**Attendees List:**

1. Diane DeGroat – Senior Attorney, Legal Aid Society of Northeastern NY
2. John Hartigan – AIDS Institute, Bureau of Community Support Services
3. Kate Thorpe – SCCAYA, Albany Medical Center
4. Lauren Quinn – Albany Med Specialized Care Center
5. Lyndsi Wickert – Albany Damien Center, Employment Pathways
6. Scott Daly – PLWHIV, and Peer Advocate Ellis Family Health
7. Steve Sawicki – NY Links, NYS DOH
8. Kyla Loucks – Albany Medical Center
9. Sue Johnson – PrEP Specialist, Whitney Young Health
10. Jeff Hotaling – Alliance for Positive Health
11. Grace Fay – Alliance For Positive Health, She/Her/Hers
12. Karen Bovell, AIDS Institute
13. Lauren Quinn – Albany Medical Center
14. Alex DeSacia – Albany Medical Center
15. M Carbone
16. Haydon Marshall – Legal Aid Society
17. Ashley Smith – ATC @ Albany Medical Center
18. Amy Palma – Unity House
19. Lisa Currin

**Call to Order** – Co-chairs Kyla Loucks welcomed everyone and called the meeting to order at 9:06 a.m.

**Welcome** – Kyla Loucks & Vanessa Gonzalez, Committee Chairs – Vanessa will not be attending today’s meeting.

**Minutes Review – Kyla Loucks**

* **Motion to approve the minutes from the November 2021 meeting. Motion made by Grace Fay; Lyndsi Wickert seconded the motion. All were in favor, and no one abstained from or opposed the motion.**

**Legislative Updates – Perry Junjulas**

No updates at this time.

**Subcommittee Updates**

1. Youth Sub-Committee: Lauren Quinn, Co-Chair

We’re having a meeting today and Lyndsi has been awesome to do the hybrid option form the Damien Center. We’re trying to make the agenda flashy and put in some agency updates. Hoping to plan an event with Marz to do a paint pouring event. And trying to recruit some members for the new committee. We put in for funding for some support from the state for our committee to try and get refreshments and supplies for the paint pouring event. Hopefully that will be approved.

1. Adult HIV Testing Sub-Committee: Chris Wasik, Co-Chair

We’ll discuss later. Chris is moving on from her position at Albany Med. We’re looking for someone to take that subcommittee over if we decide that is still a priority focus for us. If anyone is passionate about doing new sub-committee let us know.

1. Linkage & Navigation Sub-Committee: Steve Sawicki, Chair

NYLinks is going virtual again. We were optimistic about doing it last year and now the beginning of this year, and that’s not happening. Was just told June or July are not going to happen. We’re now looking at September for in person meetings. We have a lot of webinars coming up. In the January email it has a list of all the things we’re doing. We have a PEP webinar next week and have a lot of guests coming from around the country and the world. Those who have been attending NYLinks regional meetings should expect to see something. We’ll do a virtual meeting the end of February or early March. We’ll look at cascade data; I have access to regional data that we can look at. We’ll do some QI training. We did a big training of continuing of consumer involvement and we had about 170 people attend. We’ll repeat that in April. The biggest thing, on Feb. 1st we are planning a support session from 10:00-11:00, on supporting staff during this Covid surge. It’s open to everyone. It may be beneficial to talk about how to support staff, medical professionals and ourselves. We need to focus on the things we have control over. We have a long list of things we’ve got scheduled through April. If you’re interested, send me an email and we’ll send you an invite.

Karen – Would it make sense to include something for older adults?

Steve – The older adults and HIV is being targeted by so many people, so we’re staying away from that. There are so many others doing workshops and webinars; we don’t want to step on anybody’s toes. For the moment we won’t be looking at that. We won’t do another telehealth because so many others are. There are still things we still don’t know how HIV impacts the body, and the medication. We have a lot of folks that are engaged in a long-term study. Thanks for the idea, Karen.

1. PrEP Sub-Committee: Sue Johnson, Chair

We did not mee for Dec. As you know Donna Muller has moved on and she’s doing really well. I have proposed previously that we disband the sub-committee since this meeting has the most attendance and has the most areas covered. I get a sense that now a lot of the meetings aren’t getting attended like this one. I think we can bring everything to this group once a month.

**Conversation about a new direction for the ETE**

Kyla – We’ll skip agency updates for now and talk about new business and talk about the survey outcomes and about what we want this group to look like going forward. If anyone opposed to the idea of disbanding the subcommittees and working collectively as a whole on things with focuses.

