

CONSUMER INVOLVEMENT COMMITTEE

February 21, 2025

10:00 AM - 12:00pm

Meeting Minutes

MEMBERS PRESENT:

Susan B. Co-Chair
Pam B. Co-Chair
Avis G.
Barbara G.
Cathy M.
Denise R.
Eileen B.
Ernest B.
Gaius C.
Gerard S.
James C.
Juanita C.
John V.
Joseph P
Lance M.
Lisa C.
Nancy D.
Paul B.
Traci B.

MEMBERS ABSENT:

Angie
Arthur B.
Brian H.
Clara C.
June T.
Patricia R.
Tyrone B.
Wendy A.

GUESTS

STAFF:

Gerogette Beal
JoAnn Henn
Marcela VanTassel
Myra Alston
Nancy O'Keefe

STAFF Absent

Katie Ramirez

I. Welcome/Introductions

Susan B., Co-Chair opened the February 21, 2025, CIC meeting at 10:07am with a welcome and introductions. She requested a moment of silence to remember those who have paved the way before us, those whom we have lost, and those who are unable to join us,

II. Approval of October 11, 2024 and December 6, 2024 Meeting Minutes

Both the October and December meeting minutes were previously tabled. Mr. Marrow made a motion to approve October 11, 2024, meeting minutes with minor corrections. Mr. Burke seconded the motion

10 approvals 9 abstentions 0 opposed

Motion carried.

The December meeting minutes had some attendance errors. Mr. Marrow made a motion to accept the corrected December 6, 2024, meeting minutes. Mr. Burke seconded the motion.

9 approvals 5 abstentions 0 Opposed

Motion carried.

III. CAB Updates/Emerging Issues/Regional Trends

CAB updates used to be a standing agenda item. It has been reintroduced to give committee members the opportunity to voice concerns, share information, and address specific issues, as well as encourage discussion before reviewing the 2025 CIC workplan.

One member informed the committee that Gilead was approved for the six-month Cabenuva shot and suggested that a Gilead representative give a presentation at a future meeting. Another member shared his experience with Cabenuva injections. For the first three and a half years, it was successful and then complications occurred. He warned that a small percentage of people may be negatively impacted by Cabenuva.

Many committee members expressed concern and anxiety about the impact of potential funding cuts especially in the areas of housing assistance, continuation of benefits, and needed programs. Ms. Beal informed the committee that there are funds to close out the fiscal year and that a partial award was promised to start the new year. Information and resources were shared to provide help and support during these challenging times. Individuals were encouraged to contact 2-1-1; Ms. Tobar spoke to the committee about submitting a Project Warmth application to obtain heating assistance.

Some people felt that fear was preventing vulnerable populations, such as the undocumented and the LGBTQ+ community from seeking needed health care. Others felt that the needs of heterosexual men and women living with HIV should be addressed, stating that they are a hidden community; there are no statistics, data or social messaging. Support groups are needed. NMAC offers a support group for heterosexual men and women of color. The organization is currently in the process of getting approval for another women's support group. Sun River Health offers several support groups, including the Positive Space Program geared towards those aging with HIV. In addition, a cancer support group meets the second Friday of the month at noon and separate recovery support groups for men and women meet the last Friday of the month. While registration is required, an individual does not need to be a client of Sun River Health to attend the support groups. Thursday's Child hosts a group the third Thursday of the month at the Sun River Health Patchogue location, alternating between discussion and interactive activities.

Providing this opportunity for discussion was beneficial. The challenge of uncertainty notwithstanding, it is important to stay focused and supportive. During the most recent project

officer call, there was no news to report as HRSA has not sent out any new guidance or direction. As more information becomes available it will be shared with the committees and Planning Council.

IV. Develop and Approve FY2025 CIC Work Plan

A draft CIC Workplan for FY25-26 was shared with the committee. The workplan goals include activities related to: Outreach/Engagement, Needs Assessments/PSRA Process, Trainings/Development, and World AIDS Day. Some primary objectives of CIC are to increase consumer involvement by assisting in the recruitment of PLWH members to the Council and its committees; increase public awareness of important community issues related to the epidemic; and provide a safe place for consumers of Ryan White services to share their experiences.

