“Planning Pregnancies in 2014: Options and Opportunities for Care of People and Couples Affected by HIV.” *This text is being provided in a rough draft format.*

>> Speaker: Hello, everyone. Welcome to the webinar “Planning Pregnancies in 2014: Options and Opportunities for Care of People and Couples Affected by HIV.” Thank you for joining us today. Before I begin I would like to ask everyone if possible to press star six. Please press star six to mute your line. This will ensure better sound quality for everyone. So if you could press star six that would be much appreciated. Before we begin I do want to let you know that this webinar will be recorded and few days after today after the webinar itself and before we begin with our wonderful presentation I’ll run through technical slides so you're comfortable with the WebEx platform for the webinar. Technology is two-fold and you should have the presentation on your screen and audio component which you have called in for. If it is not progressing you could reload or restart the browser and it should solve the problem. Again, thank you for both pressing star six and muting the microphone on your phone. That should improve the sound quality.

This is what you should see in the browser window and to see what is by the presenter and PowerPoint presentation click on the tab beside the event info tab and screen and you can move back and forth between these tabs. Here on this other slide you will notice that an area has been highlighted in the red box and this is your panel and in this red box you can find areas such as participant list and Q&A and then adjust the size of the panel by dragging the left border back and forth with your mouse but it is however possible to send in some questions throughout the webinar using

the Q&A section in this red box in this panel.
We are going to save questions until the end. We will be monitoring questions throughout presentation and if something requires immediate attention you will be sure to raise it. Otherwise we will keep the question and answer period until the very end and hopefully we will have time to get through most of the questions, otherwise what we will do subsequently is make sure that your questions are submitted and collect them and develop a word document that you would be shared after the presentation to make sure all questions are answered, even if we don't have to get time to get to them in this 1 hour period.
To make the presentation take the computer screen, click the full screen button at the top right. This will ensure that the presentation fills up the whole screen if you want to exit full screen you can press the escape key on your keyboard. So with that being said, technical matters sorted, I'm very happy to be here for the first webinar in series that's being organized by IHPREG to give you information about these two partners, IHPREG are leaders on the issues associated with HIV during preconception, pregnancy, postpartum and in any circumstance following pregnancy and CATIE is Canada’s source for information about HIV and hepatitis C. We are very, very happy to be collaborating with IHPREG on this webinar series which will feature three webinars over the next few months. In addition to today's webinar which is going to be looking at planning pregnancies in 2014, the other upcoming webinars are, “A Complicated Dilemma: HIV and Infant Feeding” and will take place toward the end of November and “Life with Baby: What Happens Next” which will be taking place in December. We will be communicating all of this information with you and details as soon as they become available and you will be

registered and signed up for the information list and we'll send you dates as soon as they become available.
And we also want to highlight the fact that right now this webinar series is in English, we will be organizing a webinar series in French in 2013 in the New Year and that having been said we welcome questions in both languages. (speaking French)

With that being said we can introduce today's webinar and speakers and we actually have two speakers. Gladys will be speaking after Mona and it's wonderful pleasure to have the opportunity to invite Mona to present this webinar. Mona is very accomplished doctor as many of you know, she is a clinician scientist at Women's College Hospital as well as Associate Professor in the Department of Medicine at University of Toronto and Director of the Women and HIV Research Program at Women's College Research Institute and also practices at Maple Leaf Medical Clinic in downtown Toronto which serves over 2700 HIV-positive patients. In addition to all of this Dr. Loutfy dedicates her time working with rural, remote and underserved women and is a very, very busy person and it's a wonderful honor and pleasure to have her join us here today for this webinar so without further ado, welcome Dr. Mona Loutfy.

>> Mona: Thank you, Sophie, so much, that's such a nice introduction and we have a tight schedule today so I'm going to jump right in and I see we have great participation over 50 participants from right across the country and it is great to see everybody so I recognize many names and say hello to all of you. I would like to declare that I have no conflicts related to this work.