Diane DeGroat – I think it’s a good idea. I have not joined a subcommittee because of the commitment of the additional time. We can always revisit.

Lisa – I like the idea too. I know it’s hard to make subcommittee meetings.

**Conversation about Goal Setting:**

Kyla – Another thing I’d like to talk about is setting goals and projects – For example, we had asked what ETE goals would you want to focus on. Focus ideas include:` Racial justice; trauma informed care; injection drug use & opioid overdose; aging and HIV or older adults and HIV. Do we want to pick a focus and then create measurable goals?

Ashley Smith – I like the idea of working on projects by using the collective wisdom and experience of the group to identify where we see things that are falling through the gaps. We are finding that the providers that are diagnosing them are not putting in an order for their test, so they’re not fully informed about how to council the patient, inform them of their status and then link them into care. I’d love to know from other people, what are we finding and what are the gaps. Do we need to do better communication with each other?

Kyla – I agree. Something that we take some time before our next meeting. **Each of us reflect in our own agencies – what can we bring to the table; what priority do we want to focus on? what we can we come to agreement on.** This doesn’t have to be for the next year or next three year; it can be for the next two meetings. Ashley said we want to focus on HIV issues related to seniors. How do we access sustainable care, housing, legal aid, food for HIV folks who are aging?

Scott – This committee was originated from the Governor’s plan; each region was to have a committee like this that was to provide information to ending the epidemic across the state. Not sure if the subcommittees were to provide the ETE the statewide committee with information that they needed in order to see how we were progressing with ending the epidemic. I think before we come to a conclusion on what to do with the subcommittees, we might need Perry’s input. I believe he was the one who originated this committee. I would want to hear, were these subcommittees part of the origin of the ETE committees across the state to provide the statewide committee with input.

Karen – the ETE committee did originate to give inputs to the blueprint. All the discussions were implemented within regional steering committees. Charles King had the encouragement that those groups remain in existence. Once the blueprint was established and approved as a plan that we would use, he thought and supported and encouraged the chairs at that time with continuing regional discussion to do a few of the things that you just talked about. One is to remain in communication with the AIDS Institute. Also to assess what the regions want to do with the blueprint. How they want to implement it; how they want to organize themselves to do the ETE work or continue to do the mission. Each committee looks different; some have subcommittees, some do not. Each have their independence to create the group how the group sees fit how to address issues.

Grace Fay – The Alliance for Positive Health has an aging group that meets monthly­­­, and would be interested if we decided to pick a topic to focus on to have those attainable goals and involve those consumers. Because of Covid we are not meeting in person. I think we should pick a couple of goals and meetings those goals.

Kyla – What voices are we currently missing at the table who can help inform our decisions, who can help create better, sustainable goals? Especially folks within communities we are not a part of, so they can share first-hand experience. If you know someone living with HIV or people who are within communities that are affected by HIV or folks who have a passion for the work that we do, invite them to a meeting. What voices are we missing at the table.

**Survey Results:**

1. Education, reducing stigma and normalizing HIV testing
2. Equal access to HIV housing support
3. More consumer involvement
4. More providers prescribing PrEP

Sue – There’s been a disconnect of those going to urgent care or ED, especially for PEP. The PEP hotline has been helpful to people. There’s no follow-up there. There’s no one saying ‘let’s take a look at your sexual health’. There’s been a drop off in referrals in ED’s and urgent cares, saying ‘here’s a general practitioner you can go to’ or ‘this is where you can go to, on a general basis’. Testing and follow up is something I’m passionate about.

**Conversation about bringing in Speakers:**

Kyla – We can maybe have folks who can come and talk to us; especially about those topics we’ve been discussing. Maybe use 30 minutes of our meeting.

Lauren – At AMC we’re in the process of getting a new electronic medical records system that will have different systems for inpatient and outpatient have a different system. One of the doctor’s recommended putting it in questions about STI testing and putting it on the intake process. And asking would they benefit from PrEP, are they interested in PrEP? He was going to talk to someone (on the PED’s end) to see if that’s doable. It could be a start, at least at our hospital.

Ashley – I want to echo what Sue and Lauren were saying. Identify opportunities as a group to identify when to reach patients, and a combination of brainstorming of doing new things. Also, how can we use the structures that are already there? Like NYS law saying that every provider providing something like primary care should be offering the HIV testing at least once in their lifetime of visiting that provider. How can we increase that? How can we increase ED’s offering HIV testing as a routine thing and then knowing what the process is to follow, whether going towards the HIV treatment or recommending PrEP. Or having general talks about having sexual wellness. There’s a lot that’s already out there but it’s not being implemented, and I think all of us see it at different points of the spectrum regardless of where we are. I’d like to work together to see what our clients experiencing, then we try to figure out who to talk to or what to do about this, so we can get together and work in this. Scott does a great job on who we can have come talk to us.

