding an issue which troubled us and seemed to be a barrier throughout many other regions both in our area and throughout the nation.

The issue was how best to recruit and retain consumers who are willing to participate in the process of having their voices heard and their opinions counted. We had tried many methods in the past and realized that everyone did not have the same degree of commitment nor was their stake in the game the same.

The committees reached an agreement that this void needed to be filled to obtain success in working within the framework of our mission statement, and in fulfilling the task which had been charged to us. We needed to create a formal membership orientation and process to guide consumers through the Ryan White CARE Act titles. The purpose would be to increase knowledge of the Care Act titles, explain their various dynamics and be familiar with the functions of all titles. We also realized the importance of knowing the various planning groups and bodies where we as consumers could participate on many different levels. We recognized that a formal process would help eliminate a number of the obstacles we were encountering: it would help to maintain involvement, in turn creating

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LTI Community Advisory Board

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SOUTH AFRICA – 2003

by Julian Bain

BACKGROUND

I'd like to begin with some sobering estimates and projections from the U.S. Centers for Disease Control regarding HIV/AIDS in South Africa:

- ▶ South Africa has more HIV-positive individuals than any other country in the world - 4.8 million.
- ▶ Each day 1,600 people are newly infected; two-thirds of them aged 15 to 20.
- ▶ As of 1999, one-quarter of a million people had died from AIDS in South Africa; by 2015 AIDS-related deaths will be 4.4 million.
- ▶ In 1998 South Africa had approximately 100,000 AIDS orphans; by 2008, 1.6 million children will have been orphaned by AIDS.

When I first visited Cape Town last year, I was, of course, struck by the natural beauty of the land and of the people. I also saw first-hand how HIV/AIDS is devastating South Africa, affecting the whole society now and for many years to come. Orphans and street children are everywhere in great numbers and key sectors that are critical to an effective national response to the pandemic are being undermined as farmers, health care workers and teachers die at alarming rates. The Medical Research Council found that 85% of the AIDS-related deaths occur to individuals between the ages of 20 and 40, leaving households without breadwinners and without parents. I have read reports stating that more than 50% of the teachers are HIV+.

I also observed many of the social forces contributing to the difficulty of addressing the pandemic in South Africa: the residue of apartheid, male dominance, lack of education and high unemploy-



ment. Last year I discovered that while the policy of apartheid officially ended in 1994, the residue of apartheid remains. Blacks, "Coloreds" (under apartheid, anyone not designated "black" or "white") and Whites were taught to distrust each other. They still live in separate communities and don't mix readily. Many Blacks and Coloreds have been unwilling to accept either prevention or treatment information, which they see as coming from the White establishment. In addition to racism and segregation, South Africans deal with sexism. South Africa is a male-dominated culture. Women don't have the right to say "no" or to insist their partner use a condom. Thus, they are often unable to protect themselves from being infected with the virus – even when they have the necessary information. When coupled with a woman's biological susceptibility to the virus, this accounts for the fact that HIV/AIDS among women in South Africa is growing at an alarming rate. Finally, visiting many townships, I discovered a lack of formal education, high unemployment, crime and violence – all contributing to the spread of the virus.

Against this backdrop, I returned to Cape Town in August 2003 to do prevention education at elementary and high schools during the African HIV/AIDS Education Week.

SOUTH AFRICAN QUILT – SCHOOL TOUR – 2003

The school tour began with several days of orientation and mandatory training. Two teams were formed, each consisting of a social worker, a psychologist, and two PWAs (one American and one African). Both teams visited two schools each day. At each school we spoke to assemblies of 200-300 and then several smaller classes. The prevention message is South Africa is strictly "ABC – Abstinence, Be faithful and use Condoms." I talked with the students about confidentiality, compassion for others, stigma and shame. I told the children testing was a "Positive-Positive," encouraging them to do so. I also encouraged the children to establish peer groups to continue to spread the prevention message.