So the objective of my talk in the next 30 minutes are going to be to review factors, making fertility increasingly relevant in the context of HIV and then to review issues that are of performance to fertility and HIV and you probably joined because you have a particular interest in prevention of horizontal transmission so I will go over that in quite a bit of detail and hope that you have heard of the Canadian HIV Pregnancy Guidelines and I will review those for you and then, before we move on to questions last minute, we have had the pleasure to add a speaker and community member with two pregnancies and two children and one of the pregnancies was planned so we have brought them here today.

In terms of background probably all of you on the phone have a lot of experience in HIV so I don't have to remind you that over the last three decades the field has greatly changed with introduction of combination ARVs and that morbidity and mortality have decreased. Now, when young person is diagnosed with HIV, we can tell them that their life expectancy with antiviral drugs will be 50 to 60 years from diagnosis. Life expectancy has really prolonged and even more recent data suggesting that it is starting to be equal to that of the general population. Other factor that's important when we talk about fertility planning is that there's increasing prevalence of people living with HIV in across the world that are women. So globally, over half of the people living with HIV are women and in Canada it is stabilized at 23%. Not just women, men with HIV, the majority of them are reproductive age. Many of you know the breakthroughs that have happened over the past decades to prevent vertical transmission so that transmission of the virus from the mother to the child has gone down

and we are able to do that with antiviral drugs and in Canada (worldwide less than 1%) but Canada, in fact, the rate is less than .5% with any treatment and with reasonable anti-viral treatment is less than .1% and for all of these reasons we believe that persons living with HIV are going to be interested in pregnancy planning and many of you may have seen this in your clinic or know friends who are interested in pregnancy planning.

A study in 2008 surveyed 490 HIV-positive women of reproductive age that were living in Ontario were asked what their fertility desires and intentions were and what we found out was 50% -- 57% of them actually, intended to in the future and that's a large number and large percentage and we feel -- felt that the HIV healthcare service needs to be ready as well as the fertility clinics potentially to serve these women and potential couples. So because of that we started something called the Canadian HIV Fertility Program and about 2009 and this program's vision was to champion a collaborative program that guides people with living with HIV in Canada with fertility desires and pregnancy planning in a holistic, ethical, supportive and medically sound manner. I always like reading that. It has been awhile actually. So we have been working on number of different projects related to the fertility program to try to meet that vision. One of the program's main goals is not just to promote fertility and pregnancy planning but it is also to promote the uptake of counseling and discussion regarding pregnancy between healthcare providers and all HIV positive individuals and contraception discussions and allows for discussion of sexual health, healthy sexuality, relationship, risk of transmission and criminalization. One of the main goals for the project was to bring that discussion to the front line of -- between healthcare providers and all HIV positive patients.

Studies have shown in women with or without HIV is -- if a pregnancy is planned there are better maternal and infant health outcomes. But then also specifically in the context of HIV reducing vertical and horizontal transmission and thinking of how to do that is that much more important.

70 national stakeholders and potentially some of you on the phone were involved and brought together fertility specialists, HIV specialists, obstetricians, gynecologists, community members, social workers, psychiatrist, policy makers, researchers, pediatricians and really an exciting time probably one of the most exciting feature was fertility specialist how we connected with HIV specialists across the country. Sometimes I would go to a city where one city with HIV specialists in the same city hadn't actually met each other and we would bring them together and to have them start to work together. So that linking was such an important step.

Through this -- this linking we developed national guidelines on pregnancy planning which I will show you and we, also in partnership with CATIE, developed pamphlets and then we have a workshop like this. We have facts sheets that we would like to disseminate a bit more and we have our IHPREG website. So these are actually the different headings guidelines to see there and more detail and for example sharing a healthy mother and baby and families utmost important go over that and anti-retroviral drugs and options for reducing horizontal transmission but there's other really important sections in the guidelines and psychological and mental health issues which I will not go into detail and also the legal and ethical issue section which I will not go into. Grab a copy of the guidelines which I have

right here. They're available in English and French and at the website and they are a great read and find them.
Here is first section of the guidelines on pregnancy planning and usually talking to infectious disease specialists so imagine I have to encourage infectious disease specialists to some places patient only see infectious disease specialist because there's lack of access to primary care. So I have to inform them need to talk about pregnancy planning, find out about what your patient's reproductive goals are and if they want to become pregnant write the prescription for folic acid.

