**Attendees List:**

1. Kyla Loucks – ATC @ Albany Medical Center
2. Vanessa Gonzalez – In Our Own Voices
3. Diane DeGroat – Senior Attorney, Legal Aid Society of Northeastern NY
4. Lauren Stairs - Public Health Education Coordinator, Schenectady County Public Health Services
5. Scott Daly – PLWHIV, and Peer Advocate Ellis Family Health
6. Steve Sawicki – NY Links, NYS DOH
7. Sue Johnson – PrEP Specialist, Whitney Young Health
8. Jeff Hotaling – Alliance for Positive Health
9. Grace Fay – Alliance for Positive Health
10. Karen Bovell - AIDS Institute
11. Lauren Quinn – Albany Med Specialized Care Center for Adolescents and Young Adults
12. Al DeSacia – Albany Medical Center
13. Melissa Carbone – Hudson Headwaters Heath Network
14. Megan Green – RN, Albany Med Specialized Care Center for Adolescents and Young Adults
15. Akeem Tyrell – Albany Damien Center, Employment Pathways
16. Brooke Strauss – Albany Med Specialized Care Center for Adolescents and Young Adults
17. Charmaine Graham - Chair of the Bronx ETE Regional Committee
18. Jeannie Haller – Ellis Medicine
19. Ashley Smith – ATC @ Albany Medical Center
20. Meghan Thompson – Retention Adherence Specialist, Ellis Medicine
21. Kate Thorpe - Albany Med Specialized Care Center for Adolescents and Young Adults
22. Lisa Currin – AIDS Institute

**Call to Order** – Co-chairs Vanessa Gonzalez welcomed everyone and called the meeting to order at 9:07 a.m.

**Welcome** – Kyla Loucks & Vanessa Gonzalez, Committee Chairs

**Minutes Review – Kyla Loucks**

* **Motion to approve the minutes from the 1/18/2022 meeting. Motion made by Grace Fay; Sue Johnson seconded the motion. All were in favor, and no one abstained from or opposed the motion.**

**Legislative Updates – Perry Junjulas**

1. **Rest of State PWH Housing** – We have suggested budget language changes to be put in the Governor’s 30-day amendments that will allow low-income PWH outside of NYC to only pay 30% of their income toward rent.  If the Governor does not include this in the 30-day amendments, we will be working with legislators to add to the one-house budget bills.  We feel the language fix in the budget is the fastest and easiest way to get this done this year.  Thank you to Ashley Smith for your help in providing testimony on how we are impacted locally here in Albany!!  It continues to be UNFAIR that PWH in NYC have access to this rent cap while the rest of us in Update & Long Island do not, just because of where we live in NYS.
2. **340B CareOut** – the carve-out is still scheduled to go into effect in April 2023 and thus we are imploring the Governor to **rescind the 340B Cuomo-Carve-out** in this year’s budget amendments.  Should the carve-out stay in place, millions of dollars in resources will be taken out of our HIV providers throughout the state.  This pre-Covid pandemic-Cuomo-era budget decision was indeed a bad one, and we are pushing for a full repeal of this **racist** budgetary action, as this carve-out predominately will affect our Black and brown communities in the cutting of safety net services.  The Save the Safety Net Coalition, VOCAL-NY, and Damien Center will hold a press conference on Monday Feb 7 on National Black HIV/AIDS Awareness Day on repealing the carve out.
3. **The AIDS Advisory Council’s Legislative Education Day** is set for virtually being held on Feb 16.  The AAC’s ETE Budget and Policy Platform is attached.  For more information contact : aac@health.ny.gov

If you are interested in joining our bi-weekly ETE Legislative Meetings on Thursdays at 11 AM, please e-mail Seth Pollack at s.pollack@housingworks.org to be added to the list-serv.

Thank you to everyone for your continued group strength in helping PLWHA in our region while working to prevent new infections!