I am pleased to report our team was very well received, particularly myself as a Black American living with the virus. I was delighted that many students remembered me from my visit last year. Others had never met an African-American before and meeting me was an education in itself. I was deeply honored when a group of students presented me with a "Living Quilt" that had my name on it, along with the names of the others on our team. I treasure this gift and their lives - and will display this quilt at my presentations.

VIDEO INTERVIEWS AND PROFILES

This year, in addition to the School Tour, I interviewed and video-profiled several individuals representing organizations:

Carol Jacobs, South African Quilt
Founder of the South African Quilt in 1989 and Director of the Western Cape AIDS Training Information and Counseling Center, Carol Jacobs is a powerfully insightful visionary. She trains administrators throughout the provinces.

SOUTH AFRICA

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Ryan Dalton, Beautiful Gate

A 21-year old White American, Ryan is from Tennessee and has been an outreach social worker with Beautiful Gate’s Street Children’s Project for 4 years (starting as a missionary).

Beautiful Gate Ministries is an international and inter-denominational Christian organization. They run three programs in South Africa: 1) a home for 12 boys (6-14 years old) who have been orphaned by AIDS; 2) a street outreach program connecting children with various organizations and showing them other options; and 3) an AIDS Care Centre, for children infected with the virus, serving 40 children (ranging in age from 1 month to 7 years).

Verie Johnson, Tafelsig United AIDS Project and Support Group

Verie Johnson, the Director, is extremely dedicated, as is the staff of 4, plus 5 volunteers. TAUP is an impressive organization with a demonstrated ability to use linkages and collaborations, receiving referrals from a variety of CBOs. In addition to outreach, prevention education and support groups for PLWHAs, TAUP feeds 370 individuals (80% women and children) twice a day, 7 days a week. They receive some financial aid from the government for their meal program, but none for their HIV/AIDS programs (outreach and peer advocacy).

Faghmeda Miller, Positive Muslims

Deputy Convener of Positive Muslims (an awareness-raising research and support group for Muslims living with HIV/AIDS in Cape Town), Mrs. Miller was the first HIV+ Muslim woman to “go public.” Even though she was a good Muslim and was infected by her husband, she was ostracized by her community when she was diagnosed. Last year Faghmeda Miller was nominated as “Woman of the Year” by a national South African magazine.

Brett Anderson, HIV/AIDS in the Workplace Consultant/Educator

Brett is a successful TV producer, Chairperson of the Quilting Project of South Africa and the “poster boy” for HIV/AIDS in Cape Town (having appeared in many TV ads and on billboards). When he was diagnosed as HIV+, he committed to helping others live positively with the virus. I attended one of his training sessions geared to helping executives, managers and employees deal with HIV/AIDS in the workplace. Brett enthusiastically addressed the need of employers to provide supportive environments for individuals to be tested and receive treatment. More and more employers are recognizing this need.

Ms. Kuku, Phillipi East Education Support Center

As the Superintendent of the Phillipi East Education Support Center, Ms. Kuku suggested I meet with a group of about 30 teachers to discuss an opportunity proposed by Senator Thomas Duane to connect teachers in South Africa with teachers in New York State for mutual support. These teachers were receptive and signed off on this collaboration initiative.

Patrick Zulu, resident of Zambia

Patrick teaches electrical engineering in Zambia and traveled 3 days via bus to meet me. He brought me information about Zambia and an appeal for help.

This was Patrick’s first trip to Cape Town, and I was pleased to have the opportunity to show him around and introduce him to some educators and medical personnel. Patrick collaborated with the educators and had an opportunity to observe children teaching peer education programs. I’ve received word he is already utilizing this information in his country.

CONCLUSIONS

My trip to Cape Town this year was enlightening, enriching – and exhausting! I was pleased to observe that the messages concerning HIV/AIDS are more prevalent and people are talking more openly about the virus than they were last year. I noticed this particularly during my work at the schools where children were more willing to speak about family members and people they knew who had HIV or had died with AIDS. Some even quietly self-identified.