So folic acid can be given one to 5 milligrams a day before pregnancy. It should be taken at least 1 month preferably three months with pregnancy and first trimester and recommended whole pregnancy to prevent neural tube defects. What I have found recently what I have done is if we write the prescription for 5 milligrams of folic acid they can pick it up from the pharmacy which is now the allowed dosage in pre-pregnancy and in pregnancy and started to do that more and more. Encourage the women not to smoke or drink and have a balanced diet and terminate recreational drugs and use a harm reduction model for anything that they would like to do.
I just realized there was a delay, so I'm sorry about that. In terms of anti-retroviral drugs and fertility there was key points that are new in terms of what to start and when to start. New guidelines actually indicate that it is better for a woman who's planning pregnancy to get on to anti-retroviral drugs even before planning the pregnancy and making sure that her viral load is undetectable before planning the pregnancy so you can see there we would like her to be on antiviral drugs and have suppressed viral load

for three to six months prior to the pregnancy. The reason for that is once she becomes pregnant and having nausea and vomiting and we don't want to be adding anti-retroviral drugs that cause nausea and vomiting and don't know which one it is and have her stable with undetectable viral load and also some studies that have come out of France showing that if there's a delayed start in anti-retroviral in pregnancy and suppressed viral load, transmission can still happen. Because of both of those reasons and pretty much guidelines recommending anti-retroviral therapy for all patients, maybe not someone who's long-term non-progressor but otherwise recommending it for all patients to start anti-retroviral therapy and make sure everything is stable.

Make sure anti-retroviral drug and pregnancy except for the first six weeks. So class D drugs cause birth defects in babies and class D meaning there's been two to three human cases of neurological abnormality and, however, that abnormality happens in the first six weeks of pregnancy and that's when organs are forming. If a woman is on Efavirenz and passed first six weeks of pregnancy she can stay on Efavirenz. These new pieces of information are in the guidelines. D4D, ddI and ddC should never be used in pregnancy. We use standard regimens, three ARV drugs, 2NRTI and classically Combivir and we are not using it anymore because of toxicity in terms of mitochondrial toxicity so we do not prescribe it anymore and just this year, in March 2014, the American guidelines added Truvada and Kivexa and recommend Truvada and NNRTI, Efavirenz is in the preferred list for NNRTIs if you can believe it and that's because first six weeks has passed there's very little toxicity to Efavirenz. Other important point to know about the guidelines of anti-retroviral drugs in pregnancy is if a woman becomes pregnant on her regimen they recommend not

changing that regimen because more complications and drugs and side effects. Another important feature to know is both mother and father should not have HCV treatments six months before conception and specifically that is the component. We potentially know even less regarding pregnancy and those drugs right now. And last bar there of potent combination and this is even data from 2002 and 1% and data in Canada shows that actually it is 0.04% and delivered and non-adherent and in Canada there's been no transmission of HIV to the infants when proper antiretroviral therapy has been used. And more details on anti-retroviral use in pregnancy can be found from these guidelines, U.S. Public Health Service Task Force guidelines on HIV and pregnancy and go into anti-retroviral use and use of Cesarean section and ARVs and not breastfeeding.

So we've spoken about how important it is for the mom to do general pregnancy planning items like taking folic acid. We talked about that we want the prospective mom to be on anti-retroviral therapy and to be stable. The next thing to talk about regarding pregnancy planning is that to actually become pregnant there are two types of bodily fluids that have to potentially mix and trying to be funny, don't know if anyone is laughing usually but really want two cells to mix with sperm and egg and to be able to do that it potentially could put someone at risk for the acquisition of HIV. So we want to prevent that horizontal transmission. In the guidelines what we actually have done is listed a bunch. Scenarios where people with HIV could want to become pregnant. You could have HIV process woman with HIV negative man. You could have HIV positive woman who's single who wants to become pregnant or HIV positive woman in same sex relationship who wants to become pregnant. In the guidelines we have put all of those scenarios together because in terms of the prevention of horizontal

transmission it is the same issue that comes up. And we have HIV positive man with negative woman and serodiscordant couple and HIV positive man who's single or in same sex relationship or couple seeking egg donation or surrogate and there may be other scenarios and on this list I have seen every kind of couple. What we recommend is regardless of what the individual or the couple scenario is, the best thing to do is review all the different options for insemination and conception and to review the continuum of risk and what the knowledge is regarding the risk of horizontal transition for each one and for the individual -- the couple to decide what they want to do.

