

Community Involvement Activities MEETING SUMMARY

Wednesday, October 23, 2019, at 5PM-7PM
Willing Heart Community Center
555 Martin Luther King Blvd. Newark, NJ 07102

The Planning Council believes that the voice of the community is paramount. The purpose of the CIAs is to help bridge the gap between the community and service providers by creating opportunities to involve community members in the planning process. In addition, community members will receive crucial updates on changes in the Ryan White and related health/social services.

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, those who have passed, and those affected by HIV/AIDS.

2. Mission statement & Ground rules

Warren Poole, CIA Chair, read the mission statement and reminded all attendees the Ground Rules previously agreed on.

3. Speaker/Presenter; Q&A “HIV and Aging” by Gilead Pharmaceuticals Allison Modica

Warren Poole, CIA Chair, commented that last month was National HIV and Aging Awareness Day and this month CIA will continue conversation with a presenter from Gilead, Allison Modica. Allison Modica, the Community Liaison for Gilead, provided a presentation about “Living Well with HIV as You Age”. Modica mentioned that End the Epidemic Program is a State and County program. Modica also mentioned that Essex and Hudson County are part of the End the Epidemic in the State of NJ. A consumer asked: ‘How far away from the cure?’ Allison Modica mentioned that Researchers in different industries have not found a cure yet because the HIV attaches to the CD-4 cells and the HIV virus is able to multiply itself. Modica mentioned there is Rapid Initiation Treatment to avoid the virus to keep multiply and eventually become undetectable. A consumer asked about the effects of the HIV Medication. Modica advised all attendees to talk to their Dr. once they start experiencing side effects from the medication. Modica mentioned that their provider can change their current medication to avoid having those side effects. Modica mentioned that if currently taking Truvada, it could be change to Descovy. Modica mentioned that when patients adhere to medication, they can live longer lives. Modica stated that Life expectancy for People Living with HIV has increased; adding that next June the NJHPG will have a Long-Term Survivors Day event.

Modica mentioned that 1 out of 3 People Living with HIV were over 50 in 2008. Modica also mentioned that half of People Living with HIV were over 50 in 2015 and 73 out of 100 People Living with HIV will be over the age of 50 in 2030.

Modica asked attendees about the importance of talking about HIV and its effects with Age. A consumer responded because the body changes with age. Modica commented that People Living with HIV have a higher risk of developing health problems at an early age such as Mental Disease, Heart Disease, Cancer, Liver Disease, Kidney Disease and Bone Mineral Density Loss. Modica encouraged all attendees to adhere to the medication as prevention of any of these health issues.

Modica mentioned that Truvada had the risk to lose bone density and affect the renal function as a side effect. When medication was changed to Descovy, these issues decreased within a few weeks. The presenter explained that as people ages, their internal cells also age. She explained that the Immune System of People Living with HIV ages faster and might not protect them from infections as before. Modica mentioned that inflammation is a long-term silence process and is the disease of Aging. Modica mentioned that People Living with HIV could potentially experience Inflammation earlier than those who are HIV-. Modica explained that eating habits affect the overall help including inflammation.

Alisson Modica mentioned that the medication protects the internal organs. Modica mentioned that the Department of Health and Human Services have started the HIV medication earlier on patients within 3 days of being detected. Modica mentioned that before it used to take 30 days for a patient to start taking the HIV medication. Modica encouraged all to adhere to the medication so that CD-4 cells are not under attack and to prevent inflammation and other health issues. Modica asked:” Who likes their Dr.?” 8 out of 16 consumers raised their hand. The presenter mentioned that a good relationship with the provider needs to be established thus the patients can talk about any health issues with the provider. Modica also stated the importance of having access to medical care.