Of course, the exciting news is that the South African government has announced that antiretrovirals are coming and will be rolled out soon. They are in the process of creating an infrastructure for service delivery. This is an enormous job, of staggering proportions, requiring participation from all levels of the society. Most certainly PWAs with strong advocacy skills need to participate in this process. ●

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



"HI-HO, HI-HO..."

From the time the LTI program began in 1997 we've continually asked our graduates for input about what kinds of workshops and training they'd like to see the LTI offer. Although the LTI's mission is fairly narrowly focused on "advocacy, public policy advice and community planning activities," graduate interest in new training topics has always included feedback on more issues than the LTI could realistically address. We PWHA need and want training and information on a much wider range of topics than any one program can offer.

One such issue is employment. From the very beginning, perhaps no issue has been so consistently raised by LTI graduates as the need for information and training around returning to work or, for many of us, going to work for the first time. Many of us left jobs and careers due to illness or to decrease intolerable levels of stress in our lives; many of us never had a consistent work life, due to lack of education, addiction, substance use or other issues. Increasingly since 1996 – when highly active antiretroviral therapy hit the scene – more of us have found that we are in fact able to work, and the psychological and emotional benefits that can come with employment make the idea attractive even beyond the expected financial ones.

Ten organizations in New York State have been funded to provide training, job placement services and on-going support and case management to assist HIV-positive individuals to enter or re-enter the workforce. Programs take an individual's current abilities and health-related needs into consideration, and each program includes counseling on entitlements, to help determine how employment would affect a client's existing benefits.

In this issue of *The Circle* we present contact information for these ten programs. Though all of them have similar eligibility requirements and offer similar services, each one operates within its own structure, so there is some variation among the programs. If this is something you'd like to know more about, we encourage you to contact a local program directly to get their most up-to-date information. Though full-time (or, in some cases, even part-time) work is not appropriate for all PWHA, many of us can take advantage of the assistance offered through these programs.

PROGRAMS OUTSIDE NEW YORK CITY

ROCHESTER REHABILITATION CENTER:

Contact person: Deborah Burke
Telephone: 585-263-2690 ext 109
E-mail: d-burke@rochesterrehab.org
Area Served: Monroe County
Note: Participants for this project will be recruited from the current population served by the Community Health Network (CHN).

LIBERTY RESOURCES:

Contact Person: L. Robert Ciota
Telephone: 315-425-1004 ext 252
E-mail: bciota@liberty-resources.org
Area Served: City of Syracuse and Onondaga County

MAXIMUS:

Contact Person: Carol June-Washington
Telephone: 518-438-2951
E-mail: caroljune-washington@maximus.com
Area Served: Albany, Rensselaer, Schenectady counties
Partners: The Damien Center, Trinity Institution

CWI/COMPETITIVE EDGE:

Contact Persons: Sally Belyea and Julie Prendeville
Telephone: 518-792-7548 ext 139
E-mail: julie@cwine.org
Area Served: Warren and Washington Counties
Partners: Glens Falls office of the AIDS Council of Northeastern New York, Catholic Charities

THE ALTAMONT PROGRAM, INC.:

Contact Person: Lisa Brown or Cathy McDowell
Telephone: 518-465-8034 ext 134 or 135
E-mail: lbrown92963@yahoo.com or csmcdowell@yahoo.com
Area served: Capital District

WESTHAB, INC.

Contact Person: Joseph Matcham and Victoria Rivera
Telephone: 914-667-0638
E-mail Address: jobtrain@cloud9.net
Area Served: Westchester County

NEW YORK CITY PROGRAMS

HOUSING WORKS, INC.

Contact Person: Linney C. Smith
Telephone: 212-645-8111 ext 167
E-mail: smith@housingworks.org
Area Served: 5 boroughs of NYC

NEW YORK ASSOCIATION FOR NEW AMERICANS, INC.

Contact Person: Nestor Tebio, Program Coordinator
Telephone: 718-651-4983
E-mail: ntebio@nyana.org
Area Served: Located in Queens (open to residents of all boroughs)

AMERICA WORKS OF NEW YORK, INC.

