

**Ryan White Planning Council of the Philadelphia Part A EMA
Positive Committee
Meeting Minutes
January 12, 2015
12:00-2:00p.m.**

Office of HIV Planning, 340 N. 12th Street, Philadelphia, PA 19107

Present: PH (18), PA (6), NJ (2)

Staff: Nicole Johns, Jennifer Hayes

Call to Order/Moment of Silence/Introductions: D. Gana called the meeting to order at 12:10p.m. He read the mission statement.¹ A moment of silence followed. Those present then introduced themselves and participated in an icebreaker activity.

Approval of Agenda: D. Gana presented the agenda for approval. **Motion:** W. W. moved, M. Coleman seconded to approve the agenda. **Motion passed:** All in favor.

Approval of Minutes (*December 08, 2014*): D. Gana presented the minutes for approval. **Motion:** K. Carter moved, L. Way seconded to approve the minutes. **Motion passed:** All in favor.

Report of Chair:

No report.

- **Participation Acknowledgments**

D. Gana recognized attendees who were attending their first Positive Committee meeting with a token of their participation.

Report of Staff:

N. Johns thanked all members who called in RSVPs. She noted that timely RSVPs helped her order the right amount of lunches. She stated that an AACO representative would be arriving at the meeting around 1:30 to answer any questions.

Discussion Item:

- **Consumer Education FAQ**

N. Johns stated that the Positive Committee had discussed a Consumer Education FAQ at their last meeting. She pointed the group to the draft copy of the FAQ in their packets. She stated that she had tried not to be too specific, as she wanted the FAQ to apply to everyone. She said she had also tried to avoid repetition. She invited feedback from the group.

M. Coleman asked if there were resources to assist newly-diagnosed individuals. D. Gana stated that newly-diagnosed PLWHA could talk to their case managers. K. Carter stated that he'd like to include information about food banks in the FAQ. N. Johns noted that the FIGHT resource directory was a comprehensive guide listing where to access services. She stated that she had also included the URL

¹ Mission statement: The Positive Committee supports and enhances the role of people living with HIV/AIDS to empower their participation in the decision-making process of the Ryan White Part A Planning Council and the HIV Prevention Planning Group.

for the AIDS Library in the FAQ. A community member stated that he'd like to include information about SPBP recertification on the FAQ. W. Walters asked if there was transportation available to food banks through Ryan White, and N. Johns replied that there was not. She noted that Ryan White only provided transportation to medical appointments.

K. Carter suggested adding information about continuing education opportunities to the FAQ. He stated that FIGHT had many programs to educate consumers. A community member mentioned that aging was an important topic for PLWHA. D. Gana noted that PLWHA aged more quickly. K. Carter proposed including information in the FAQ about emergency funding through DEFA. M. Coleman suggested adding a phone number for a crisis hotline. D. Gana explained that the FAQ was intended to give information about Ryan White services. He suggested keeping a narrow scope for the FAQ. K. Carter asked if the FAQ would include information for persons with disabilities. N. Johns replied that she could include a generic statement referring clients to their case managers for more information on other services they might need.

W. Walters asked if there were still Ryan White support groups. N. Johns stated that there were many support groups for PLWHA, but few were paid for by Ryan White. W. Walters noted that many health centers had support groups. M. Coleman stated that support groups were held at Cooper Hospital in Camden, NJ at 6pm on Wednesdays.

A community member asked if case managers were required to attend medical appointments, and N. Johns replied that she was unsure. She explained that it was a standard of care for case managers to attend medical appointments, but was possibly not mandatory or enforced. She noted that patients could opt out of having case managers accompany them to appointments. D. Gana stated that, to his knowledge, case managers in Bucks County were required to attend appointments once a year. W. Walters and M. Coleman said they felt it would be very helpful if case managers accompanied clients to medical appointments. K. Carter stated that consumers should be proactive about making appointments and advocating for themselves. He said that patients should arrive prepared to appointments, with all necessary labs done and a list of any questions they wanted to ask the doctor. A community member suggested that consumers who were having problems with their case managers should talk to a supervisor or call the AACO helpline. K. Carter pointed out that clients could change case managers and could access case management services anywhere in the EMA.

