

Hudson Valley RW HIV CARE Network

Consumer Involvement Committee Meeting
40 Saw Mill River Rd. Hawthorne, NY 10532
280 Broadway, 4th Floor Newburgh, NY 12550
November 19th, 2009 12:30pm-3pm

Present: (Hawthorne) Victor A., Glenn A., Darlene B., Patricia B., Maria D., Dawn K., Victor M., Richard N., David N., Thomas S., Michael S., Gerald Y.
(Newburgh) Ben B., Nathan B., Agripino B., Larry C., Ricky D., Kelvin J., Jorge M., Rachelle R., Leon W., Ronnie W.

Overview

Everyone received the agenda, the minutes from June 18th, election results, the 2010 CFA (Continuation of Funding Application/Work Plan), a packet of information about the Jeff Crowley conference call, and a document about H1N1. Committee updates were given.

World AIDS Day Announcements

The World AIDS Day Committee in Orange has organized an event for Newburgh on December 1st @ 6pm. It will take place at Mount St. Mary's on 120 South Street. There will be singers, awards, catered food, DJ, and testimonials. Flyers will be sent out.

Old Business

- **General Membership Overview**

- The following members were elected to the Executive committee:
Anne Anderson-Dutchess County
Dave Kreuter- Sullivan County
Teri Saari-Aliotta- Rockland County
Otto Klotz- Ulster County
- There was a presentation by Gilead about treatment adherence, an analysis of the Network's Quality Assurance program by Eva Whitney from Columbia University School of Social Work, InfoRock and Joseph Juste from Rockland County Department of Health (RDOH) presented on the services in Rockland County and the RDOH program with Haitian exchange students.

New Business

- **H1N1 and HIV**

The H1N1 Recommendations for the HIV positive population were reviewed. There was a brief discussion about H1N1 flu and how it relates to someone living with HIV.

Discussion points given by the group were:

- It may not be worth taking the flu shot for fear of side effects.
- If they were healthy enough, they may not even need it.
- If you risk not getting the vaccine, that you will be worse off.
- It is a personal decision to be made after getting enough medical information about the vaccine.

- **Living Quilt-UPWORDS Initiative**

- This project involves the creation of a website devoted to people's stories and struggles living with the virus, hence, a living, virtual quilt. This initiative is being led by Ben Barile, who was inspired by the Southern AIDS Coalition's website.
- Web design students and public relations majors from Marist College were asked if they would like to work on this project; they agreed to it.
- Ben is currently seeking funds for the project.

- The committee's help will be needed in recruitment efforts, promotion and other logistics. The seven counties of the Hudson Valley to be involved and then eventually the goal is to go statewide.
 - The motion to support this initiative was unanimous.
 - It was then asked if we could put together an ad hoc committee made up of point people from each county. They would be required to be on conference calls, get biographies from people, interview, etc. Volunteers for this committee included: Gerald Yarn and Mildred L.
 - **Action Item:** Barbara will put together a proposal and description of the initiative and have Ben sign it and send it out to the committee.
- **Meeting Frequency and Contact Protocol**
 - There is a motion in the Executive Committee to hold meetings every other month because of budget and other work constraints. We may have periodic conference calls to keep everyone updated.
 - It was also mentioned that from this point forward, committee members will be expected to contact Network staff if they want to attend meetings. It is becoming increasingly time consuming and counter productive to make phone calls to the entire committee especially as our membership continues to grow.
 - **Action Item:** Maria Diaz volunteered to help with phone calls to committee members. She can make the phone calls at ARCS.
 - It was asked how we can help people remember to come to meetings; tips included: highlighting the Network meetings on the calendar when you receive it and posting it up somewhere you'll see it.
- **Continuation of Funding Application (CFA)/Work Plan 2010-2011)**
 - The contract year ends in March 2010. The work plan goals from last year were reviewed as a springboard to see what needs to be added for next year's work plan.
 - On the work plan for 2009-2010, there was a Youth Group Education goal. It was asked if this was achievable and the consensus was that it may not be. Schools and the PTA may not support a speaker coming in to speak about HIV and the demographic of our committee may hinder our abilities to reach young people.

The following are activities for the 2010 Work Plan:

 - **Activity #1: Support the Living Quilt/Upwords Initiative**
 - Various tasks will be needed such as promotion, recruitment, etc.
 - **Activity # 2: Legislative Education Day- Albany and local offices**
 - **Activity #3: Promote Network in Rural Areas**
 - This can involve something small such as going to local hospitals, community centers and clinics and asking if Network members can leave promotional network brochures or going in groups to these places to educate people about the Network and how they can get involved. Victor Alvarez and Gerald Yarn offered their help and support to anyone in the rural areas who may need it.
 - **Action Item:** Victor and Gerald also agreed to do a presentation in March to help give some ideas. We can provide transportation for people in the Lower Hudson to attend the meeting in Newburgh.
 - **Activity #4: Identify Alternative Resources (housing, outreach, transportation, etc.)**
 - With the current economic state and as services for people living with HIV get de-funded, we have to come up with alternative ideas for people in order to live better lives.

- **White House Office of National AIDS Policy Conference Call**
 - Dan Tiez from AIDS Institute invited all of the Networks and their consumers to plan for a conference call with the White House on December 9th. The call's purpose is to get feedback from consumers in New York State to plan for a National AIDS Policy.
 - Committee members were given a packet of information about the Jeff Crowley White House conference call that included: AIDS Institute proposal/the purpose of the call, conference call notes, and tips to form effective community testimony to shape a results-oriented National HIV/AIDS strategy.
 - Also included was a voting slip so that members can choose who they think would best represent them on the conference call. The voting was done in a top-down approach with members ranking their preferred speakers from 1-3.

- **Web site review**
Deferred till January

- **World AIDS Day event & Focus Group**
This event will be on December 3rd at Locust Grove in Poughkeepsie. The Network is putting together a focus group at the end of the event about services in the Hudson Valley.

- **Faith Initiative-Consumer Focus Group**
Deferred till January

Announcements

- Deborah May, ARCS Regional Trainer may come to either our January or March meeting to discuss confidentiality.
- Dr. Smalls from Westchester medical Center will present at our next meeting in January.
- At the next meeting, we can look at the evaluation analysis that was presented at the General Membership meeting and figure out ways to make the Network more representative of the area.

Next meeting: January 21st, 2009

Meeting Adjourned.

Respectfully submitted,

Michelle Amatulle
Program Assistant