Contact Person: Dr. Johnny Pita
Telephone: 212-244-5627 ext 165
E-mail: JohnnyMBK@aol.com
Area Served: NYC, Bronx, Brooklyn, Staten Island and Queens
Partners: Latino Commission on AIDS, Beth Israel Hospital and the Salvation Army

GAY MEN'S HEALTH CRISIS

Contact Person: Reshard Riggins
Telephone: 212-367-1007
E-mail: reshardr@gmhc.org
Area Served: NYC
Partner: MTS

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For those of us interested in focusing our attention on our representatives in the U.S. Congress, AIDSWatch 2004 is coming up, and we include contact information for anyone wishing to know more about it.

Finally, the LTI training calendar is taking shape for the year ahead (that begins on April 1, 2004). In this issue, our calendar insert lists dates and expected locations for trainings through June 2004. We generally try to avoid scheduling trainings for July and August, so this calendar will take us into the autumn. The next issue of *The Circle* will have our schedule for the rest of the year.

As we look toward this new calendar, it seems a good time to lay out a few changes (hopefully improvements!) we've begun implementing to make the program run more smoothly.

- ▶ First, you've probably noticed that most of our trainings are being held fully or partly over weekends; this is in response to feedback from grads that weekdays were harder in terms of work schedules, child care, etc., and that weekend trainings would be easier to attend.
- ▶ Second, we're working seriously to improve communication between LTI staff and participants; for example, any time you register for a training, you should hear back from the LTI staff (usually Jenny, occasionally Petra or me) within two weeks that your registration has been received and entered. **YOU WILL STILL NEED TO CONFIRM YOUR REGISTRATION AND PLANS TO ATTEND AS THE TRAINING DATES GET CLOSER**, but this has already helped to reduce the number of "lost" communications we used to have. If you register and don't hear from us within two weeks, please call Jenny on our toll-free number (866/PWA-LEAD x231) so she can follow up.
- ▶ Finally, we're trying to place participants in trainings held closer to their

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, COORDINATOR
Tel: 718-622-8184, ext 101
Email: eve117@ptd.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: 718-231-3598
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

INGRID GONZALEZ
Tel: 212-926-8000, ext. 21
Email: igonzaez@nyul.org

East Harlem HIV Care Network

JOSE MARTIN GARCIA ORDUNA
Tel: 212-828-6143
Email: jorduna@unionsett.org

East New York Brownsville HIV Care Network

GWENDOLYN EDWARDS
Tel: 718-907-3726, ext. 3725
Email: enybhcn@aol.com

Lower Hudson Region HIV Care Network

KELLI EVERETT
Tel: 914-428-2114, ext. 230
Email: ulwswd@aol.com

Mid-Hudson Region HIV Care Network

ANITA WYATT
Tel: 845-563-8058
Email: anita8059@hotmail.com
Web: www.mid-hudsonhivcare.org

Nassau Suffolk Region HIV Care Network

DEBRA ROSS
Tel: 631-940-3700, ext.6480
Email: dross@unitedwayLI.org

Queens HIV Care Network

COORDINATOR TBA
Tel: 718-389-5100

Rochester Region HIV Care Network

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

Staten Island HIV Care Network

REBECCA ORTIZ
Tel: 718-448-8789
Email: rebecca.ortiz@siatf.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

RICHARD FERREIRA
Tel: 718-455-6010, ext. 138
Email: referreira@earthlink.com

homes whenever possible. This helps us reduce travel and some hotel costs, and allows folks for whom travel is physically difficult to have easier access to the trainings. While our resources won't allow us to offer as many workshops or locations as we'd like, this approach should help many of our graduates connect with others in or near their own regions.