A community member noted that he was new to the Ryan White program. He explained that younger and newly-diagnosed PLWHA like himself didn't know much about the Ryan White program. He asked what the program funded. D. Gana responded that Ryan White was a federal program that funded case management, ambulatory care, dental care, transportation to medical appointments, emergency housing, legal aid, and nutritional support. He explained that individuals accessed services using their Ryan White certification card, and had to be recertified every 6 months. He stated that a wide range of people qualified for Ryan White services. He added that Ryan White clients could get services anywhere in the EMA. A community member encouraged attendees to be proactive about their health and to use free internet resources around the city to research the Ryan White program. Another participant urged Positive Committee members to help newly-diagnosed individuals navigate the care system. W. Walters remarked that newly-diagnosed individuals were often scared and overwhelmed. She recommended that newly-diagnosed PLWHA take classes through Project Teach at Philadelphia FIGHT.

H. Bennett asked if clients had to go to their case manager to be recertified. N. Johns replied that they did not. She explained that all Ryan White providers were supposed to be able to certify clients. She

stated that clients would provide supporting documentation at the point of certification. W. Walters suggested including a list of requirements for Ryan White certification on the FAQ. N. Johns noted that clients needed to live in the EMA, make 500% of the FPL, and provide proof of income, positive HIV status, and residency, along with a photo ID. H. Bennett stated that he had to wait for his case management office to re-open over the holidays in order to renew his certification, which caused him personal hardship. He suggested the FAQ explicitly state that clients could recertify at any Ryan White service providers to help others avoid similar situations. A community member urged anyone experiencing an emergency related to Ryan White to call the AACO helpline or a support person for assistance. N. Johns implored attendees to call the helpline anytime they encountered a problem with case management.

M. Coleman stated that some clients were confused about the difference between their Ryan White certification card and their insurance card. W. Walters explained that many insurance plans did not cover some services like dental care or case management. She stated that Ryan White would cover these services.

Old Business:

H. Bennett noted that a holiday toy drive had been suggested at a previous meeting. He informed the committee that there were other groups doing holiday toy drives.

New Business: None.

Announcements:

M. Coleman reported that the Christmas party at the William Way Center had gone well, and around 75 people had attended.

M. Coleman stated that the Free Library of Philadelphia (at 19th and Vine) was holding a prison art reception tomorrow at 5pm.

M. White stated that he co-facilitated an HIV support group at Esperanza Health Center called Breaking The Limits: United. He explained that the group met on the 2nd and 4th Fridays of each month from 10a.m. to 11:30a.m.

Adjournment: The meeting was adjourned by general consensus at 1:33p.m.

Respectfully submitted by,

Jennifer Hayes, Staff

Handouts distributed at the meeting:

- Meeting Agenda
- December 8, 2014 Meeting Minutes
- Consumer Education FAQ Draft
- OHP Calendar

Monday, January 12, 2015

12:00-2:00pm

Office of HIV Planning 340 N. 12th Street Suite 203
Philadelphia, PA

Mission Statement- The Positive Committee supports and enhances the role of people living with HIV/AIDS to empower their participation in the decision-making process of the Ryan White Part A Planning Council and the HIV Prevention Planning Group.

○ Call to Order/Moment of Silence
Introductions

○ Approval of Agenda
○ Approval of Minutes

○ Report of Chair
• Participation
Acknowledgements

○ Report of Staff

○ Discussion Item:
Consumer Education FAQ

○ Old Business

○ New Business

○ Announcements

○ Adjournment

AGENDA

POSITIVE COMMITTEE

**PLEASE TURN ALL CELL PHONES AND PAGERS TO
SILENT OR VIBRATE.**

*The next meeting of the Positive Committee is
February 9th from 12:00-2:00PM at 340 N. 12th Street, Suite 203,
Philadelphia, PA 19107. Please refer to the Office of HIV Planning calendar
of events for committee meetings & updates (www.hivphilly.org). If you
require any special assistance, please contact the office at least 5 days in
advance.*

**Ryan White Planning Council of the Philadelphia Part A EMA
Positive Committee
Meeting Minutes
December 08, 2014
12:00-2:00p.m.**

Office of HIV Planning, 340 N. 12th Street, Philadelphia, PA 19107

Present: PH (14), PA (3), NJ (1)

Staff: Nicole Johns, Jennifer Hayes

Call to Order/Moment of Silence/Introductions: D. Gana called the meeting to order at 12:08p.m. He read the mission statement.¹ A moment of silence followed. Those present then introduced themselves and participated in an icebreaker activity.

