



Community Involvement Activities MEETING SUMMARY

Wednesday, May 22nd, 2019, at 5PM-7PM
Willing Heart Community Center
555 Martin Luther King Blvd. Newark, NJ 07103

1. Welcome and Moment of Silence

Warren Poole, Committee Chair, welcomed all in attendance. A moment of silence was observed for all those living with and have been affected by HIV/AIDS.

2. Community Involvement Activities/ Community Conversations

Background, mission statement, goals, and ground rules

3. Introductions/ Icebreaker

4. Public Comment

5. Old Business/New Business:

- Presentation: Chronic Diarrhea – Mytesi medication for HIV related diarrhea. New product about a topic that is not talked about that often because of the stigma around the subject. Some patients had had HIV for more than 50 years and HIV medication was causing it. During the past years, it has been shown that medication is not the only cause for diarrhea. Another reason is the damage caused by the HIV VIRUS to the stomach mucus alignment.

Presenter asked: "If HIV patients are not detectable after taking the medication, why they are not cured?" One of the members answered that it was because the virus stays on reservoirs. The presenter added to this answer that some of those reservoirs are on the small intestine deteriorating the stomach lining and causing diarrhea in some patients. When a stomach biopsy was done, researchers found that the virus reservoir was already on the stomach mucus alignment. After 2 weeks of been infected, the small intestine has already been affected by the HIV Virus causing the stomach lining to deteriorate and producing diarrhea on some patients.

Chronic diarrhea is defined as having 1 or more loose stools in a day for more than a month. Mytesi is the only drug approved by FDA to treat chronic diarrhea for HIV patients. Mytesi has been in the market for a couple of years but has been relaunched on the market for 1 year and a half. This drug does not cause constipation like other drugs used to treat this issue. Mytesi is made up from the red bark sap of the Croton Lechleri tree, which grows in Peru, Colombia. Indigenous people from those areas have been using that tree extract for healing wounds, stomach issues. This ingredient cannot be modified or created in a lab.

Presenter encouraged all consumers to advocate for their health and speak up about all the issues they might have. Warren mentioned they could take the pamphlet and talk to their doctor about this medication and mentioned it is covered by the insurance companies.

Presenter stated that patients need to take this medication at least for 2 months to have the most benefits from it. This medication does not go to the bloodstream and it will not affect any other medication already taking. It does not damage the kidneys. Medication goes strictly to the stomach and does not get into the bloodstream or kidneys like other medications. FDA fast tracked this medication in 3 or 4 years because medical trials did not show any major side effect. Usually, Imodium is prescribed as a medication for chronic diarrhea, but it is an opioid and might cause constipation.

A Study was made with people with HIV taking ART who had diarrhea for 1 month or more. This study had a group of people taking Mytesi and the other took a placebo. People took the medication twice a day, once at morning and once at night. After 20 weeks of the treatment, 9 out of 10 people had fewer watery stools than they did before the study. 5 out of 10 people had NO watery stools at all.

Warren shared his testimony about an instance he was given an opioid medication to stop diarrhea and he became constipated because of it.

This drug has been prescribed by GI Drs. for other medical issues like gastroenteritis, diverticulitis among others and it has been successful on treating those issues.

- Approval of New members – 3 candidates applied for the CIA/CC Committee.
Mr. Dexter
Nancy Nieves
Tawana Ramos
No one opposed and they were welcomed to the committee.
Members would have some benefits and they will have to be present at the meetings.
- Review non 75/25 resource allocations (approved by the PC in May) –
During the announced Warren mentioned some of the increasements on resources allocations based on the survey.
Tania mentioned that allocations changes are applied if core service waiver application is accepted. This will allow for funds to be applied on the non 75/25 resources allocations. Recommendations made were based on the consumers survey and based on consumers priorities. He emphasized the importance of attending committee meetings.
- NMAC BLOC training – Announcement was made about this 3-day training in Maryland. Warren encourage all interested consumers to apply for the treating.

6. Announcements

On June 5th, National HIV Long Term Survivors Day, Peter Ho Memorial Clinic is hosting a 3-day program (June 5th, June 12th, June 19th). On June 12th, Dr Slim will be holding a presentation on the What to expect (aging)? event. On June 19th, the topic will be Living my Life like It's Golden.

Warren mentioned the dates of the planning council meetings and the importance of assisting to those meetings. He mentioned some of the changes made in the allocation was based on consumer's feedback. Warren emphasized that meetings have public testimonies, where consumers can voice their concerns. Warren encouraged all attendees to assist to the planning council and other committees meeting, so their concerns are heard.

On June 22nd, there is an event hosted by La Casa de Don Pedro about LGBTQ+ Hear our Voices. This event will be held at Rutgers University - Paul Roberson Campus Center.

On Sept 27th is the 6th Annual Gay Men's Awareness Day hosted by the NJ HIV Planning Group's Gay Men's Committee. This is an all-day event from 9am to 4pm. Registration is required but bus will take all attendees to Rutgers - New Brunswick campus. Food is served and free.

7. Next Meeting

The next CIA/CC meeting will be held on June 26th, 2019 at 5 pm at the Willing Heart Community Center located at 555 Martin Luther King Blvd. Newark, NJ 07103.

8. Adjournment

This meeting was adjourned at 6:22 pm