**Workspace**

* 1. ETE Stigma Campaign and discussion of new ETE goals

Kyla – We talked about the movement and ETE and where we want to go. We talked about the ways stigma can impact different communities. We talked about education and the need for provider education; education around older adults with HIV; we talked about long-term survivors and the process of aging with HIV and the process is new and folks want more education and to be better informed about what’s happening in their own lives; we talked about PReP and prescribing PReP, and how there needs to be more education in the way of health care providers. We also talked about where we wanted to move the ETE.

Vanessa – there was a lot of great conversation and a lot of great work with the committee. We were talking about what this could look like and wanted to see what your thoughts were. We were thinking, something to potentially do would be a campaign; HIV and an anti-stigma campaign, and share across the Capital Region. We would do it as collaborative work. The information would be spread out. For example, for In Our Own Voices – we would focus on folks of color and LGTGNC so we would focus messaging around that. If you’re working with folks who are aging with HIV, your focus would be that. If you’re working with youth, that would be your focus. We’re looking at a different way of focusing on this work and how it impacts the communities. We could have fliers or campaign messaging under that around the overall message that we could share with our different groups and communities so they’re all receiving this information and education. Perry could use this as a funding campaign at the legislative level, that funding needs to come to us as well. It could show what we do up here as well. The timeline is maybe by World AIDS day in December. Looking at folks who have a creative lenses or marketing under their belt as a way of assistance.

Karen – What would the campaign focus on?

Vanessa – It would be focused on an anti-stigma campaign and HIV, for folks living with high risk, or just community, and really debunk that and what that looks like for the folks that we serve. We could do it a couple of different ways – it be a social media took kit that folks could use; similar to what was done for PReP Aware week. You could post on Instagram and Facebook. We came up with the beginning idea of the campaign and wanted to work with everyone and hashing it out and hearing all of your different voices. We were thinking if we could do this on a social media platform would be amazing. The work would highlight what we’re doing as a community and highlights the stigma. Also use it on a legislative front as advocacy.

Jeff Hotaling – We could talk about people of different demographics and age groups. Talk about what everyone has in common. Social media sounds good but it also could be addressed within our own agencies with our own clients and testing facilities and things like that. We could also post in our own offices and can be shared with the providers and the DOH’s, something grassroots. With social media, you do only hit a few people and may be just preaching to the choir. So, along with social media, I think we also need to do something physical as a way of reaching clients and potential new clients.

Vanessa – We’d have to work out how would it look and look at each piece of it; would everyone print their own material? That would be the financial side of it too. Could the AIDS Institute help us financially support the committee? I appreciate the idea of something you can hand to someone, something physical. maybe we could also hand out paper pieces for those who’d like to have a tangible object. We could also do fliers as a way to get it physically out there. Not everyone has the internet as a resource. We’ll work as a team and figure out how we want to send out the message. Use different ways to utilize folks from your organizations as well and use their expertise. If it’s up to us to print it on our own, we come into the financial aspect of it, so I think the social medial piece is still a good idea as well.

We’ll use each meeting as our working meeting, to figure out what the messaging will look like. Hopefully by December we can have this launched.

Jeff – I’ll reach out to some people on my management team to see what we can do. Cannot promise we can do anything but will look into it. We do have a grant that’s up in June, so I’ll find out if we can use any of it to support this.

Ashley – I like the idea of focusing on stigma and finding multiple ways to reach out to people. I heard what Jeff stated about finding people who work in our agencies and we don’t want to assume that folks working with people with HIV understand the stigma of people who have this in our bodies, feel. Do we have speakers out in the communities who can communicate with medical students, doctors and providers, nurses? People living with HIV voices that could be a part of yearly training for people who work in those places. When I was diagnosed, I would go out and speak at schools and educate them.

