

**CONSUMER INVOLVEMENT COMMITTEE**

**March 10, 2023**

**10:00 AM - 12:00pm**

**Meeting Minutes**

**MEMBERS PRESENT:**

Susan B. Co-Chair  
Angie P.  
Arthur B.  
Brian H.  
Denise R.  
Eileen B.  
Ernest B.  
Gerard S.  
James C.  
Joseph P  
Lance M.

**MEMBERS ABSENT:**

Cathy M. Co-Chair  
Barbara G.  
Clara C.  
Gavis C,  
James H.  
John V.  
June T.  
Nancy D.  
Paul B.  
Roni W.  
Traci S.  
Tyrone B.  
Wendy A.

**GUESTS**

**STAFF:**

JoAnn Henn  
Katie Ramirez

**Absent**

Georgette Beal  
Myra Alston  
Nancy O'Keefe

**I. Welcome/Introductions**

The March meeting opened at 10:10 with a welcome and introduction by Susan B, Co-Chair. The February CIC meeting was postponed until today. The next regularly scheduled meeting is Friday, April 14, 2023 and will also be in person. Susan requested a moment of silence to remember those whom we have lost and those who are struggling with whatever they are struggling with. The National Week of Prayer for the Healing of HIV/AIDS (NWOP) was this week. Susan provided a testimony during the event on Thursday. Those who attended the event acknowledged the fine job she did and thanked her for speaking,

**II. CIC Work Plan**

The Planning Council and its committees are developing and updating their work plans. The CIC workplan was last approved in March 2022. A review of the workplan began with the purpose of the committee which is to recruit, advocate for, and support the voice of people living with HIV in the region for participation in Planning Council activities. One way this is accomplished is by conducting outreach and recruitment for this committee, other committees as well as the Planning Council.

There is a HRSA mandate of 33% unaligned consumer Planning Council membership. Currently there is 42% unaligned membership. Although this exceeds the required percentage, outreach and recruitment is an ongoing process. In terms of reflectiveness, youth and young adults are not represented on the Council. It is a constant challenge to attract, recruit and engage this specific group. When asked for help in identifying community events that provide outreach opportunities, Susan suggested having an outreach event with a tent, brochures and related information. The information should be written in Spanish and English. Flyers would be created to advertise the event. There may be opportunities to partner with other agencies, such as Pride for Youth and piggybacking at other events such as the Pride parade and National HIV Testing Day events.

Other suggestions included:

- Increase social media presence.
- Participate in Health & Science fairs.
- Contact Long Island colleges with strong advocacy and social justice groups.

Joseph P. mentioned Kareem Strong who is a strong consumer advocate for the AIDS Institute. He has some ideas to increase youth involvement. The suggestion was to reach out to him for ideas and suggestions. Further review and discussion of the CIC workplan is to be reviewed and discussed at the April 14, 2023 meeting.

While discussing younger consumers, the subject of those who were perinatally infected was also raised. These consumers represent a forgotten group facing similar health issues as long-term survivors, specifically bone density or the lack thereof. Many long-term survivors are experiencing bone loss as a consequence of their diagnosis and other comorbidities were unaware of the amount of loss. One consumer said he did not know the extent of his bone loss until hip replacement surgery, another shared that recovery from a serious accident which required lengthy hospital stays and medical treatments resulted in major bone loss. Neither were advised by their medical professional to have bone tests, a situation echoed by many committee members.

A committee member urged everyone to routinely go to the dentist, keep medical appointments, ask questions and take care of their health; a cautionary tale for young consumers about the importance of getting certain medical tests rather than later.

### **III. World AIDS Day 2023**

The committee agreed that the 2023 World AIDS Day event in December should be in person. Planning will begin at the April meeting. Committee members were asked to provide locations for possible venues, a theme, and award nominees, in preparation for the April CIC meeting. Details to follow.

### **V. CAB Updates/Regional Trends**

Thursday's Child together with AHF is hosting a Long-Term Survivors event on Sunday, May 21, 2023 at 1:30pm (Ducks baseball and barbeque event). RSVP is required.

Angie P. spoke about the consumer advisory meeting with the AIDS Institute on Thursday, March 9, 2023. Kareem Strong put a proposal together to engage youth and young adults. The goal is to recruit two young adults for each region to sit on a committee.

The American Cancer Society has a transportation assistance program which provides free rides for cancer patients to and from treatments. Their number is 1-800-227-2345.

**VI. Announcements/Adjournment**

A motion was made by Eileen B and seconded by Lance M to adjourn the March 10, 2023 Consumer Involvement Committee meeting. **All in Favor-Motion carried**