

CONSUMER INVOLVEMENT COMMITTEE

June 23, 2023

10:00 AM - 12:00pm

Meeting Minutes

MEMBERS PRESENT:

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

MEMBERS ABSENT:

Cathy M. Co-Chair
Brian H.
Gauis C.
James H.
John V.
June T.
Nancy B.
Paul B.
Traci S.
Tyrone B.
Wendy A.

GUESTS

STAFF:

JoAnn Henn
Katie Ramirez

Absent

Georgette Beal
Myra Alston
Nancy O'Keefe

I. Welcome/Introductions

Susan B., Co-chair. opened the June 23, 2023 meeting at 10:15 with a welcome and introductions. She then requested a moment of silence to remember those who have passed before us and those who are still suffering.

Angie P. was congratulated on her award from The AIDS Institute.

II. Approval of April 14, 2023 Meeting Minutes

Arthur B. made a motion to accept the April 14, 2023, meeting minutes as read. Ernie B. seconded the motion.

11 Approvals 1 Abstention 0 Opposed Motion carried.

III. HIV 50+Strong & Healthy Policy and Advocacy

Susan B. gave a presentation on NMAC's (National Minority AIDS Council) PowerPoint. A pre/post-test was distributed. The first slide asked committee members to state their preference

for gender pronouns, share when they were diagnosed as well as any involvement in HIV services. Most of the committee members are long term survivors. Their involvement in HIV services ranged from Council membership, sitting on committees, and participation in CABs to using Ryan White services. As the presentation continued, committee members were asked to be respectful of other viewpoints and experiences, be open to learning, and be assured that what happens here, stays here (Vegas Rule) Topics covered included, advocacy, the Denver Principles, a history of AIDS activism, aging with HIV, and taking action at a national level.

Advocacy is the act or process of supporting a cause or proposal. Key elements of advocacy are drawing attention to an issue, presenting solutions, and engaging in activities to educate the public and build support. Advocacy methods include meetings with policymakers, using social media, engaging, traditional media, and other creative campaigning tactics/strategies. Advocacy entails speaking for yourself and others. You are the experts of your own lived experiences. Committee members were encouraged to welcome others who can also speak to their experiences.

The Denver Principles were created forty years ago by the Advisory Committee of the People with AIDS and is a good way to cite the history of the PWA self-empowerment movement. To quote the principles articulated in Denver in 1983, which are as relevant and powerful today; *We condemn attempts to label us as “victims” a term which implies defeat, and we are only occasionally “patients”, a term which implies passivity, helplessness, and dependence upon the care of others. We are “People with AIDS”.*

The Denver Principles which include recommendations and rights, were reviewed. A brief summary:

- ✓ Recommendations to All people are to: Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.
- ✓ Recommendations for People with AIDS include: involvement at every level of decision-making and serving on the boards of directors of provider organizations. Also, substitution of low-risk sexual behaviors for those which could endanger themselves or their partners, as people with AIDS have an ethical responsibility to inform potential sexual partners of their health status.
- ✓ Rights of People with AIDS include: full and satisfying sexual and emotional lives, privacy, confidentiality of medical records, human respect and the right to choose their significant, to die and live with dignity.

A History of AIDS Activism was part of the presentation and included such topics such as Act Up, People with AIDS Coalitions, and Buyers' Clubs. The needs of older people living with HIV, were also addressed. Given the diversity of long-term survivors, needs may vary. Some common needs are, better coordination of HIV and geriatric care, mental health support, food and housing stability, Social Support, such as peer support and social opportunities. Isolation and

loneliness can be major issues for older people living with HIV and can impact physical and mental health, providing more opportunities to socialize is important. Senior citizen centers and meeting apps were suggested. Thursday's Child hosts long term survivor events which are included in the weekly grant mailing. On the national level, there is the Ryan Program. There is also the Older Americans Act, federal legislation to address the needs of older Americans by supporting delivery of social and nutritional services to older Americans and their caregivers.

The National HIV & Aging Advocacy Network (NHAAN) is a network of individuals advocating for our collective and cumulative interests as persons aging with HIV. Membership is open to individuals 50+ living with HIV. This organization envisions a world in which all people thrive as they age with HIV: physically, socially, financially, spiritually, emotionally, and in all aspects of their lives. Some of those present are already NHAAN members, others were interested in joining. The committee members thanked Susan B, for an informative presentation.

III. World AIDS Day 2023

World AIDS Day is observed on December 1st, which is the anticipated date of our 2023 WAD event. The committee decided to have it in person. There will be a virtual World AIDS meeting on July 7, 2023 to begin the planning of the event.

VI. Announcements/Adjournment

Beginning July 5th, Thursday's Child will be having social support groups (2pm-4pm) the first and third Wednesdays of the month at Sun River Health in Patchogue. The first Wednesday will be an art/writing group, the third Wednesday will be a presentation and activity.

NHAAN (National HIV & Aging Advocacy Network) is looking for new members. Gerard S. informed the committee about HEAP program that is providing air conditioners for those in need.

A motion was made by Eileen B. and seconded by Joseph P. to adjourn the June 23, 2023, Consumer Involvement Committee meeting. **All in Favor-Motion carried.**