Scott – Back when the NAMES Project had its Albany chapter, we had opportunities to be welcomed to the high schools in order to be able to talk about AIDS. A school in Schenectady allowed us to Mohonasen, Schenectady and Scotia-Glenville high school. The Ellis School of Nursing allowed us to speak on it. Since the Albany Chapter dissolved, we’re not seeing those types of invites anymore. Not sure how we rekindle that and get back out there. It was usually done around AIDS World Day. Maybe we should reach out to the high schools to see if they continue to have AIDS Advisory Boards, then see if this is something we can do again. Through them maybe we could get speakers that could go into the schools again.

Jeff – Don’t forget the universities as well.

Ashley – Some of my patients said to me it used to be meaningful to have folks go out into the schools and talk and is there a way to do this again? This could be turned into something where I can help people living with HIV and to teach other people. I think we could find people would like to speak on this again.

Kyla – Vanessa and I thought it’d be a great way to focus our efforts. We can create sub-groups one of them can focus on the voices of long-term survivors, then you can come up with the messaging. Come up with what you want to say and how you want to say it. We can have a group that talks about youth and folks that work with youth. We work in the focusing on creating an event. We all have amazing ideas so we can all work on our focuses. We can work in breakout groups in Zoom. Reigniting the Speakers Bureau and creating it from here.

Jeff – You can’t underestimate the stigma with the healthcare providers. We have the two groups, but how about a third group, that will educate the providers. The PrEP committee had a successful event with providers and maybe we can do this again. we had limited funds and we were still able to do it. we had about 77 providers show.

Ashley – I agree that we should cover health care providers. The stigma is massive and it starts with testing.

Karen – Even PrEP use has its own layer of stigma in terms of why are you taking that and what does it mean and all of that. There might be some interesting resources up on our website. If you want to move forward with any of these ideas, I sent Vanessa and Kyla the concept paper template. You can work on a draft on that to see if any funding can assist on the project.

Vanessa – Any other thoughts or ideas on this? I love the Providers idea; maybe we can do work groups on that; addressing the community as well as providers; it may look a little different. We can start by doing breakout groups and start focusing on the messaging piece.

Kyla – I’m writing down everyone’s comments and I am splitting everyone up into provider and all their ideas, per side. and where each group can work. One group is focused on community and consumers and the other is focusing on providers.

Diane – I think it makes the most sense to have the two tracks – one helping people who are affected and one for those who can have access to helping.

Jeff – Something to think about with providers and education is doing STI testing.

Karen – What is highlighted is the missed opportunity is to link HIV with STI services. We need to do a better job of doing a partnership with HIV and STI testing.

Ashley – What you said earlier about people not taking PrEP. I’ve heard it from partners of patients coming in. There’s a lot of lack of understanding and the view is people who are on PrEP are out to have as much sex as they can. The idea of linking the testing of HIV and STI can go hand in hand. If we can get providers to use this as a regular part of health their health system in their medical office, it takes away the stigma, that it just happens to certain kinds of people with certain types of lifestyles and behaviors.

Jeff – The status neutral approach is used with the New York City model, so if anyone wants to look at it they can. It was their way of reducing the stigma and just making it a normal part of life.

Kyla – I want to echo Jeff’s comment about Agency when it comes to community involvement and your sexuality is your own responsibility. We do a lot of testing with college kids, and my first question is – are you sexually active? Do you have a chat with your partner about your sex life before you kind of do things? I get a lot of “no one talks about it, so why would I talk about it”? I like to say it like “this is agency and this is you choosing to do something about it”. I like to talk about it because no one talks about it. This is a piece of something that is yours. There’s something very empowering about that for some folks. We can educate providers to the point where they’re asking, and we can educate the community. There’s a way we can narrow that down. We can put on poster or put on a palm card, to either give out to the community or give to providers. another way we can get that out there.

Jeff – There’s one group that we’re missing. We’re talking about youth aged up to 24-25. And we the older 50-60 folks, but there’s that middle ground that we’re missing. There’s a big chuck of folks in their 30s and 40s. There are so many groups to reach.