We hope these changes will continue to improve your experience of the LTI. And we anticipate that after our statewide needs assessment is completed this summer, we'll have more ideas and information to guide the LTI's evolution. Thanks for all your input - we'll see you in training! ●

**THE LTI NOTES WITH GREAT SADNESS
THE PASSING OF LTI GRADUATE AND TRAINER
CHARLES GANT
FROM BEACON, NEW YORK**

Charles was an employee of AIDS Related Community Services and a member of the Mid-Hudson Ryan White Title II HIV Care Network. He was also a previous Co-Chair of the Dutchess County Ryan White Title I Planning Council. Charles was one of four New York representatives who participated in the HRSA consumer meeting on Ryan White Re-Authorization, held in conjunction with the United States Conference on AIDS in New Orleans last fall. Charles was recently appointed to the New York State AIDS Institute's consumer quality of care committee and would have attended his first meeting in March of this year. He was also a past recipient of the New York State Commissioner of Health's World AIDS Day Award.

Charles was a kind man who advocated tirelessly on behalf of People Living with HIV/AIDS locally, statewide and nationally. His passing is a great loss to the Mid-Hudson region and New York State.

Not long after taking the LTI Core training in 1998, Charles wrote a letter describing his experience with the program. With loving memories and in his honor, we re-print the body of that letter here:

"My relationship with LTI began on May 5, 1998. At that time, I participated in the Core training, which was held in Poughkeepsie, NY. What an experience! I learned so many things that I, a person who had never felt any kind of empowerment, could do to make an impact on decisions which determined the quality and quantity of services for myself and other people living with this deadly virus.

"From knowledgeable trainers, to formats designed to reach people on all levels, this Core training and subsequent advanced trainings have furthered me greatly in my quest to advocate both for myself and for others.

"For anyone who is infected, and truly interested in becoming an integral part of the solution, LTI is a vehicle that works. Designed by and for PLWHA's who have a sense of commitment and purpose, it allows us to be everything we can be. On my journey as an advocate there have many obstacles. I've learned how to overcome these obstacles through training and by maintaining a personal relationship with the staff and leadership of LTI."

Thank you, Charles, for everything.

HAIL AND FAREWELL!

All good things must come to an end, and this past December several long-time members of the LTI CAB reached the end of their terms. With profound gratitude, deep admiration and not a little sadness, we'd like officially to thank Julian Bain (Northeast), Anita Paige-Bowman (Lower Hudson), Joey Lopez (NYC), Joan Warner (NYC) and John Wikiera (Central) for their dedication and service to the LTI and to the PWHA community.

At the same time, we're very pleased to welcome several new members to the LTI CAB: Diego Betancourt (NYC), Christopher Davis (Lower Hudson), Raymond Tracy Moran (Mid-Hudson), Daphane Sanders (NYC), Erwin Scott (Central) and Robin Smith (NYC). (We did not receive enough nominations in our December round from the Northeast region to make a selection, so that region's representative will be named in March 2004.)

Remember, LTI CAB members are the folks who are charged with bringing information about the LTI to regions throughout the state, and with making sure that each region's concerns – needs, complaints, announcements, whatever – are brought to the LTI CAB. Your help in making sure they know about problems (and/or compliments!), regional "happenings" and any gaps in information, is greatly appreciated! ●

PWA LTI

AIDSWATCH MAY 17-19, 2004

MAKE YOUR VOICE HEARD!

Share Your Story With Congress! Speak Out About HIV and AIDS!

Come to Washington May 17-19 and Tell Congress to Do the Right Thing

Each spring, hundreds of AIDS advocates from across the U.S. travel to Washington, DC, to speak to their elected officials with a strong voice, united in support of a solid federal commitment to AIDS programs. AIDSWatch focuses on increased federal support to meet the needs for domestic and global prevention, care and treatment; research and housing. All people living with HIV deserve comprehensive care and treatment. All people at risk of HIV infection deserve comprehensive prevention and education.

Join the Largest Annual Constituent-Based Federal HIV/AIDS Advocacy and Education Event in the U.S.

Participants include people living with HIV and AIDS and their families, care providers, and other advocates. AIDSWatch is a project of the National Association of People with AIDS (NAPWA). Many other national organizations concerned about HIV and AIDS also participate in the planning, funding and support of this event.

