



the circle

Spring 2011, N° 29

leading lines advocacy outreach community

SURVIVING AND THRIVING!

by John Hatchett

As the weather begins to tease us with glimpses of spring and its promise of new life and growth, the LTI is undergoing some renewal as well. Cicatelli Associates Inc. (CAI) has been awarded the LTI contract for another five years, and we're excited about plans for improving the program.

Our staffing is shifting a little, and we're pleased to announce that Petra Berrios, the LTI's Deputy Director for the last 10 years, has been named LTI Project Director, assuming the role long filled by John Hatchett. John has been named CAI's Vice-president for Peer Programs, a position that will allow him to stay close to the LTI to provide support, help develop some new components with the project, and keep a hand in the Self-Management trainings (SMTs) as time allows.

The rest of the LTI staff team remains in place, and staff will be more visible in the community in the year ahead, doing some more traveling around the state to work with our CAB members, LTI mentors and other graduates to reach our peers who don't yet know about the program. We've set enrollment goals for each of the eight SMTs planned for the year (one training in each region of the state outside New York City, and two in New York City), and we'll be working hard to reach as many PLWHA as possible to let them know about what the LTI has to offer.

Perhaps the most exciting change is the creation of an SMT designed specifically for young adult PLWHA, ages 18-24. The curriculum has been adapted to address issues of particular concern to adolescents and young

(continued on page 2)

Bright, Eager and Fresh— Interviews with Young Adult Mentors

by Justin LiGreci

In February, LTI kicked off our Young Adult Self-Management pilot program. Not exactly starting from zero, we plunged into new territory, adapting the Self-Management Training and Mentor Training specifically for young adults. We identified participants from our contacts in all the regions of New York State and finalized a list with eleven people—some of whom were previously unknown to us—who were ready to become mentors to HIV-positive young adults.

As our participants trickled in for the first day of training, we saw bright, eager, faces ready to learn about being LTI mentors. By the end of the first day LTI staff could barely contain our excitement. These young adults were quite serious about mentoring – coming together from their separate regions and succeeding in showing us that they have what it takes to be peer mentors. After the training I approached two of the participants and asked them if they would mind talking with me for the LTI newsletter about their experiences at the training. Cassie, a young woman from the Northeastern New York region, and Kareem, a young man from New York City, are both brand new to the LTI experience and shared with me their thoughts on the training:

JLG: Going into the training, what were some fears you had?

Cassie: I've never really done anything like this before, never really been open about my HIV status with anyone beyond family and healthcare providers. I was most apprehensive about meeting others and being comfortable with something I didn't know too much about. I was very interested, though, to see if it would be a good fit for me.

(continued on page 3)

LTI Community Advisory Board

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SURVIVING AND THRIVING!

(continued from page 1)

adults, such as transitioning from adolescent care into adult care, and dating and healthy relationships. The first Young Adult SMT was delivered at the end of March to a dozen participants from all across the state, and a newly trained group of LTI peer mentors are already offering their support and encouragement as their mentees work toward achieving their individual HIV health care improvement goals.

Over the next twelve months the LTI will offer this Young Adult training once upstate and once in New York City, and we hope to reach prospective participants through a reinvigorated outreach plan that includes a greater emphasis on working directly with HIV health and human service programs, and with groups of consumers.

We will also have a calendar of SMT dates for every region of the state for the entire year, which will be published in this newsletter as well as on the LTI web site by the end of June. The web site itself is undergoing some much-needed development, with plans in the near future to introduce an online space where SMT participants, graduates and mentors can communicate with each other and share information.

Along with outreach, training and follow-up, there's no shortage of advocacy issues that need our voices: threatened cuts to HIV services due to state budget gaps, changes to Medicaid, health care reform, implementation of the National AIDS Strategy, growing ADAP wait lists in eleven states and the 2013 Ryan White reauthorization all need PLWHA—from every demographic and every part of the country—to be informed and involved. The policy and funding decisions made in the coming months will affect all of us for years to come.

Finally in this issue we introduce three of the LTI's newer Advisory Board members: Arquelio Gonzales, from Northeastern NY, Lance A. Marrow from Long Island, and Leland K. Vann from Western NY. Though none of them is new to the LTI, they've all joined the CAB in the last year, and we're happy to welcome them to their roles as regional representatives. ●

CARE NETWORKS: GONE BUT NOT FORGOTTEN!

Like our peers and colleagues all over the state, we at LTI are acutely aware of the loss of the state's eleven Ryan White Part B HIV Care Networks, defunded as of December 31, 2010. The Networks have traditionally been places where consumer involvement could flourish and PLWHA could grow and develop our advocacy skills, so of course it's disappointing that such a great resource for consumers is no longer available to our communities. But some dedicated community advocates, lead agencies and service providers are working to fill the gaps left by the loss of the official Network system. Below we provide a list of their contact information. This list may evolve and change, but it is current as of 3/21/11.