Outreach/engagement- Consumers play an integral role in educating the community about the presence of the Planning Council and the role of consumers in the planning process. A proposed activity is to develop a targeted outreach plan for maintaining and retaining PLWH membership on the Council and its committee with a focus on how to outreach to the next generation. This activity is ongoing. The targeted outcome is to recruit 5 new members each year and to retain at least 3 new members. This past year, 3 new members were recruited, and all 3 members have been retained. Increased active consumer participation on the Council and CIC is enhanced through an orientation for members as well as mini orientations as needed. An annual CIC orientation was conducted in February of last year. Another one is scheduled for the April meeting. Consumer representation at community events, mentoring, speaking positively about the benefits of consumer involvement, and serving as liaisons to subpopulations, sharing experiences with other consumers is important and beneficial and can also assist with engagement and retention. While consumer attendance remains fairly constant at CQM meetings and has increased by 10% at SAP meetings, a targeted outcome is to increase CQM attendance by 10%.

PSRA Process/Needs Assessments- Consumer involvement in setting priorities for the region and assisting in the allocation of funding is vital in developing a comprehensive system of care in the EMA. Consumer perspectives on the realities of living with HIV/AIDS and gaps in services are vital parts of the PSRA process. An activity for FY 25-26 includes making suggestions to the SAP committee about additional needs assessments that are needed and should be conducted in the region. Although lack of funds prevents conducting needs assessments on a large scale, possible topics for smaller needs assessments using regional data include examining topics such as: Aging With HIV, Women's Health, and Heterosexual men living with HIV. Membership in other planning bodies is encouraged.

Trainings/Development- It is important to increase awareness and educate community stakeholders on HIV/AIDS issues as well as improve advocacy skills for CIC members. A list of training topics for FY25-26 was compiled. Suggestions included: a follow-up computer training, HIV and Aging; an update on how benefits may be impacted with this new administration and

one major consumer training/presentation for the year. The Medical Nutrition Therapy Conference, an event planned for 50 consumers, will be on Friday March 28, 2025.

World AIDS Day- The last part of the workplan is to promote the observance of World AIDS Day. A WAD debrief is included on the February CIC meeting agenda. Planning for the event includes reviewing the previous event, selecting a date 2025, theme and venue. Targeted outcomes include the amount raised through sponsorships, patrons, raffles and 50/50 as well as the number of expected attendees.

Joseph P made a motion which was seconded by Lisa C. to approve the FY2025 CIC Work Plan. All in favor.

V. MNT (Medical Nutrition Therapy) Conference Update

The purpose of the Medical Nutrition Therapy Conference is to increase awareness and knowledge of MNT and how it can improve the health of people living with HIV. The conference is scheduled for Friday, March 28, 2025 (10am-2pm) at the Sons of Italy Hall at 2075 Deer Park Avenue in Deer Park. Presentations will be conducted by the Part A registered dietitian nutritionists, representatives from Cornell, and there will be a panel discussion about the importance and benefits of Medical Nutrition Therapy. Dr. McGowan will speak on weight loss drugs. The event will also have food preparations and sampling, chair Yoga, nutrition Bingo, and there will be a resource table. A healthy lunch will be served. Flyers were distributed and committee members were encouraged to spread the word about the conference

VI. World AIDS Day

The 2024 World AIDS Day event was a success. More than 150 individuals registered and 146 attended the event. \$13, 556 was raised through sponsorships, patrons, raffles and 50/50 tickets, Planning for the 2025 World AIDS Day event will begin with a review of the previous event and continue with selection of the theme, awardees, and other related matters. Captain Bill's has been reserved for Friday evening, December 5, 2025.

VI. Announcements/Adjournment

Committee members were reminded to register for the MNT Conference if they have not already done so and encouraged to spread the word about the MNT conference.

A motion was made by Barbara G. and seconded by Cathy M. to adjourn the February 21, 2025, Consumer Involvement Committee meeting. **All in Favor-Motion carried.**