Approval of Agenda: D. Gana presented the agenda for approval. **Motion:** K. Carter moved, M. Coleman seconded to approve the agenda. **Motion passed:** All in favor.

Approval of Minutes (*November 10, 2014*): D. Gana presented the minutes for approval. **Motion:** K. Carter moved, L. Way seconded to approve the minutes. **Motion passed:** All in favor.

Report of Chair:

D. Gana reported that AACO representatives attended the last RWPC and Comprehensive Planning Committee meetings. He explained that AACO had changed the name of the Health Information Hotline to "Helpline."

• **Participation Acknowledgments**

D. Gana recognized individuals attending their first Positive Committee meeting with a token of their participation. He noted that pins were also available for any attendees who were interested.

Report of Staff:

N. Johns stated that Ryan White Part A Planning Council Primer packets were available on the front table. She said that the packet explained the roles and responsibilities of the Planning Council and AACO (the grantee). She stated that the packet also explained how the Planning Council looked at needs and allocated funds. She said that the packet was written in 2008 but was still current.

N. Johns asked that all Positive Committee attendees RSVP in advance of the meeting so that she could order the proper amount of lunches. She requested that RSVPs be called in by noon on the Friday before the meeting. She stated that the Needs Assessment Committee would be meeting later this afternoon. She explained that M. Ross-Russell had presented a set of maps to the Planning Council several months earlier and would be presenting more of these at today's Needs Assessment meeting. She stated that the committee would also be discussing Needs Assessment interviews that had taken place on the state level. She invited all who were interested to attend.

¹ Mission statement: The Positive Committee supports and enhances the role of people living with HIV/AIDS to empower their participation in the decision-making process of the Ryan White Part A Planning Council and the HIV Prevention Planning Group.

N. Johns stated that the OHP had carried out prevention focus groups centered around how Philadelphians used healthcare. She explained that some participants were HIV positive and some were negative/unknown status. She said that the YMSM and high-risk heterosexual focus groups had been completed, and that no further focus groups would be conducted until February or March of next year. She said the next focus groups would concentrate on Black and Latino MSM from ages 25-55. She stated that recruitment would begin next year. She thanked all committee members for their help with recruiting for the groups that had been held so far. She said she was hoping to present some results from the completed focus groups by January.

Discussion Item:

- **Consumer Education FAQ**

N. Johns reminded the committee that last month they had brainstormed ways to get out information to consumers about Ryan White. She noted that they had decided to put together an FAQ. She explained that, at this time, there was no central location where people could find information about how to access Ryan White services. She said this could be a function of the Positive Committee's FAQ. She asked participants to brainstorm about what information to include. She stated that, based on what the Positive Committee decided, she would research and bring back more information to the next meeting.

K. Carter suggested that the FAQ list Ryan White providers by service type. He noted that many people did not know how or where to access dental services, for instance. He stated that his dental provider required patients to bring documentation to their appointments, including their Ryan White certification card, proof of income, ID, state insurance card (Medicaid/Medicare) if applicable, and a copy of recent lab draws (within the last 6 months). D. Gana noted that consumers often told him they needed dental work but could not afford it. He suggested including "How do I get dental work?" on the FAQ.

A community member suggested starting the FAQ with "What is Ryan White?" He said they could outline what the program was for, where the money came from, and who it was meant to serve. He said that, for maximum clarity, the eligibility requirements for accessing services should be laid out at the beginning of the FAQ. N. Johns pointed out that many of the requirements were the same across all services. She explained that providers did not share information about clients' Ryan White eligibility, and that this was the purpose of the Ryan White certification card.