Technically unprotected intercourse with an HIV positive individual on anti-retroviral therapy with fully suppressed viral load is an option for insemination. However, it's not ideal. Since women ovulate only one day a month or individuals ovulate only 1 day a month, the second option is what we would recommend, unprotected intercourse used with timed ovulation because it is intercourse that is then limited to the timing of the ovulation limiting exposure and fully suppressed viral load. Home insemination is option so that is known as the "turkey baster" method or the syringe method and that would be when the sperm donor provides semen and woman has to be -- person has to be ovulating and using a syringe (or turkey baster) and inject the sperm close to the cervix and that's home insemination. Also, they could do uterine insemination in fertility clinic at the time of ovulation they take the semen from the sperm donor and with a catheter place it inside the uterus. Also, sperm washing following IUI is option, at an infertility clinic where they spin the sperm and they get a sperm pellet which is free of HIV in the liquid. Other options theoretically have lower risk and in vitro fertilization and sperm insemination, gestation

or surrogate carrier and adoption. Technically we can do all of these options with a couple or an individual, it's for them to decide what they want to do. For the guidelines with what's recommended for each scenario. Experts have come up with one or two methods that they recommend as the preferred choice or method of insemination. When woman is HIV positive and man HIV negative home insemination with syringe poses zero risk to the man. So that's why that's the -- that's the preferred choice or intra-uterine insemination poses zero risk so both of those could be recommended. When the scenario is -- when man is HIV positive and woman is HIV negative, the guideline development team, chose sperm washing as the preferred choice and this is back in 2009 and guidelines published in 2012 and what was -- and this was based on in the next slide in Europe they have done thousands of sperm washing followed by IUI and negative transmission and it was based on that data that guideline development team recommended sperm washing followed by IUI for that scenario.

However, I put in pink on my next slide whether unprotected intercourse with ovulation on antiretroviral therapy should also be an option that should be acceptable and recommended for the scenario of HIV positive man and HIV negative woman and we had actually -- just got a CIHR meeting grant to pull together the development team again of the guideline to review the new data regarding unprotected intercourse and presented to them to review whether that should be amendment to the guideline and commentary about the guideline. So I think all of you know about the HPTN052 study which was a randomized control trial that randomized about 1800 serodiscordant couples. One was HIV positive and one was HIV negative and ran to HIV positive individual to get anti-retroviral therapy

right away versus delayed when the CD4 count went below 250. And the primary end point was actually transmission of HIV to the uninfected partner. And what was found was that there were 28 link transmissions, 27 of them were in delayed arm so not on anti-retroviral therapy and one was in early where -- transmission occurred at three months after the start of anti-retroviral therapy and the viral load was not suppressed. Okay? So this was one of the first major studies showing that unprotected intercourse with a fully suppressed viral load might be a viable option. However, it is important to note that in this study the participants were counseled to use condoms and 98% reported using condoms and that's caveat for this.

Pre-exposure prophylaxis (PrEP).