Brooklyn:

NYC HHC Kings County Hospital Center
451 Clarkson Ave., Brooklyn, NY 11203
718/245-3131

Bronx:

Montefiore Medical Center
3058 Bainbridge Ave., Bronx, NY 10467
718/920-4321

Manhattan:

Jose Martin Orduña
Union Settlement Association/
Manhattan HIV Care Network
158 East 115th Street, Suite #218
New York, NY 10029
212/828-6141

Queens:

Nathaly Rubio-Torio
516-322-1959

Staten Island:

Care Network Volunteers Group
Community Health Action
of Staten Island
56 Bay St., 6th Floor
Staten Island, NY 10301
718/808-1300
Staten Island HIV Advocacy Network
www.chasiny.org

Central New York:

John Wikiera
Central New York Health Systems Agency
5700 Commons Park Dr.
East Syracuse, NY 13057
Tel: 315/472-8099
Fax: 315/472-8033
www.cnyhsa.org

Finger Lakes/Rochester:

Sharonette Foster
Rochester Area Task Force on AIDS
1150 University Ave.
Rochester NY 14607
585/224-3102
www.knowingisbetter.org

Hudson Valley:

Robert Maher
Hudson Valley HIV Community Network
209 Route 9W

Long Island:

Kathryn Kilkenny
United Way of Long Island
819 Grand Blvd.
Deer Park, NY 11729
631/940.3716
www.unitedwayli.org

Northeastern New York:

A new coalition is currently being put together by providers and consumers in this region. For more information please contact:
Joseph F. Kerwin
Albany Medical Center
AIDS Program Administrator
47 New Scotland Ave.
Albany NY12208
518/262-4399
KerwinJ@mail.amc.edu

Western New York:

Christina Trachtenberg
Administrative Assistant
The AIDS Network of Western New York
Lafayette Presbyterian Church
875 Elmwood Ave.
Buffalo NY 14222
716/882-7840 (phone)
716/882-2139 (fax)

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; GLong@cicatelli.org



INTERVIEWS WITH YOUNG ADULT MENTORS

(continued from page 1)

Kareem: I had fears because I didn't really know what I was getting into and it was all new to me. But I was looking forward to it all. For me, it was really just the fear of the unknown.

Cassie: After my first day this apprehensiveness changed; everything was completely overturned, and I was able to connect and get along with everyone. A lot of my apprehensions about fitting in went out the window. I stopped being concerned and couldn't wait to come back the next day.

JLG: Can you describe for me your overall experience at the YA Mentor training?

Cassie: I feel in general this experience was invaluable. I felt very fulfilled and energized, I was very happy that I was chosen to participate and that I was able to follow through with it. I hope these feelings were shared by everyone there, and I hope it all carries over to the mentees.

Kareem: It was a great experience, an excellent experience. I liked that I was able to learn different things and interact in activities with other people. Learning the different techniques and skills to become a mentor was really helpful.

JLG: What was one thing that really stuck out for you during the training?

Kareem: The disclosure piece really stuck out for me, at first I really didn't know how it would all work – especially between a mentor and a mentee. For example, if my mentee was talking to me about finding a job, without the training I would not have known what to say if the mentee asked me if they should disclose to their employer. But because of the training I now understand how it works.

Cassie: One thing that really stuck out for me during the training was how quickly the group came together and bonded. By the end of it, I felt the mentors and all the trainers were like a little family, and we were all very comfortable with each other. The vibe within the group is so beneficial; it formed a strong foundation that will help with the mentees.

JLG: Do you think being a mentor will help your personal growth?

Cassie: I think it did (help my personal growth). In my experience at the training, I was disclosing to people in a 'matter of fact way' – it was like tearing off a Band-Aid that I've been trying to get off for a while now. I think I internalized a lot of the stigma, which kept me from talking to others about it, and because of the training I was able to overcome that stigma. I know I want to be involved in advocacy, so this growth is something I am very grateful for. It made me a lot more confident and has released having HIV as a barrier to reach out to people.

Kareem: Yes it did help me grow – especially when it comes to talking with your doctor. Having a personal one on one with your provider, even when it comes to labs and not just going in and getting your counts, but being prepared with questions to go in with and knowing what you're asking. I also didn't know much about having a health proxy, so the training really helped me grow in areas I didn't know a whole lot about.

JLG: Any thoughts or feelings about meeting your mentee in March?

Kareem: I'm looking forward to it! I can't wait to use my training to work with my mentee. I think my mentee will have a great sense of humor and personality, someone that is willing to accept the help a mentor can give.