Alisson Modica mentioned that there are some things attendees could do to stay health and prevent any health issues mentioned previously. The following were mentioned:

- a. Eating Well (Modica asked what is eating healthy. A consumer indicated that eating veggies and fruits),
- b. Stop Smoking (Modica added that this also includes vaping because anything on the lungs could cause problems),
- c. Be Active (Modica asked” What is being active?” A consumer replied: “exercising”).
- d. Sharpening your mind (Modica asked what does sharpening your mind mean? A consumer explained that it could be done by reading. Another consumer suggested that meditating. The presenter added that learning a language or brushing your teeth with the opposite mind are also things that could help sharpening your mind.),
- e. Support Systems (Modica mentioned that it is important to have support systems.)
- f. Plan for the future.

A consumer asked if a woman is pregnant and has HIV, would the baby also become infected. Modica explained that if the mother takes the medication on a regular basis and is virally suppressed, the baby is born by C-Section and id not breastfed, the baby will not be infected. Modica revealed that there was a case where a baby was infected by being breastfed. Modica explained that to be virally suppressed, a patient must take the medication for a least 6 months and continue to take it every day. Modica mentioned that once the patient is undetectable, the HIV virus would not be transmitted to the partner. Allison Modica mentioned that researchers are still looking for the cure but there are some tools to End The Epidemic through treatment as prevention using PrEp. Allison Modica mentioned that in efforts to End the Epidemic, Gilead offers free medication.

A consumer asked about the issue the South is having. Modica explain that there have been more cases of infection in the South lately. Modica mentioned that there is a lot of work to do in the South to End the Epidemic. Presenter stated that there are about 38 Counties in the South in the End the Epidemic plans in comparison with the two Counties in NJ.

A consumer mentioned that it is good to talk about HIV prevention and living with HIV and asked: ‘What about the communities that are not HIV positive or LGBTQ? Consumer explained that she has seen announcements on social/dating apps for LGBTQ communities but have not seen those

announcements on social/dating apps for the heterosexual population. Consumer also explained that Heterosexual population is not open to talk about HIV like the LGBTQ population. Consumer asked how to reach the heterosexual population. Modica mentioned that Gilead has a Healthy Sexual campaign to get the heterosexual population to talk about HIV more openly. Modica also mentioned that everyone should talk about prevention. Modica also commented that Gilead went to ESSENCE, an African American Woman event to expand on the conversation and to reach out to different populations. Modica commented that all communities should be reached out.

A consumer asked about a recent medication that was on the news. Modica explained that it could be Biktarvy (A smaller pill that does not have a booster) because Truvada was been changed recently to different medications. A consumer commented that when someone changes their medications, they could experience resistance to the medication and will no longer be undetectable. Modica explained that data has shown that if a patient was undetectable and has changed their medication, the patient will remain undetectable if the patient adheres to the new medication. A consumer claimed that his changed his medication a couple of times because it stopped working. Warren Poole, CIA Chair, stated that if the medication is not being taking consistently, resistance to the medication could be developed. Poole also mentioned that if a medication is working for a patient, the patient should stay with it. Tania Guaman, Support Staff, asked: "why is it important to maintain medical appointments and adhere to medication to stay undetectable?" Modica explained that medical appointments are important because they do a blood count to measure T-Cell levels.

4. Approval of Last Meeting's Summary

5. Old Business

6. New Business

- a. Ryan White Part A Updates – Core Service Waiver
- b. Barriers to Viral Load Suppression

- Support Staff noted that in representation of the Newark EMA Planning Council, who is very interested in hearing the input from individuals affected by HIV/AIDS, staff was there to hear about the experience experiences of People Living with HIV/AIDS in accessing medical and support services.

Tania Guaman, Support Staff, mentioned that the Planning Council is interested in hearing from Affected and Underserved Communities' input to decide where to allocate the Ryan White Funds. Guaman explained that their HIV status is not being disclosed if the person does not want to, and that staff respects consumer's privacy. Guaman stated that even though notes are taken to provide feedback to Planning Council, there are no names as to who shared that statement. Guaman encouraged all attendees to look at last month's summary as an example. Guaman asked the following to all attendees:

- What do you think are some of the challenges faced by people living with HIV/AIDS?
 - o Internal / External Stigma
 - o Taking medications – A consumer stated that sometimes we forget to take the medications. Another consumer stated that remembering to take the medication is a reminder of the trauma of living with HIV,
 - o Having a trusted provider with experience in the field,