Could we give the HIV negative woman Truvada and Efavirenz? 46 couples used prep with unprotected times intercourse but none -- none of the female partners had acquired HIV. Now, going by a study that has 46 couples who took PrEP is not very good science. It is not a robust study so it is hard to say what if they didn't take PrEP? Would they still not have acquired HIV? What we did in our group at IHPREG with a student – Masters' student, Michelle, did economic evaluation of conception strategies for serodiscordant couples where female neglect and male positive and timed ovulation on antiretroviral therapy and suppressed viral load versus the same with PrEP or with sperm washing. Okay? And putting in all the variables we know in terms of risk of transmission of HIV to the negative partner, worst case scenario in terms of that, cost of HIV, cost of the sperm washing, probability of getting pregnant. Most cost-effective strategy for that type of couple to get pregnant is unprotected intercourse with timed ovulation and using PrEP with cost increase of $438 and sperm

washing of $14,000. This is not a clear – it's still evolving and we hope that we can provide a commentary about this from the development team of the guidelines soon as this topic evolves. New data this year came out at the -- at conference called CROI which was the PARTNER study where they have enrolled 1,110 serodiscordant couples and they're following them prospectively forward in time. Inclusion criteria included sex without a condom some of the time. No PrEP or PEP and had to be antiretroviral therapy with a fully suppressed viral load. Presented at the conference in March and two years data aimed to finishing 2017 and presented on 767 couples and there were no transitions between couples. Again, preliminary data, but as the data comes more and more we are finding that there's no transmission with unprotected intercourse with fully suppressed viral load. However, no transmission and studies does not mean zero risk so that's important. Now, in terms of if both partners are HIV positive what's recommended is that both individuals be on anti-retroviral therapy and have a fully suppressed viral load and unprotected intercourse with method of insemination. The guidelines also review this very important point that HIV positive people should be counseled about fertility issues that occur in the general population. Most important one is actually advanced age so many people with HIV might have fertility issues. Not at all because of HIV but actually because of advanced age and also the guidelines print out that infertility investigation in treatment should be offered to HIV positive people if acquired just like the general population. On that note, I would like to show you these pamphlets we have made with CATIE, they are available through CATIE in French and English and you can call their call center and order them, pregnancy planning information for HIV positive men and their partners and pregnancy planning information for HIV positive women and

their partners are very useful pamphlets and I'm going to end on this note which is that pregnancy planning for individuals and couples with HIV and Canada is important and a reproductive rights issue and the WHO (World Health Organization) says that all couples and individuals have right to decide freely and responsibly the number and spacing of their children and to have access to the information, education and means to do so and we believe in that principle and that's why we are doing the work we are doing. I would like to thank the team and our funders to be able to put all of this work together and I will hand over now and also really like to thank CATIE for organizing these webinars. I think they are just a really important knowledge translation and exchange of tools and methods that will be able to use across the whole country. So on that note I will pass this on to our community member who can give you her lived experience regarding pregnancy planning.

>> Speaker: Thank you very much, Mona, for a wonderful and very interesting presentation. I want to flag the fact that we are going to be distributing a resource list or resource list will be available after the webinar which will include links to the pregnancy planning guidelines and pamphlets that were just highlighted. So you will be able to find all of this information in one spot. Without further ado I want to welcome Gladys to generously participate in the webinar. I don't want to take up too much time so just introduce Gladys and hand over the mic. Gladys has been working as peer research associate on number of projects for over five years and as research assistant in Toronto and collaborates closely with HIV positive women and healthcare providers and is particularly proud of the work she did in the HIV Mothering Study that looked at HIV positive women and the

first year of motherhood. Her work has mostly revolved around women's health and well-being and she is mother of two that lives in Toronto. Thank you, Gladys.

>> Gladys: I'm happy to be here and I have ten minutes to jump in and talk about my experience. So 2006 (indiscernible) I was diagnosed with HIV so was really also -- this is the end of dreams at some point and think for a long time I was sitting there very ashamed of myself and really thinking great to be disappointing and so along with mourning that I could never have children, something that I wanted for a long time I was now -- like in my culture women, at 31 you can expect questions when are you getting married and have children and it was shattering those dreams of having children at some point but as time went on I put my energy into volunteering at organizations and learning about the disease itself and was involved with Voices of Positive Women and around that time this organization that really embraced me and give me strength and other women positive and, you know, the experience of actually having children. So my dream started coming back again and I could see myself having children at some point but wasn't any information regarding women besides the women nobody experienced it, so information was -- wasn't very helpful in terms of went to conferences or workshops. Medication and as maybe for children because of the education. That kind of really again took me -- again information about what was happening and what was happening or maybe really looking for the right information and right person, not sure, and I started hearing about different initiatives about medications and how it should be used and pregnant women and if women took medications and there was relatively good news. So again, I think -- I