Vanessa – Thinking about some of us who are in are late 20’s and early 30’s; some of the education piecers were missing for us when we were in school. You go to the doctors and they’re not providing that education to you either. They’re professionals or they’re at home with their kids and they’re doing their everyday things and life gets in the way. It wasn’t shared with me until I got into this field. How do we provide that information that they have access to? It’s planting the seed for everyone else. How do we reach out to them and get them the information?

Grace – We can’t forget about the age group that’s just out of college. 20% of new infections are people between the ages of 20-35, that we can’t forget about; those professional who are non-professional that are hanging around.

Diane spoke about the perpetuation of stigma that exists every time she is required to ask patients about their sexual history when doing an intake. She would like to know how she, as a non-medical provider, can do to reduce stigma and not subject folks to being uncomfortable.

Jeff – We struggle with that within our own agency grants for example. They’re like “I’m just here to pay my utility bill” “why do I need to tell you who I’m having sex with”?

Diane – To what extent are we part of the problem on serving this community? How can we lessen that impact?

Ashley – As a person living with HIV, I understand and thank you for being aware of that as a problem and ways that we can address that stigma.

Karen – Diane and Jeff, I hope you have shared your thoughts with your contract managers. I encourage you to share that with us, so we can think of ways to make this more beneficial to others and less hurtful.

Jeff – The AI is aware of it and they’re thinking “how can we figure it out”?

Diane – Karen I appreciate that. we’re talking about it and how can we ease these interviews? We’re starting a 5-year grant term, so It’s a good opportunity to figure out how can we improve our processes and procedures.

Lisa – I think some of the ideas you have coming out of the QI brainstorming we’re doing with Jeff and his team; some are not medical so asking those questions as a legal person are uncomfortable and makes it more stigmatizing. Dominque had the idea of giving those persons more individual and doing it in a way that’s not making people feel uncomfortable.

Jeff – one way to help take the stickiness, is having them fill out the paperwork in privacy and without vocalizing it.

Lisa – I would encourage you to reach out to your contract managers as well. We’re doing site visits and we’re doing very extensive evaluations, but this is something you can include.

Diane – As a non-medical care provider, that information has never been shared with me; particularly with the services that I am providing. I understand the overarching need for statistics and trends. I have wondered, with the niche area that we’re in, are we providing critical information to the patients or are we just asking the same questions that they’ve been asked to ask for the last 10-20-25 years without more critical thought about do we need this information and how will this be used.

Lisa – That is a good point; it would be helpful for the AI to share that information. The information is used and we’ve used it recently. The information that has been collected has been used within the last year. Direction and clarity would be helpful so I’m going to pass that along as well.

Vanessa – This is great conversation. Information is used to help others and it can hurt them quite a bit. For example, a black trans woman asking “are they just asking me this because I’m a black woman”? They think things are being assumed. I appreciate the two lenses that were brought up. Our goal is to touch as many people that we can and do it with integrity. Want them to know we’re doing it for their benefit.

Karen – when it comes to messaging, I’ve been in a lot of circles. The white gay men. Somebody will always feel left out or spoken to. It’s important to focus on the individual and behaviors. Not try to put individuals in boxes. Food for thought as we asses what our message looks like.

Vanessa – I was part of the PReP campaign and there were folks that felt like they weren’t a part of the community and they felt left out. Black trans men felt like they weren’t being seen. Someone is always going to feel not seen or heard. We want to show up and let everyone know they will be seen and heard.

Vanessa – For next meeting we can start working on messaging and what we want to put out there. And start working on the two fronts.

Lauren jumped off the call early but Schenectady County Public Health want to be involved as much as they have capacity to assist with this effort of increasing education to decrease stigma and make testing a routine thing that happens at all provider offices.

**Closing Comments**

None

Meeting adjourned at 10:10 am

**ETE Capital Region Meetings are from 9 AM to 10:30 AM on the 3rd Tues of each month**

Next ETE Meeting is Tuesday, March 15, 2022

**Co-Chair Contact information**

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ETE Webpage at <http://www.albanydamiencenter.org/capital-region-ete.html>