Cassie: I'm a little nervous, but more excited than nervous. We have a strong support system with the mentors and Cicatelli, so any issues that come up with our mentees I know we will be able to get through it. I think we'll be seen as a support system, someone our mentees can relate to.

JLG: Being brand new to LTI, what would you tell others who might be thinking about becoming a mentor but aren't sure?

Cassie: I would encourage them to attend the first day, because you never know until you try it – that's how I walked into it. I think after that first day, if you don't feel comfortable, fine, but I doubt anyone would be unsure of being a mentor after starting this process. You know, see where it goes from there, because being involved gets so much easier once you have a good grasp of the program – it's not as scary as it seems in the beginning.

Kareem: I would tell them to just give a try. You never know what

you can learn that you didn't know before, and even if you think you know it there might be things you didn't know completely and you can touch up on areas for clarity.

JLG: Why do you think it is important for young people to be part of this process?

Cassie: I think there is a personal benefit of being able to manage your own healthcare, but beyond that, it helps to break down stigmas and barriers to getting help, and it is so important to maintaining physical and mental health – especially when it comes to young people. From my own point of view as a young person, I think other young people need to get involved to really understand that there is a whole positive community out there, and that we all have a responsibility to this community. This issue we are dealing with, we deserve to have the same care, the same rights as anyone else, and sometimes younger generations overlook this, so it is really important for us.

Kareem: I believe it is important for young people to be part of this so they can become educated about HIV and AIDS. That they (youth) can take this education and apply it to themselves and also to their community, or their family and friends.

JLG: Is there anything else you would like others to know...any final thoughts?

Kareem: It's a great training, wonderful. I loved it. There are wonderful people who are there to help you best advocate for yourself in life. That's all there is to say about it.

Cassie: If anything, going through the training, and the materials, and the trainers all together, I realized how much I was isolating myself. Attending the training – you call it a training but it's a lot more than that – I really felt a lot less alone and a lot less different. If mentors and mentees can get that out if it, even if that's not what they are looking for, it's so valuable. Being a part of this process will let the world understand a bit better about HIV and AIDS.

Kareem: We need people to become more involved! Especially for future mentors and to help future mentees!

Cassie: This is something I hope to be involved with in the future – I wish I could have done it sooner! ●

MEET THREE OF THE NEW LTI CAB MEMBERS!

Prepared with assistance from Gabrielle Long

Lance A. Marrow

Lance has worked with F.E.G.S. as a PAL – Peer Advocate Leader. He has also worked with United Way of Long Island’s Consumer Advisory Board and Planning Committee. Lance has been a consumer/speaker for Educational Opportunity Center and a consumer/speaker for Options for Community Living Inc.

Lance’s hobbies and interests include: cooking, reading, walking, bike riding, rollerblading, helping others, dancing, and writing for United Ways and F.E.G.S. newsletters. Lance likes to learn more about computers, and would like to receive more training to be effective in helping individuals living with HIV/AIDS, and be a more effective community member. He likes to teach about HIV/AIDS issues and speaking in public forums. Lance helps disconnected positive individuals in care and get connected to services and helps with outreach efforts. Finally Lance has an interest in getting back to college to be a case manager.



Leland K. Vann

Leland is a part-time consultant in the field of psychiatric social work and resides in Western New York. Leland’s volunteerism has been inspired by LTI trainings and Robert Frost’s “Promises to Keep.” Leland spends his time as a community advocate for PWHAs in the Western NY region and is actively engaged with the NYS Quality of Care Committee, NYS Prevention Planning Group, and co-facilitates a community support group for HIV+ men.

Leland’s hobbies and interests include movies, plays, reading (especially documentaries), listening to classical music or jazz, and bird watching.



Arquelio Gonzales

Arquelio has worked with Centro Civico of Amsterdam NY as an Outreach Educator and Community Organizer. He has also been a part of the Red Ribbon Partnership and the Albany Damien Center.

Arquelio has spent time with the Adirondack Empowerment in Action’s Advocacy & Support Group, and has been a member of the Community Involvement Committee with the Care Network. Hobbies and interests that Arquelio likes are fishing, camping, painting, and drawing.



Mark Your Calendar!

Adult Self-Management Trainings will be offered in each region of the state between June and December 2011 — stay in touch for updates! If you or someone you know would like to learn more about your HIV health care, or would like to improve the way you work with your care providers, give us a call! We’re taking applications now for all 2011 trainings.

In addition, the LTI’s new Self-Management Training for HIV-positive young adults (ages 18-24) will be offered twice in the year ahead: once upstate and once in New York City. Call 212-594-7741 and ask for Gabrielle (x231) or Justin (x246) for details!



NEXT ISSUE

Meet some of the newly elected LTI CAB members!

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Look for information about Upcoming LTI Trainings

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Read about new happenings with LTI!