think 2007-8 doing a lot of workshops in communities, about having children. So I was excited about that and attending workshops and hearing more about how children can -- positive women can have children. So my support at the time has really been community talking about trying to get children and never brought up the idea of childbearing at 31 and my desires with providers and they never also brought it up to me. So conversations with my providers at the time was go to see the doctor. I wasn't on medication at the time and so just questions are you using condoms and end of it and remember talking about any goals or do you plan to at some point having children but never brought it up to my care providers and took ARVs for a long, long time hearing and other women experience it with having children. (indiscernible) started talking and then cultures are very different. Where I come from and children depending on where you come from, where I come from, get married and getting along but because experiences, not because getting older and just wanted to have kids, desired with enough information and negative children. My conversation was help with them. Do you want to have children? Yes. So I knew I was set. Good for you. Right outside and what we went in and become pregnant and relationship and so it wasn't like planned in way that okay, so how do we do this successfully? So I knew I was pregnant so now I wanted to find out okay, I'm pregnant, on medication and what should I do? Went to family doctor and had a good relationship with my specialist and family doctor. Again, really very fortunate and given conversations before and using condoms and now I need to say I had unprotected sex but test is new so the person knew about that and there was so much support. I can say I'm one of the few lucky women with providers and delivery, everything from the get-go I had tremendous

support and first baby was not planned but second baby was, so my first child was born in 2009 and around three and a half years later, we started talking and some point we did talk about it and again, because I was now on medication we needed to plan and then again relationship is long-distance relationship and out in Toronto so to kind of plan these kind of ovulation and knowing days --

>> Speaker: Ovulation.

>> Gladys: Planning was -- try to do this again and it actually worked perfectly. Born last year. 20 months now. Wanted to emphasize the guidelines is that in most cases people don't feel comfortable talking to the healthcare providers because I was positive and positive or negative is families what we are going through and this is negative. For me to actually plan for a healthy baby where we need to be utilizing the and talking about getting pressure from the families and with my family doctor wasn't sure if I was supposed to bring goals but at the same time I didn't know how to bring that up because always been about are you using a condom and in my head using a condom all the time and so that I can prevent pregnancy and never felt comfortable to go up to my healthcare provider and what I actually did was 1 day decide -- how do I talk that way and get information I have to be able. Where I am today is through attending workshops and lectures and don't know how many women are out there are able to do that and right to have a child. And we should be able to have children and to -- sorry to say that when I lookback and see my accomplishment, my daughter five years old and makes me get up every morning and to do what I do and giving me good in my life and look forward to it. In 2006, I think, and kind of like planning to see and related and never been -- never felt like I had HIV and waiting to get sick and die at some point and very,

very and supportive like I say, and when I do and doctors and healthcare providers and very supportive and encourage and really utilize guides I have to work with positive woman and not shutting people out.

>> Speaker: Thank you so much, Gladys for sharing your experience with us. We really, really appreciate it. We are nearing 3:00pm so in the interest of time, if you do have questions that are related to today's webinar and make sure they are answered promptly. If you e-mail us at questions@CATIE.ca we will make sure questions answered and share them on the webinar series website. On related note you will -- as I mentioned prior we will circulate a resource list shortly after -- in the next few days which will have links to the Pregnancy Planning Guidelines and several other documents and resources that are available online that come from various groups and organizations in Canada. We will also be -- we hope to see you for our next webinar which will be taking place in the -- late November. Exact date will be communicated to you shortly and it is going to be looking at issues around HIV and infant feeding. With this having been said I want to conclude by saying very, very heartfelt thank you to Dr. Mona Loutfy and Gladys for generously sharing their time and their expertise with us today and I also want to thank Logan and Muna for helping us getting this webinar series organized and everyone here at CATIE and finally I want to thank all of you, participants for joining us today and hope that you would be back with us for the continuation of this series. So once again thank you very much to our speakers and to our participants and enjoy the rest of the afternoon. Bye-bye.