D. Gana suggested the FAQ clarify that Ryan White was the "payer of last resort". K. Carter said that many clients would want to know "How do I get a case manager?" N. Johns added that some consumers were confused about whether or not they could access Ryan White services if they had private insurance, so she suggested adding "What if I have insurance?" She noted that Ryan White was often able to pay for costs that private insurance did not cover. H. Bennett suggested adding "Can I get assistance for housing through Ryan White?" W. Walters noted that Ryan White housing was on an emergency basis only.

N. Johns stated that some questions on the FAQ would direct clients to call the healthcare information helpline or to speak with their case manager. She noted that the case manager should be the first point of contact for most inquiries. She stated that the assistance of a case manager was needed to access certain services. H. Bennett said that the FAQ should explain the need for a case manager. N. Johns noted that there was currently no wait to get a case manager in Philadelphia. D.

Gana said that anyone who was having problems with their case manager could call the helpline to get connected to a new case manager. W. Walters stated that helpline representatives sometimes asked clients with complaints to stay with their case manager for a time while they were set up with another one. She said delays were more common in the PA counties than in Philadelphia. She remarked that she frequently got transferred between case managers due to high turnover. N. Johns pointed out that the entire case management system experienced high rates of staff turnover. D. Gana stated that clients who were dissatisfied with how often they were being switched between case managers could also call the helpline and discuss this with AACO.

K. Carter proposed adding "Where can I get services?" to the FAQ. He stated that many consumers were unaware they could access services anywhere in the EMA. N. Johns commented that all services were not available in all areas of the EMA. She suggested adding items to the FAQ about ADAP and SPBP. She said the FAQ could ask "Can I get help paying for my medications?" W. Walters asked if SPBP covered non-HIV medications. N. Johns replied that SPBP covered non-HIV medications if they were on the formulary. She noted that the formulary was extensive, and included many medications for managing side-effects and opportunistic infections. D. Gana stated that the SPBP formulary was posted online in a downloadable format.

K. Carter suggested adding "Can I get legal services?" to the FAQ. D. Gana remarked that the "What is Ryan White?" item at the beginning of the FAQ could be followed by "How do I get Ryan White services?" A community member said the process of getting certified might be easier to understand if it was laid out in a step by step format. K. Carter proposed the committee add "How do I get transportation to an appointment?" D. Gana pointed out that there were inconsistencies in the quality and type of transportation services available across different regions of the EMA.

D. Gana suggested the FAQ include "How can I get food?" He said that there were many food banks available through the Ryan White program. A community member asked how she could get assistance with utilities. She noted that she was a Section 8 client and was therefore ineligible for DEFA. L. Way responded that her case manager would likely know about other assistance programs. W. Walters suggested she speak with her housing grant manager, because there might be utilities supplements available to her.

H. Bennett pointed out that case managers also knew about many services that were available to satisfy client needs outside the Ryan White program. L. Grimes remarked that she had recently learned about a pet food pantry in Huntingdon Park, which also offered free neutering and shots. She said that accessing these services required a Medicaid card and ID.

N. Johns said she'd look into the questions that participants had suggested, and the committee could continue working on the FAQ in January.

Old Business:

D. Gana noted that he had talked about life insurance during the past few Positive Committee meetings. A community member stated that he thought he could not get life insurance. D. Gana replied that he had signed up for a \$10,000 policy that cost around \$65 a month. He said the policy would pay out the full \$10,000 after 2 years, and a portion of it before that. He noted that policyholders could borrow against the policy. He said he purchased his policy through E-Financial, a brokerage service. He reported that Metlife and Global Life Insurance also provided policies for PLWHA. He said customers had to provide information about pre-existing conditions (including HIV), and these affected the price of the policy.

A community member stated that low-cost life insurance policies were available through AARP for members. D. Gana cautioned that life insurance policies may cost more than their advertised prices, especially for PLWHA.

