Statement by Paula Donovan, Co-Director, AIDS-Free World
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The UN's gag order on reproductive health

Invitees who attended back-to-back World Health Organization (WHO) consultations at the start of February were required to sign confidentiality agreements prohibiting them from talking about the meetings. They had to promise not to divulge anything that was said during the three days – not to colleagues, not to their networks, and especially not to journalists, who might misreport the facts. The world health body explained that journalists often exaggerate, and the UN doesn't want to induce panic. The media will be informed when WHO holds an additional meeting of UN insiders on February 15th, behind closed doors, and prepares a carefully worded public statement for release the next day.

The highly classified topic of discussion wasn't a nuclear threat or a new virus that can kill within days. It was birth control.

WHO's gag order is just the latest in a years-long effort by the United Nations' AIDS apparatus to limit how much women know about possible links between HIV and injectable hormonal contraceptives. The UN appears to have forgotten that its job is not to control women's sexual and reproductive decisions, but to inform them.

Here's what the UN knows: In July 2011, researchers led by Renee Heffron at the University of Washington in Seattle presented findings from studies involving 3,790 sero-discordant couples (one HIV-negative and one HIV-positive partner) in east and southern Africa[1]. The data compared women who had and women who had not used hormonal contraceptives during the research periods: twice as many HIV-negative hormonal contraceptive users acquired the virus. The rates of transmission from HIV-positive women to their male partners was also two times higher for users of hormonal contraceptives. (The findings focused on injectables because very few study participants took hormonal contraceptives in pill form, making the higher rates of HIV infection and transmission in that group "statistically insignificant.")

In laypersons' terms, hormonal contraceptives are products that adjust a woman's hormone levels to prevent ovulation and pregnancy. In the east and southern African countries where the research was carried out, injectable hormonal contraceptives ("depot medroxyprogesterone acetate," or DMPA) are the top choice of women who use contraceptives, and the Depo-Provera brand owned by pharmaceutical giant Pfizer, Inc. is the most widely used. Despite common side effects, popular features of the method are that one injection lasts three months, and a woman's sex partner need not know that she is using a contraceptive.

The findings by Heffron and colleagues weren't definitive; it would take years of additional research to determine beyond a doubt whether or not hormonal contraceptives actually double women's risks of acquiring or transmitting HIV during unprotected sex. But the research team was concerned enough last July to say: *"Our findings argue for policies to counsel women about the potential for increased HIV-1 risk with hormonal contraceptive use, especially injectable DMPA use, and the importance of dual protection with condoms to decrease HIV-1 risk."*

WHO and UNAIDS were not shocked. They had known for years that other research had linked sub-Saharan Africa's most widely used form of birth control to higher rates of HIV. They knew about Depo-Provera users' three-fold rates of chlamydia[2] and of gonorrhea[3], two of the sexually transmitted infections that place people at high risk of HIV, and about research showing that condom use decreased when women started using Depo-Provera.[4] They were aware that women's health advocates have been battling drug companies and policymakers for decades over Depo-Provera on a range of issues, including the ethics of clinical trials in developing countries, and the contraceptive's connection to breast cancer and to health hazards that warrant a "black box" label, the US Food and Drug Administration's most dire warning. The UN was aware that the new data on HIV and injectable hormones raised new questions about the safety of a method that women cannot reverse for three months. They knew all this and much more, but hadn't conducted a systematic review of the best evidence since 2009, when an official guidance document (which included a small-print statement that "potential drug interactions between many antiretroviral drugs and hormonal contraceptives might alter the safety and effectiveness of both"), nevertheless concluded that "women at high risk of HIV infection and those who are living with HIV can safely use hormonal methods."[5] The new evidence presented by Heffron et al didn't cause the UN to move faster.