**Conversation about barriers to care:**

Kyla – Having folks come in and sharing the barriers that they face. Does anyone have any other thoughts or direction you think we should take?

Scott – For young people, there’s lifesaving meds and they can get their meds and get on with their lives. That’s a lot different from when I was diagnosed and there were no life-saving meds. I’m having a difficult time getting young people to want to participate in peer groups. The emphasis seems to be with the long-term survivors. They are interested in hearing about HIV and aging. They want to know what to expect as they’re getting older. One of the goals is providing that kind of education regarding HIV and aging. I feel like long term survivors and again people want that information. However, it be by NYLinks webinars or however they want that information.

Steve – Scott touches upon something that’s more complex than he presented it. There is something what I call the cohort situation. What is means is that there’s an event that, in their timeframe, that defines them. There was the AZT group and then there was the next group and they have their cohorts. Each time frame is different because we were each trained differently. I want to get someone at the institute or education of higher learning to address some of the things we’re seeing on a day-to-day basis.

Lauren – working with the adolescent population. The newly diagnosed population will come an get their meds, but they struggle with their diagnosis and taking their medication daily too.

Kyla – What resources are available for younger and older folks. How to communicate with those populations. How do we have those folks guide us where we’re going. They have different and incredible perspectives and should be meaningful voices that we’re listening to.

Diane – Looking through a race equity lenses and how it impacts those of color. It cuts across all our practice areas. Considering the diversity, we have in this group and how to better serve these communities, especially with the rates of HIV and AIDS, I think we could make an impact here. At Legal Aide we’re looking at it internally.

Lisa – I agree with Diane we should be looking at across the board at the new diagnosis among those populations. The AI is focusing HIV and aging and our bureau of community support services, there’s a position that is being filled for and HIV and AIDS resource person. So we’ll be able to give more support for that issue.

**Conversation about stigma:**

Jeff – One thing is common – we talk about folks who are newly diagnosed and long-term survivors. One thing we haven’t talked about is stigma. It’s a theme that’s bringing everyone together. The younger people don’t have that trauma but they still have to deal with the stigma of telling their partners and families and others. They feel like they have that stigma that they feel that they have to carry with them the rest of their lives. When I was in D.C. a couple of Autumns ago, they brought that up as one of the main topics. I feel they haven’t brought that to the Capital Region. Stigma could also be those who come back with negative results and how they’re perceived by professions and others.

Scott – I’m glad it was brought up by Jeff. Telemed was also a plus for those who hated coming in to the hospital because they would worry about who they’d run in to. We noticed that the number of appointments missed has decreased when Telemed came about. The patients didn’t have to worry about anyone seeing them. I’ve had HIV for 35 years and stigma is still ruling the day.

Kyla –Stigma touches these groups in different ways: provider education; it touches on providers (primary and specialized), PrEP, education around primary care providers, HIV testing, housing and food insecurities, racial discrimination. Maybe this is somewhere we can start. It could be our focus for the next year or the next meeting.

Karen – The Regional Steering committee hosted a PrEP forum north of Albany and it was well attended. Also, the NYS Advisory body, we are looking at a status neutral model that can be used across the state. We’ll make sure we keep you guys in the loop on that.

Jeff – Status neutral does not make assumptions about the client you’re working with. It’s having the client come in and say here’s your results. You start neutral, once you get your result, then you adjust your conversation.

**Agency Updates**

Damien Center: Lyndsi – I am leaving the Damien Center and moving on to the CFS. Thank you all for the great work that you do. You’re in good hands with the team and everyone that is on the call today. keep sending your referrals over to us for those who are looking for employment of educational assistance. Bowling for PAWS is back and we’ll have it March 20th at Sparetime in Latham. Go on our website to register or email me and I can send you information.

Legal Aid: Diane- Hayden just joined us. Our intake isn’t available yet, but once it is we’ll let you know.

Albany Med: Al stepped up as our PrEP coordinator – excited to be here and be a part of the group.

**New Business**

1. Participants invited to reflect on topics discussed today to inform the direction we take with the ETE in this upcoming year. We will set goals and themes at the February meeting
2. If anyone has any ideas, feel free to email Kyla or Vanessa before the next meeting.

Meeting adjourned at 10:30 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, February 15, 2022

**Co-Chair Contact information**

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