September 28, 2010

Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS–OCIIO–IFC
P.O. Box 8010
Baltimore, MD 21244–8010

Comments Re: File Code OCIIO–9995–IFC;
45 CFR Part 152, Pre-Existing Condition Insurance Plan Program;
Interim Final Rule

Dear Secretary Sebelius:

We thank you for helping make health care reform a reality and look forward to supporting the Department of Health and Human Services (HHS) in carrying out the implementation of the Patient Protection and Affordable Care Act (the Act). The below signed organizations work to empower and meet the needs of women living with HIV, their families and affected communities through direct services, as well as legal and policy advocacy.

The Act makes significant strides in expanding access to care and prevention, particularly for those most vulnerable in our health care system. The creation of interim Pre-Existing Condition Insurance Plans (PCIPs) is an important element of this progress. For that reason, we are writing to express concern with certain aspects of the Interim Final Rule that affect our constituents and clients. Specifically, we note the following concerns and recommendations:

1. **The high premium costs are prohibitively expensive for many people living with HIV/AIDS (PLWHA) and will lead to the exclusion of a large number of PLWHA from the PCIPs.**

While many people currently excluded from private insurance due to pre-existing conditions will be able to access care through the PCIPs, and though the plans may be cheaper than market rates, for many HIV-positive individuals, the plans are still prohibitively expensive. While some PLWHA may earn too much to qualify for Medicaid, many remain unable to pay the premiums and out-of-pocket expenses associated with the pre-existing condition pools. Others, who are categorically ineligible for Medicaid, are desperate for low- to no-cost coverage.

HHS should take steps to make PCIPs more affordable and available for PLWHA. Health care reform was premised, in part, on an understanding that delayed care, and a lack of routine and preventive care are both harmful to individual health and expensive to society as a whole. The PCIPs offer an opportunity to provide health coverage for more PLWHA, but only if further steps are taken to reduce the cost of the programs to consumers and insure eligibility for PLWHA.

- HHS should encourage states to allow AIDS Drug Assistance Program (ADAP) expenses, and prescription drug costs generally, to count toward out-of-pocket costs for PCIP participants. This would go a long way toward making PCIPs more affordable for people living with HIV/AIDS.

- HHS should encourage states to consider reducing the cap on out-of-pocket expenses, currently set at $5,950, a cost that makes coverage unattainable for lower-income individuals.

- Given the large numbers of people who will be unable to afford the PCIPs, HHS should issue guidance to states encouraging them to expand Medicaid eligibility under the Section 1115 Waiver program before the Medicaid expansion scheduled for 2014.

- HHS should provide guidance to states clarifying that Ryan White coverage does not preclude eligibility for PCIPs. Rather, Ryan White services should be considered as wrap-around coverage for people accessing care through the PCIPs.

The PCIPs and other interim measures such as expanded funding for community health centers will help to bridge the health care gap for many people leading up to Medicaid's expansion in 2014. But for people living with HIV/AIDS, continuity of high quality and affordable health care is essential to a healthy and long life. Given that community health centers often lack expertise in HIV care, it is essential that PCIPs provide truly affordable coverage for PLWHA, who have faced chronic discrimination in accessing health care.

2. The restriction on abortion coverage and other reproductive health services for the PCIPs is unnecessary and harmful to women living with HIV/AIDS.

Women living with HIV/AIDS, like all women, need affordable and safe access to the full range of family planning services. This includes access to abortion services when a woman chooses to terminate her pregnancy as well as access to reproductive tools such as in vitro fertilization when traditional conception is not possible.

Pursuant to Section 152.19(b) of the proposed regulation, abortion services shall not be covered by the PCIPs, except in cases of rape or incest or where the life of the woman would be endangered. Additionally, in vitro fertilization, artificial insemination or any other artificial means used to cause pregnancy will not be covered. These exclusions are unnecessary.