On the contrary, WHO reacted in July 2011 to the latest and most concerning observational data (uncovered in the process of looking for something else) by announcing that they had scheduled a 'technical consultation' for February 2012, seven months down the road. But in the interim, on October 4th, Heffron and colleagues published their research in *The Lancet,* and it was reported in *The New York Times.* Word began trickling down, by word of mouth and in distorted versions, to contraceptive users in east and southern Africa. Even then, neither WHO nor UNAIDS felt obligated to address women's questions, quell the rumors, or correct the misinformation that naturally circulated in the absence of facts. The February 2012 meeting wasn't moved up. Unlike swine flu, which gave rise to nine Emergency Committee meetings at WHO before it eventually killed roughly 19,000 people worldwide, no urgent response was triggered by the threat of a doubled HIV risk for 20 million hormonal contraceptive users on a continent where annual AIDS deaths are counted in millions rather than thousands. WHO made no effort to send a balanced, cautionary message out to the general public. No information was issued to government health officials, nor to the healthcare providers who offer birth control or HIV testing, prevention, and treatment services; no one was reminded to stress the need, now more important than ever, of using condoms along with hormonal contraceptives. No attempts were made to make male and female condoms more widely available to hormonal contraceptive users, at prices and in quantities that could encourage their use, and no public information campaigns have been initiated to spread the word.

WHO and UNAIDS each posted statements on their websites—separate ones, with different messages—which were seen by people who regularly comb the WHO and UNAIDS websites. WHO's statement did not remind those readers about the importance of condom use.[6] But both statements

offered disturbing insights into why the UN was withholding information from hormonal contraceptive users – 20 million in sub Saharan Africa, including 12 million who make use of injectable methods and 8 million who opt for pills. They were afraid that African women might abandon hormonal contraceptives altogether. That would result in more pregnancies. More pregnancies would lead to more maternal deaths, since pregnancy is especially risky for women who have HIV. More unintended pregnancies might cause more women to undergo unsafe abortions. And if more HIV-positive women went through with pregnancy, that would put more babies at risk of infections.

Those possibilities are all real. So is the possibility that hormonal contraceptive use will increase a woman's risk of HIV infection.

But it's not the right of the United Nations to make that choice for a woman.

Says the UN, when it's speaking in public:
"The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health…"[7] and

"Failure to provide information, services and conditions to help women protect their reproduction health…constitutes gender-based discrimination and a violation of women's rights to health and life."[8]

WHO and UNAIDS have violated human rights by withholding the information. They have failed to inform women that using hormonal contraceptives *may* carry some risk, and that it is especially important now for women who use them to protect themselves and their partners from HIV by using condoms at the same time.

Women have the right to make fully informed sexual and reproductive health decisions, whether or not the UN likes those decisions.

AIDS-Free World asked a WHO spokesperson how the agency would communicate to women after their February consultation. She answered that they hadn't thought much about it; mass communication isn't WHO's strength. Perhaps they'd publish an article in a medical journal and in *The New York Times*. They certainly would welcome our input. We asked if we could attend the February meeting, and were told that, "As our capacity for participants is limited, we have representatives from UNAIDS, IPPF, the International Coalition of Women Living with HIV/AIDS and the Family Life Association of Swaziland attending the consultation. We apologize for not being able to accommodate additional organizations and representatives." (We eventually got hold of the participants' list. Invitations were issued to 81 people, just one representing women living with HIV. Of the 61 non-UN staff, nearly half were experts from the US.)

AIDS-Free World turned to UNAIDS (the body responsible for coordinating all the UN's AIDS work, ensuring no overlap and no gaps) with an appeal to hold an urgent meeting in conjunction with the early February consultation WHO was planning. We asked the Executive Director to gather a small group of communications experts to help the UN develop a rapid dissemination plan. That way, right after the WHO technical meetings, UNAIDS would be ready to disseminate clear, factual information through every possible channel to reach the women who need it. We argued that the UN's information

lockdown had to end: women who are making decisions that have to do with sex and birth control and HIV have the right to know what the UN *does* knows and what it *doesn't* yet know -- *today.*
On December 13th, the UNAIDS Executive Director replied: "I am pleased for UNAIDS to help convene all partners to take forward this communications meeting." UNAIDS would host; the timing and venue were settled. A week later, his staff backed out of the commitment. On second thought, UNAIDS thought such a meeting would be premature. And expensive. Sometimes teleconference calls are a more efficient way to plan global strategies than in-person working sessions. And (said the UN's AIDS coordinating body) their WHO colleagues might perceive a UNAIDS meeting as 'oppositional' to theirs.