Registration Details

There is no cost to register for AIDSWatch. The information you provide will be helpful in arranging your congressional meetings. Your contact information will be forwarded to the State Director for your state, who will contact you directly. Your State Director has volunteered to make congressional appointments for the participants from their state and serves as a resource for participants regarding advocacy training and grassroots mobilization.

Learn to Be an Advocate for People Living with HIV/AIDS

A full day of training is devoted to providing participants with up-to-date information about federal HIV/AIDS policy and funding issues. Organizers also provide hands-on training to prepare you to visit with your elected representatives and their staff members. Your State Director will arrange visits to your elected representatives for you and others from your state and congressional district. In some cases, you may be joined on your visits by staff and board members from national HIV/AIDS organizations, while in other cases you may be asked to attend meetings with representatives from other parts of your state or region.

Lodging Information

AIDSWatch has arranged a special rate for AIDSWatch participants at Radisson Barcelo Hotel Washington in Dupont Circle. Call the hotel directly and identify yourself as an AIDSWatch participant. The Radisson Barcelo Hotel Washington at 2121 P Street, NW, can be reached at 202.293.3100 or via www.radisson.com. Rates: \$129.00 single/double + 14.5% tax. AIDSWatch rates are in effect between Thursday, May 13 and Wednesday, May 19.

For other hotel options, consider www.wdcahotels.com or www.quikbook.com. Both sites offer a variety of accommodations throughout Washington. Please note that hotels listed on these sites are NOT official AIDSWatch hotels.

Can't Make it to DC for AIDSWatch This Year?

Even if you have not secured financial resources to pay for your travel to AIDSWatch, we hope you will register. Your State Director may be able to help identify resources. And if you absolutely cannot make it to Washington, D.C., you can still participate. Your State Director can help arrange visits in your home districts with your Representative and Senators and/or their staffs. Members of Congress work for you, and they want and need to hear your concerns and priorities.

The deadline for AIDSWatch registration is April 30, 2004. If you have any questions, please call 866.243.7282 or e-mail aidswatch@highnoon-communications.com.

We look forward to seeing you at this exciting event and having you participate in AIDSWatch 2004 in Washington or at home.

UPCOMING CONFERENCES

MARCH 11-12

REUNION LATINA 2004: PREVENTION SAVES LIVES IN THE FIGHTING AGAINST AIDS

Crowne Plaza Hotel
State and Lodge Streets, Albany, NY 12207

Tel: 212-675-3288

Web: www.latinoaids.org

MAY 8-11

2004 NATIONAL STD PREVENTION CONFERENCE: SHARING SUCCESSES AND STRATEGIES DURING AN ERA OF UNCERTAINTY

Philadelphia Marriott Hotel
1201 Market Street, Philadelphia, PA

Web: www.stdconference.org

JUNE 16-19

HIV PREVENTION LEADERSHIP SUMMIT

Omni Hotel at CNN Center
100 CNN Center, Atlanta, GA 30303

Registration Deadline is May 14, 2004

Tel: 202-483-6622

Web: www.nmac.org

JULY 11-16

XV INTERNATIONAL AIDS CONFERENCE

Bangkok, Thailand

Early Registration deadline: passed

Standard registration deadline: May 1, 2004

Web: www.aids2004.org

SEPTEMBER 10-12

STAYING ALIVE

Atlanta, GA

National Association of People With AIDS
(NAPWA)

Tel: Aryka Chapman at 202-898-0414,
ext. 116

Email: achapman@napwa.org

OCTOBER 21-24

UNITED STATES CONFERENCE ON AIDS 2004 (USCA)

Philadelphia Marriott Hotel
Philadelphia, Pennsylvania

Scholarship applications are due to the
National Minority AIDS Council (NMAC) by
5:00 p.m. on July 2, 2004

Early bird registrations must be post-
marked by July 12, 2004

Tel: 202/483-6622 ext.343

Email: pwoods@nmac.org

Web: www.nmac.org

"YOU'VE GOTTA BELIEVE"

(continued from front)

greater participation, while empowering consumers and increasing true representation in reflecting the HIV epidemic in the Mid-Hudson area.