The restriction on abortion coverage, pursuant to Executive Order, goes beyond the limits within the Affordable Care Act and denies plan participants, including women living with HIV/AIDS, the range of reproductive services they may require. With advances in medicine and risk-reduction protocols, women living with HIV are able to give birth to healthy, HIV-negative children. Yet, women should have the ability to terminate their pregnancies if they choose. Women living with HIV juggle myriad responsibilities: they must care for their own health, which is often a fulltime job; they are often caretakers of their own children as well as other family members; they may work multiple jobs, and yet continue to be paid less then men for the same work. For those women who are able to participate in the PCIPs, and pay the monthly

premiums for care, the exclusion of abortion services represents an undue burden and a dangerous infringement on reproductive rights.

Central to the value of reproductive freedom is the right to bear children. Among serodiscordant couples—where only one partner is HIV-positive—sperm washing or in vitro fertilization may be the safest form of conception. For these individuals, the exclusion of coverage for "artificial means" of reproduction is discriminatory and infringes on the right to have a family.

3. The required 6-month period of no coverage threatens the health of PLWHA by ensuring a protracted disruption in care.

Section 152.14 requires, in part, a six month gap in coverage to qualify for a PCIP. This requirement will serve to guarantee negative health outcomes for PLWHA. Disruptions in HIV care, and discontinuance of HIV medications, even for brief periods of time, are dangerous to the health of HIV-positive individuals. Further, HIV infectiousness rises when HIV is untreated. For PLWHA who have lost their health insurance because they've been priced out, or because their plan has left their area, being forced to go without coverage for six months until they may be eligible for PCIP coverage is counter-productive, and bad health policy.

Further, without clear guidance from HHS, states may consider PLWHA who currently receive drug assistance through ADAP or supportive services from Ryan White to have had credible coverage for the past six months and to be presumptively ineligible for PCIP coverage. HHS should provide guidance to states clarifying that ADAP and Ryan White coverage does not preclude eligibility for PCIPs. Rather, ADAP and Ryan White services should be considered wrap-around coverage for people accessing care through the PCIPs. Finally, to ensure a smooth transition to PCIP coverage for those people currently receiving Ryan White services, Ryan White providers should be included in PCIP networks.

4. States should classify HIV disease as a "presumed eligible" condition for purposes of PCIP eligibility under Section 152.14.

The experiences of PLWHA suggest that having HIV is a significant barrier to acquiring private health insurance. We regret that HHS has declined to declare HIV a "presumptively eligible condition." We hope that HHS will take this opportunity to urge states to include HIV disease as a "presumptively eligible condition" for purposes of PCIP eligibility.

5. The enrollment and disenrollment guidelines in section 152.15 of the interim final rule do not provide for an adequate appeals process

Disenrollment from the PCIPs due to late or non-payment may be necessary but must include an adequate appeals process and forgiveness mechanism for those with legitimate reasons for late or non-payment. People living with chronic and critical health conditions like HIV, may have legitimate reasons for late payment of premiums due to extenuating health-related circumstances. Therefore, an appeals process for late and non-payment of premiums should be mandated for all PCIPs with special consideration for those able to demonstrate legitimate and health related reasons for delinquent payment.

The creation of the PCIPs is essential to helping medically vulnerable individuals with pre-existing conditions access the health care they need in a timely manner. The above recommendations are critical to making the PCIPs accessible to PLWHA, and especially women living with HIV, and to ensure that they provide the range of services needed to keep women and their families safe and healthy.

We thank you for your consideration of our comments and concerns. For more information, please contact Alison Yager at ayager@hivlawproject.org or Brook Kelly at bkelly@womenhiv.org .

Sincerely,

AIDS Alabama
The Center for HIV Law & Policy
Center for Women & HIV Advocacy at HIV Law Project
Community HIV/AIDS Mobilization Project (CHAMP)
Women's HIV Collaborative of New York
WORLD (Women Organized to Respond to Life-threatening Disease)
U.S. Positive Women's Network