



the circle

Fall 2010, N° 28

leading lines advocacy outreach community

SURVIVING AND THRIVING!

by John Hatchett

Welcome to another issue of *The Circle!* Autumn is here, and we at LTI have been very busy: training a new group of LTI mentors and beginning outreach for the fourth round of our Self-Management trainings around the state; updating our Self-Management training materials to incorporate the latest information from the summer's international AIDS conference and other sources; re-organizing our Ryan White Part A information for the NYC "Planning Council Series" of workshops; and generally keeping up with developments in a wide range of areas. Some of those include: a lively community-wide discussion of the best time to start HAART; the release of the National AIDS Plan; growing awareness and intensified examination of issues such as bone loss, vitamin deficiencies and inflammation among PLWHA; increased action in response to growing ADAP wait lists in a number of states; advocacy for housing protections; new approaches to HIV testing and more.

However, other recent news has had an even more immediate and profound effect on the LTI community around the state, indeed, on the HIV community as a whole: the September 15th announcement that the state's eleven HIV Care Networks will lose their funding at the end of 2010. That information hit hard, and our conversations with LTI grads, Network members and many others have made

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All You Ever Wanted to Know About ADAP

by Justin LiGreci

The AIDS Drug Assistance Program, known as ADAP, is a federally funded program run by each individual state to help PLWHA who are uninsured or underinsured. ADAPs have helped people get their medicines and in some cases receive primary care services. Many medical professionals credit ADAP with saving thousands of lives by providing essential treatment medications and covering certain procedures. **ADAP covers roughly 30% of those infected with HIV in the United States. ADAP first began in 1987 to help people pay for AZT; today it continues to be instrumental in getting people medicines.**

If you need access to HIV drugs, ADAP might be the right program for you. A case worker can help you with the application process, and being part of ADAP can help you get connected with local AIDS service organizations. All people living with HIV/AIDS in this country have a right to the medications they need. Being part of ADAP shows state and federal governments that there is a real need for increased funding to the program.

ADAPs have limited means to balance resources and demand for those resources. There are three basic pieces of ADAP: 1) Eligibility – who is covered, 2) Formulary – what is covered, and 3) How much is paid for medicines and care. The most recent reauthorization of the Ryan White Program in 2009 changed the way federal funding is distributed, leading to new ADAP requirements. For New York State, the Department of Health workers are responsible for updating the eligibility requirements and formulary changes to ADAP. These changes can occur for many

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CONNECTIONS IN UPSTATE NEW YORK

by John Wikiera

Something new is happening in the Central New York region: "CNY Connections." This program includes a secure social networking site and weekly toll-free conference calls for Poz Men and Poz Women. The calls happen on two different days: Tuesdays for Women, Thursdays for Men. Anyone living in NYS can join the weekly conference calls. The Women's call facilitator is an LTI grad, current Mentor, and previously served on the LTI CAB for four years. She has the knowledge and experience that are a great help to the Poz Women of NYS. I am the facilitator for the Poz Men's call, and I also help to maintain the CNY Connections site.

As a member you can also post information, pictures and videos that might relate to things happening in your region, or events that you have attended. As long as the content you want to post is not discriminatory, judgmental or bashing an organization or person, it will be posted to the CNY Connections page. We are concerned with everyone's privacy and respect, so all content needs to be approved before it is posted. We would not change things ourselves, if that is what is needed; we would contact you and talk about your submission with you.

I think that CNY Connections is the best idea that has been hatched from consumers and staff working together on a grassroots effort in a long time. With some very hard work from the lead agency staff at Central New York Health Systems Agency (CNYHSA) and consumers, we came up with a way of delivering information, education and networking solutions to meet the needs of even our most rural area consumers. How great is that! We put the skills we learned through the LTI self-empowerment trainings and the new Mentoring program, and got the job done.

Without LTI grads' and other consumers' input and help, we wouldn't have come up with this resource. Just like we were shown over and over in LTI trainings and videos, the beginning of the HIV movement in NYS happened because the many came together as one. I know LTI has been a big part of my success. **I honestly think my years of involvement with the LTI program have improved my quality of life.** The knowledge I have gained is a wonderful tool and it is something I can now pass along in a new way.

CNY Connections can be a way of sharing your knowledge and words of inspiration with others who might be newly diagnosed or looking to learn more about an issue they are facing. Part of LTI has always been to share with others what you have learned along the way - show them the ropes so to speak - and then they pass it on to others and so on. I truly think that the LTI is part of the reason that NYS has become such a leader in HIV education, empowerment, advocacy and quality of care throughout our country. I would hope that reading this sparks your interest enough that you would like to check out our social networking site and weekly conference call.