Looking around the table, we saw that there was one thing that was consistent among the consumers who participated in the process. They were all LTI graduates! One of the things which had deterred us in the past was that, because LTI trainings were done across NY State, we as an HIV Care Network had no way of knowing and connecting with LTI graduates from our area who were potential members. We realized the importance of having a region-specific LTI training in the Mid-Hudson area. Creating a Statement of Need, we asked for and received the support of the Title II Steering Committee, who in turn provided input to the goal we were attempting to achieve. At that time we decided to contact the AIDS Institute, LTI (Cicatelli Associates Inc.), and the Mid-Hudson General Network Committee.

There were many follow-up conversations with all the entities we were networking with. And, at times, it seemed that our goal was getting more distant, rather than closer. However, a sense of commitment and a belief that our efforts would eventually take us to the place where we were attempting to arrive was a saving grace.

We began the process of developing a Power Point presentation, which directly addressed why there was a **need** for consumers to be involved, and the benefits that are also reaped by providers when consumers and providers *together* address the issues which surround HIV/AIDS. In conjunction with this presentation, documents were developed which

helped support the main thrust of our focus: a membership application, a commitment statement, and an Internal Buddy/Mentor System. These items, addressed in our Statement of Need, fine-tuned our idea that there had to be something in place that enabled consumers to navigate the maze that, at times, became a barrier to feeling comfortable, and to having a sense of having an equal voice in the process.

In developing all the instruments we produced, we relied on resources that were mainly already in place. We discovered how much information was out there, while also discovering the difficulty of finding a single resource we could rely on that would cover the spectrum of HIV policy, guidelines and regulations. We mainly relied on Title II Guidelines and accessed HRSA websites, which posted Title I and Title II manuals.

For all of us who labored so long and so diligently, the results of our work were very gratifying. When we presented at the Mid-Hudson LTI Training of September 12th-14th, 2003, the obvious reaction of all attending *and* those presenting was an incredible sense of giving and receiving. At this training we utilized visual and audio references and also distributed hard copy lists of Planning Councils, Consortiums and Support Groups in our area. *At the first Title II Steering Committee meeting after the training, there were twelve consumers at the table who had attended the LTI training!*

New life was breathed into us as we all accepted the realization that mountains can be crossed if you believe they can, that one's dream can become one's reality, if you really believe, and that the journey of a thousand miles begins with one step. You can reach whatever your destination is: ***If you truly believe!*** ●

THE AIDS INSTITUTE ANNOUNCES THE PUBLICATION OF: "A CONSUMER'S GUIDE TO QUALITY OF HIV CARE IN NEW YORK STATE"

Many factors play a part in the quality of your HIV care. Can you get an appointment when you want it? Does your doctor answer questions in a way that you understand? These questions are hard for anyone but you to judge. However, other questions, such as whether you get important tests, are questions that can be answered by looking at a patient's medical record. For over a decade, the New York State Department of Health, AIDS Institute has reviewed medical records at over 150 clinics to ensure that health care facilities are providing the highest quality of care to New York State residents living with HIV.

These reviews measure whether important tests and services are provided at each clinic on a regular basis including the indicators included in this report: Management of Antiretroviral Therapy (ARV), Viral Load Tests, Tuberculosis (PPD) Screening, Pelvic Examinations, and Prevention of Mother-to-Child HIV Transmission. The AIDS Institute reviews these and many other quality indicators, and gives results of these reviews to clinics so they can see how they score and improve the quality of care they provide. The information is also provided to people living with HIV/AIDS through the "Consumer's Guide", so that consumers can see how well hospitals and clinics in NY State provide HIV services.

The "Consumer Guide" is a special edition of the full report "Clinical Management of HIV Infection: Quality of Care Performance in New York State 1999 - 2001," which provides further details such as how scores are calculated.

To receive a copy of the "Consumer's Guide" or other educational materials about HIV/AIDS, please send an email to HIVPUBS@health.state.ny.us or call (518) 474-9866 for an order form. You can also download either version of this data release at the AIDS Institute website: www.hivguidelines.org