- Housing – “if I don’t have a place to sleep, my medications are the least of my worries.”,
- Mental health, ability/fear to disclose HIV status, limited support systems, ability to trust others,
- Information/Awareness/Education of both PLWHA and those not infected too (prevent stigma)

CIA Chair mentioned that there is going to be an event on Friday where Isaac Green, HOPWA, is going to be presenting and encouraged all to attend. A consumer mentioned that some pharmacies allows patients to leave their medicine and take their medicine daily when people do not have a safe place to store their medication, housing. Another consumer stated that some pharmacies wrap their medication, so patients do not have to open and close the medication bottle. Thus, patients do not have an excuse not to take their medication. Another consumer stated that people need to train themselves to think about taking their medication daily to prevent other illnesses on themselves.

Tania Guaman, Support Staff, mentioned that Housing is the number one problem in the Newark EMA. A consumer stated that some people who did not have housing were able to obtain housing.

Housing was mentioned, was one of the key barriers to care, which has been a priority for the Newark EMA for several years. Thus, Support Staff asked follow-up questions including:

- In the past 12 months, what problems did someone you know experienced when requesting housing services, if any?
 - The City of Newark is proposing to make clean (drug-free) urine and blood tests a requirement to receive housing benefits.
 - Consumer follow up - sometimes don’t make the decision to follow-through
 - Substance Use is a barrier because people cannot take care of themselves. Counseling/support is needed to make the right choices.

Warren Poole, CIA Chair, mentioned that The Ryan White Part A service is not being utilize like it should be. Poole mentioned that Planning Council is trying to support people with HIV and not to find out if people made a good or bad decision. Guaman mentioned that Support Staff is trying to capture all barriers to care to let Planning Council know about these barriers for HIV care. Guaman stated that Support Staff is trying to advocate on behalf of consumers.

- How would the housing situation of a person living with HIV impact their ability to? Attend their medical visits as scheduled?
 - Individuals might not be able to sleep to feel rested and go to appointments
 - Not feeling clean or prepared to see the doctor – (internal stigma)
 - Homelessness
 - HIV criminalization laws. Consumer added that why would someone disclose their status if it is seeing as a crime or people do not really want to talk about.
 - Substance abuse – makes you forget

Take their medications on time as prescribed by their physician?

- Taking medications can be a challenge because “I forget to take my medications”
- Taking meds “reminds me that I am living with HIV”

To stay virally suppressed.

- Housing provides stability so that more attention is given to well-being

At the end of the questions, CIA Chair, mentioned that he attended a conference where the issues on the South were addressed. Poole mentioned that the South does not provide as many services as the Newark EMA does and it could be why the HIV virus is spreading more.

7. Public Testimony

No Public testimony was shared during this meeting.

8. Announcements

Warren Poole, Chair, announced the following:

- St Michael's World AIDS Day will be held on December 4th from 11AM until 4PM AT St. Michael's Medical Center
- NJCRI's World AIDS Day will be held on December 7th from 12PM until 5PM at the Robert Treat Hotel located at 50 Park Place Newark, NJ. Registration from 11AM until 12PM.
- Peter Ho CAB lunch and learn about the HOPWA program on October 25 from 12PM until 2:30PM at St. Michael's Medical Center. There are 9 questions on the event's flyer, but attendees are encouraged to bring their own questions.
- Programs to help pay your PSE&G bill. Attendees might be able to apply for one or more of the programs listed on the flyer. La Casa application is due on June.
- The CIA flyer has information about the Planning Council and the CIA Committee.
- CIA Applications: If interested in becoming a member of the CIA, please see Tania or Vicky for applications.

9. Next Meeting

The next CIA/CC meeting will be held on November 20, 2019 at 5 pm at the Willing Heart Community Center located at 555 Martin Luther King Blvd. Newark, NJ 07102.

10. Adjournment

This meeting was adjourned at 7:00 pm