I traveled instead to east Africa, where 40 women — women's rights advocates, researchers, medical professionals, HIV and reproductive health counselors, activist women living with HIV from Rwanda, Zimbabwe, Uganda, South Africa, Kenya and the US – met to discuss what we wanted the UN to hear from women at its technical consultation. After just half a day of discussion, there was consensus, including:

"It is not sufficient to say that the data are mixed and we need more research…. Clear information must be provided now on the potential risks of both HCT use and pregnancy. Women need clear and balanced information on what is known and unknown."

"Women will not be divided by issues of various risks – the response cannot pit contraceptives versus maternal mortality. We don't accept an "either/or" approach. Both problems need to be addressed."

Because WHO couldn't squeeze an additional chair for AIDS-Free World into its conference hall, we only know what was leaked from those meetings by several different attendees – including UN staff. They had taken the confidentiality agreement with a grain of salt: researchers can ask for signed assurances that their unpublished data won't be quoted, but WHO's prohibition against discussing anything raised during three full days seemed a bit overwrought. Speculation swirled about who has WHO so spooked: the American pharmaceutical companies that see hormonal contraceptives as a growth industry? Participating "experts" with ties to those companies?

In an ironic twist, the gag order prohibited the one African civil society representative who was invited to speak on behalf of the continent's HIV-positive women from reporting back to her network about what she had heard and learned. That's a new twist on the solemn UN principle of "Greater Involvement of People Living with HIV/AIDS". It's a new definition of "stakeholder" and a frightening new direction for facts about African women and HIV: information now flows in reverse, toward Geneva, where it's held in a reservoir until WHO allows it to trickle out.

The UN has promised to release a statement on February 16th. The communications departments of UNAIDS and WHO will work together on the wording. Their joint 'communications plan' will then amount to sending a statement to the clogged inboxes of Ministers of Health, sending a press release to media outlets, and waiting to see who bites. On Thursday, then, it will suddenly become the job of *journalists* to distribute life-and-death health information to the world's women – the same journalists who can't be trusted by WHO to get the facts straight.

AIDS advocacy organizations and women's rights groups have questions for WHO and UNAIDS as they prepare their statement. Haven't the past 30 years taught us that information is the single most important weapon against HIV? Isn't the UN in the business of *advancing* women's rights to make their own informed decisions about sex and reproduction? Doesn't the UN argue that there are enough men telling women and girls what they can and can't do with their lives and their bodies – enough husbands and fathers and brothers, in-laws and clergy and heads of state robbing women of the right to make sexual and reproductive decisions? Doesn't the right to information apply to African women, women who are living with HIV, and women with strong chances of contracting HIV? Doesn't the UN in Geneva – which can never know the unique circumstances of women's lives – trust informed women to weigh risks and benefits, and to make decisions for themselves?

And lastly, this far into the Information Age, shouldn't UNAIDS and WHO have a better communication strategy than the blind hope that life-saving information will find its way to the world's women from *The Lancet* and *The New York Times*?

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[1] Heffron R, et al., "Use of hormonal contraceptives and risk of HIV-1 transmission: a prospective cohort study," *Lancet Infectious Diseases* 2012 Jan; 12(1):19-26. The study was funded by the Gates Foundation and the U.S. National Institutes of Health.

[2] Morrison, Charles S, et al., "Hormonal Contraceptive Use, Cervical Ectopy, and the Acquisition of Cervical Infections," *Sexually Transmitted Diseases,* September 2004 Vol. 31, No. 9, p. 561-567.

[3] Lavreys L, et al. "Hormonal contraception and risk of cervical infections among HIV-1-seropositive Kenyan women," *AIDS*, 2004 Nov 5; 18(16):2179-84.

[4] Sangi-Haghpeykar H, Posner SF, Poindexter AN 3rd, "Consistency of condom use among low-income hormonal contraceptive users," Perspect Sex Reprod Health. 2005 Dec; 37(4):184-91.

[5] WHO, *Medical Eligibiity Criteria for Contraceptive Use*, 2009.

[6] http://whqlibdoc.who.int/hq/2011/WHO_RHR_11.28_eng.pdf

[7] 1995 Beijing Platform for Action, paragraph 96

[8] http://www.unfpa.org/gender/empowerment.htm

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