New Business:

D. Gana reported that FACT was hosting their Gay Bingo event this Wednesday in New Hope, PA. He explained that FACT was an organization that provided emergency funding for PLWHA that could be accessed through their case managers. He stated that he and K. Carter would be manning a Mr. Friendly table at the event, which would be held at the Firehouse near 202 from 6-10pm. He explained that Mr. Friendly was the new face of HIV awareness, encouraging HIV positive and negative individuals to openly discuss HIV without judgment. He said that the purpose of the Mr. Friendly program was to decrease the fear and stigma surrounding HIV. He added that one goal of the program was to get more people tested and in treatment. He explained that participants in the Mr. Friendly program did not have to disclose their status if they did not want to. He encouraged Positive Committee members to attend the Gay Bingo event and visit the Mr. Friendly table.

A community member stated that a Christmas party would be held at St. Luke's Church on December 19th. She said anyone who was interested in attending should RSVP to Nancy or Ben at FIGHT. She said the party would begin around 10am.

A community member suggested the Positive Committee start a toy drive for Christmas, aimed at families and children living with HIV/AIDS. He said that many non-profits and ASO's in the area used to hold toy drives in the past, but the numbers had decreased in recent years. He said the toy drive could begin in 2015, which would give the committee a year to plan for it. D. Gana asked where the collected toys would be stored. The community member said toys could be stored in the homes or offices of volunteers, or the committee could brainstorm other possibilities. He said that he'd be willing to be in charge of starting and organizing the toy drive. Another community member suggested speaking with retailers in the area about discounts or donations. H. Bennett said anyone who was interested in participating should get together to discuss the idea at lunch.

Announcements:

None.

Adjournment: Motion: K. Carter moved, W. Walters seconded to adjourn the meeting at 1:20p.m.

Respectfully submitted by,

Jennifer Hayes, Staff

Handouts distributed at the meeting:

- Meeting Agenda
- November 10, 2014 Meeting Minutes
- Ryan White Part A Planning Council Primer
- OHP Calendar

FAQ

Can I get HIV medical care and other services if I don't have insurance?

Yes, there are programs to help people who have no insurance or a hard time paying for HIV health care and medications. Their services and medications will be no cost or low cost, based on their income and insurance status.

Do people need insurance to get HIV services?

You do not need to have insurance to get HIV healthcare or medications. Call 215-985-2437 for more information on how to access services and get a case manager to help you with getting insurance and other benefits.

What is the Ryan White Program?

The federal government provides funding to states and cities to provide HIV care and medications to people who are uninsured and under-insured. These services include outpatient medical care, medications, dental care, housing assistance and other services. The federal program began in 1991 and is named after the teenage boy, Ryan White who got HIV through blood products. For more information about the Ryan White Program go to <http://hab.hrsa.gov/abouthab/aboutprogram.html>

Where can I find out more information about services?

Call 215-985-2437 for more information from the Health Information Helpline run by the AIDS Activity Coordinating Office of the Philadelphia Dept. of Public Health on how to access HIV services (including free confidential HIV testing). You can also get more information online at the AIDS Library at <http://www.aidslibrary.org/getting-help/> or by calling 215-985-4851.

Do I need a case manager?

A case manager can help you access health insurance, benefits and other services. Sometimes a referral from a case manager is required for access to services. A case manager can be very helpful for getting health insurance and navigating the health care system, especially for people new to the Philadelphia area or those recently diagnosed with HIV. You can call 215-985-2437 to speak to a social worker at the Health Information Helpline to find a case manager in your area.

How can I get help with dental care?

There are a number of places to receive low or no cost dental care. A case manager can help you get an appointment with one of the Ryan White-funded dental providers. You can also access dental care services (and other medical care) at the Philadelphia Health Centers. You can find out the addresses and other information about city health centers (and other community health centers) at



<http://www.phila.gov/health/ambulatoryhealth/index.html> or by calling the health information helpline at 215-985-2437.

Can I change doctors or case managers?

You may change doctors or case managers if you would like. It is best if you try to resolve a problem or conflict with the case manager or health care provider, but if you can't you may switch to another organization or another person within the same organization. If you need help locating a new organization or solving a conflict with a provider, call the health information helpline at 215-985-2437.

DRAFT



Produced for the Positive Committee

by the Office of HIV Planning

Updated: January 12, 2015