

## **CNY Connec+ions for Poz MSM Conference Call Report**

- ✚ **This report is for the Call held on:**
  - **November 5<sup>th</sup>, 12<sup>th</sup>, Dec 3<sup>rd</sup>, 10<sup>th</sup>, no lines were available for the other weeks of November due to DOH AI not able to provide them**

**Number on calls: (14) participants total for all dates listed above, (1) facilitator**

All persons on the call were from the 315 area code

Actual Call times varied with most running over the allotted time

### **Topics and brief summary of:**

- ✚ **Relationships** – it was mentioned that moving in with a new partner has its stress but is somewhat easier when the other is also poz, discussion followed on how to help each other with health care whether living together or not, networking with each other can be very helpful in more rural areas especially
- ✚ **H1N1 Discussion** - callers were asking if they should still get the shot if they have already had H1N1, although it is a very good question the callers were advised to speak to their ID Doc and ask their opinion, and then make their own decision
- ✚ **Local provider** - problems and problem solving were discussed in regards to the quality of care from callers local provider, callers still want to try and have a CAC set up over the phone and if the provider does not want to join, would callers still like to join and they were in favor of that, no labs are given out or sometimes are made light of when asked what the numbers are and why, suggestion was made to get a paper copy at each appointment to keep and review for callers records

- ✚ **Medicaid changes** – some callers were concerned with health care through Medicaid, changes not communicated and they are not aware of what is covered or not, facilitator said there is a list that is generated often along with ADAP to say what is covered under their plans, ask your provider to give you a copy or maybe the Rx can provide a copy too, you can also access some of this information online under the DOH AI web site
- ✚ **ONAP Dec 9<sup>th</sup> call and planning calls** – two northern region network callers agreed to be a part of the ONAP planning calls and to provide testimony on Dec 9<sup>th</sup>, drafts of testimony is being slowly worked on by callers and facilitator
- ✚ **National Library of Medicine** - callers were asked if they would be willing to answer a few questions in regards to the NLM grant received, having to do with internet access and communication, callers were in favor of this
- ✚ **Speakers for calls** – it was reported by the facilitator that this is not as easy as it was thought to be, rethinking this process it was discussed and decided that when a topic arose we would schedule it for a following call, thus eliminate the need for additional calls or changing dates or times, providers may be limited because of time restraints
- ✚ **Exercise** – the benefits of exercise were discussed after some callers complained of feeling sluggish or somewhat down, suggestion was made to always check with your provider for mental health or talk to your doctor too before doing any exercise program, some were not aware of the YMCA discounts or planet fitness rates, exercise at home was suggested too for many reasons, one caller mentioned yoga as his routine and likes it a lot and encouraged others to try it
- ✚ **Meetings in Northern Region** – callers were asked if they would still be interested in meeting face to face on occasion for Network meetings, Rx educations, Advisory meetings and such, callers were very happy to know that this can be possible still with good weather, the facilitator will again try to set up a lunch meeting in the Watertown area, that is the best location usually

- ✚ **Debriefing of ONAP call** – callers were asked how the experience was for them, what they thought worked well and didn't work well, what follow up would they like to be part of, overall the two callers were happy with the ONAP call and want to do more of this type of work in the future, some may want to try and come to Albany for legislative advocacy
  
- ✚ **Med interactions** – callers concerned over not being told about side effects or possible interactions, callers advised the Rx provider can give this information also but the Doc is also supposed to discuss any of this when prescribing meds or changing a med regiment that is a standard of care
  
- ✚ **Sleep problems** – callers brought up sleep problems, lack of or always feeling not fully rested, it was suggested to talk to their Doc about a sleep disorder test they can have, talk to the Doc about possible apnea, always ask questions and do not stop until you are satisfied , too much caffeine or sugar is not helpful late at night too
  
- ✚ **References for HIV/AIDS information and other information related to being HIV positive** – this is an update on web sites and places for information that has been suggested for callers to consider using, all are good and you may find one that best suits your needs, some are not using the internet much but will keep it in mind, Some sites mentioned are CNYHSA.com, TheBody.com, Poz.com, AIDSMeds.com, NYSDOHAI, other HIV journals, The National Library of Medicine, all are available on line and have tons of information their sites, libraries are great places to go if you do not have a computer to use, the facilitator will mention certain articles from some sites at most meetings, referencing current news and treatment information
  
- ✚ **Reminder** – callers told to don't hesitate to call or email if some assistance or a question comes up between calls or a suggestion for a topic to talk about is appreciated too and all requests can be discussed with the facilitator

 **Callers are always thanked for calling in and some calls were very productive and had great discussion of topics**

**Submitted by,  
John Wikiera**