I and the others who have worked on developing these services are very excited about how we can use them to reach the masses. Everyone needs and deserves to feel that they belong to the community as a whole, not just looking in a window from the outside. To sign up for a weekly conference call, please contact CNYHSA Staff, Patty Van Wert @ 315-472-8099 or email @ pvanwert@cnyhsa.com or John Wikiera @ 315-542-1703 or jwikiera@cnyhsa.com. To use the CNY Connections web page, go to www.connectionsny.ning.com online and sign up. We welcome any ideas, feedback or suggestions that you may have in regards to our ongoing work. We will continue to update and change things in order to make sure our consumers' needs are being met in the best way possible. ●

ALL TRAINED UP AND NOWHERE TO GO?

If you would like to get more involved, learn more about the following community planning and council groups!

NEW YORK STATE PREVENTION PLANNING GROUP

Wendy Shotsky
*Director, HIV Prevention
Planning Group*
Tel: (518) 473-8484
wjs03@health.state.ny.us

NEW YORK CITY PREVENTION PLANNING GROUP

Linda F. Battle
*Administrator, Community HIV
Prevention Planning Group*
40 Worth Street, Rm. 1519
New York, NY 10013
Tel: (212) 788-7546
lbattle@health.nyc.gov

NEW YORK CITY PLANNING COUNCIL

Office of AIDS Policy
Coordination
*New York City Department of
Health and Mental Hygiene*
40 Worth Street, Room 1502
(CN A1)
New York, NY 10013
Tel: (212) 442-6573
nyhiv@health.nyc.gov

SURVIVING AND THRIVING!

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clear the anguish that went into making the decision and that has resulted from it. It's much too soon to know what plans will materialize to help keep consumers, providers and policy makers in contact with each other and working collaboratively—something the Networks have done for over 20 years—but we do know that LTI graduates, mentors and CAB members can all make positive contributions toward lessening the impact of this serious loss.

As consumers of HIV health care and other services, our need has never been greater to educate ourselves, find our voices and use them in constructive ways to benefit our entire community. Service providers and state and local government need our expertise and real-life experience to help make often excruciating choices about where to dedicate seriously over-stretched resources, choices that almost always mean choosing among valuable and needed services that cannot be supported the way they ought to be. And no one I read or talk with is predicting the dramatic worldwide economic recovery we'd have to see

in order for funding to reach levels adequate to meet the still-growing demand for HIV care. So the upshot seems to be that while we work to secure increased resources, and until those resources materialize, we've got to do more with less – and that requires our willingness to not “sweat the small stuff,” put our differences aside and concentrate on sustaining the best system for the most people possible.

On a more optimistic note, this issue contains an article from Central New York about one of the creative ways communities are organizing to share information and support. We're also very pleased to welcome Gabrielle Long to the LTI staff as our Program Associate. From now on, hers is a name (and phone & email!) that you'll want to keep handy; Gabrielle says hello on page 4. We also extend a warm welcome to new CAB members from several regions of the state: Leland Vann (Western), Rich Fowler (Finger Lakes/Rochester), Arquelio Gonzalez (Northeastern), Richard Krushanski (Southern Tier), Lance Marrow (Long Island), and Felicia Carroll and Mildred Zeno (NYC) are all new to the CAB since Spring, and they'll be introducing themselves in upcoming issues. ●



LTI's Petra Berrios and Rusti Miller-Hill training at CAI, New York City

ABOUT ADAP

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different reasons, for example: budget changes, more people in need of ADAP programs, new medicines becoming available, and necessary medical procedures that become covered.

Recently there have been formulary changes to ADAP, which may affect those who are in the program and those who may be seeking participation in ADAP. In an upcoming issue of *The Circle*, we'll bring you an article detailing these changes, and what they may mean for you. Looking to the future, it is certain that ADAPs will continue to play a pivotal role in providing access to life saving medicines and essential medical procedures, and that they are an important resource in the fight against AIDS.

The AIDS Institute runs New York State's ADAP program, and many resources can be found by calling the **NYS DOH HIV Uninsured Program at 1-800-542-2437**, or logging onto the World Wide Web and visiting: <http://www.health.state.ny.us/diseases/aids/resources/adap/> ●

MEET THE NEW LTI STAFF

Gabrielle Long—New York, NY

Hello!

My name is Gabrielle Long and I am the new Program Associate for LTI. Prior to joining Cicatelli this past April, I worked in the healthcare and nonprofit fields in various capacities. My focus has been on health education, adolescent health, women's health, and urban populations. I graduated from Harvard University with a bachelor's degree in History and Literature, where I also completed my pre-medical studies. My areas of interest centered on Afro-American Studies; Studies of Women, Gender, and Sexuality; Sociology; and Medicine and Society. In my free time I enjoy movies, sports, pottery and Caribbean beaches.

Please feel free to contact me by phone, email, or in person—even though I am based in the office, I would love to get to know as many of you as I can. I am enjoying being part of the LTI team, and I hope you will join us for a strong and productive year!



Mark Your Calendar!

November 3rd – 5th
Northeast NY SMT

November 10th – 12th
Hudson SMT

November 17th – 19th
Syracuse SMT

December 7th – 9th
New York City SMT



NEXT ISSUE

Meet some of the newly elected LTI CAB members!

Look for information about World AIDS Day 2010!

Read about new happenings with LTI!