30 FOR 30 CAMPAIGN

May 23, 2014

Carolyn W. Colvin, Acting Commissioner
Social Security Administration
PO Box 17703
Baltimore, MD 21235-7703

RE: Public Comments on Proposed Revised Medical Criteria for Evaluating HIV Infection and for Evaluating Functional Limitations in Immune Systems Disorders (Docket No. SSA-2007-0082)

Dear Acting Commissioner Colvin:

We write on behalf of the 30 for 30 Campaign, a national membership group of organizations and individuals focused on ensuring that the unique needs of women living with and affected by HIV are addressed through policy, research, education and activism toward the elimination of health disparities and gaps in the continuum of prevention and care. Many of our member organizations provide healthcare, supportive services, and/or advocacy services on behalf of women receiving or applying for SSA benefits. We appreciate the opportunity to comment on the Social Security Administration's (SSA's) solicitation of public comments on proposed revised medical criteria for evaluating HIV infection and for evaluating functional limitations in immune systems disorders (Docket No. SSA-2007-0082).

Some important improvements have been made to the listings, yet we write with grave concern about the proposal to remove the language specific to women. The rationale states that:

> First, the proposed HIV infection listings do not contain criteria that are gender-specific. We would evaluate the manifestations of HIV infection using the same criteria regardless of a person's gender. Second, while we recognize that manifestations of HIV infection may still affect a person's ability to function, we believe that the guidance in the following sections instruct our adjudicators to consider signs, symptoms, and effects of treatment when evaluating the severity of a person's HIV infection and resulting functional limitations.

This rationale ignores the medical need for and history behind the inclusion of the women-specific language. Until 1993, the only SSA regulation regarding AIDS was one, published in 1985, which enabled those with a diagnosis of AIDS as defined by the Centers for Disease Control and Prevention (CDC) to qualify for presumptive disability benefits while they waited for an eligibility determination. The problem for women, though, was that the CDC's definition of AIDS was based on its understanding of manifestations of HIV as it progressed in men, who were primarily Caucasian and middle class. Further, the definition was not written for the purposes of defining

those characteristics necessary to qualify for SSA benefits. Only through litigation against the SSA, as well as extensive advocacy targeting the CDC (including a proposal to address the lack of inclusion of women's manifestations that was signed by over three thousand individuals and organizations and was presented to the CDC at a plenary session at the International AIDS Conference in Amsterdam in 1992), did the CDC change its definition and the SSA establish a new listing for HIV.[1] Though this history may be twenty-plus years in the past, women continue to experience HIV differently than men, and SSA-contracted doctors are likely less familiar with the manifestations in women than in men, making guidance around women's unique manifestations as important now as when the language was added. In addition, racial and socioeconomic disparities in health outcomes of people living with HIV persist to this day, and women living with HIV in the US are disproportionately women of color and disproportionately low income.

In fact, the National Institutes of Health (NIH) recognizes that women continue to "experience HIV-associated gynecologic problems, many of which occur in uninfected women but with less frequency or severity."[2] Specifically, the NIH's National Institute of Allergy and Infectious Diseases enumerates the following on their website, under the heading *Woman-Specific Symptoms of HIV Infection:*

> "Vaginal yeast infections, common and easily treated in most women, often are particularly persistent and difficult to treat in HIV-infected women. Data from [Women's Interagency HIV Study]… suggest that these infections are considerably more frequent in HIV-infected women. Healthcare providers commonly treat yeast infections with fluconazole. A [Community Programs for Clinical Research on AIDS]… study demonstrated that weekly doses of fluconazole can also safely prevent oropharyngeal and vaginal, but not esophageal yeast infections, without resulting in drug resistance.
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> "Other vaginal infections may occur more frequently and with greater severity in HIV-infected women, including bacterial vaginosis and common [sexually transmitted diseases]… such as gonorrhea, chlamydia, and trichomoniasis.
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> "Severe herpes simplex virus ulcerations, which are sometimes unresponsive to therapy with the standard drug acyclovir, can severely compromise a woman's quality of life.
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> "Idiopathic genital ulcers, with no evidence of an infectious organism or cancerous cells in the lesion, are a unique manifestation of HIV infection. These ulcers, for which there is no proven treatment, are sometimes confused with those caused by herpes simplex virus.
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> "HPV infections, which cause genital warts and can lead to cervical cancer, occur more frequently in HIV-infected women. A precancerous condition associated with HPV, called

[1] *See generally* Theresa M. McGovern, *S.P. v Sullivan: The Effort to Broaden the Social Security Administration's Definition of AIDS.* 21 Fordham Urban Law Journal 1083, 1993-1994.
[2] National Institutes of Health, National Institute of Allergy and Infectious Diseases. "HIV Infection in Women". http://www.niaid.nih.gov/topics/hivaids/understanding/population%20specific%20information/pages/womenhiv.aspx (last updated September 10, 2008).

cervical dysplasia, is also more common and more severe in HIV-infected women and more apt to recur after treatment.

> "[Pelvic Inflammatory Disease (PID)]… appears to be more common and more aggressive in HIV-infected women than in uninfected women. PID may become a chronic and relapsing condition as a woman's immune system deteriorates."

Willing away gender differences won't make them disappear and seems to fly in the face of all evidence indicating that HIV disease manifests uniquely in women. Gender neutrality is an inappropriate goal where a disease manifests differentially. The second part of the rationale seems to ignore the fact that the language about manifestations in women is essential to educating evaluators and fact-finders about the signs and symptoms of the disease in women. Removal of this language would do a severe disservice to female claimants, whose disease progression may not be as well understood as that of their male counterparts, and to those evaluators who seek to make a thorough evaluation.

Medical doctors assigned by SSA to examine claimants need not be specialists in the medical area of the presenting patient. Further, HIV does not feature prominently in the panel of claimants appearing before SSA evaluators and/or judges. Accordingly, those individuals evaluating the patient and then evaluating the merits of a claim are unlikely to be experts in HIV disease and even less likely to be experts in HIV disease among women. When the evaluating doctor knows little about HIV in women, s/he may be unlikely to recognize those manifestations that are unique to women, such as candida vaginitis, abnormal cervical cytology, or genital ulcer disease, as part of HIV disease. Important symptoms may be overlooked or misidentified as unrelated conditions. These manifestations must remain a part of the listing so that claimants and adjudicators have guidance if the examining doctor fails to identify their gender-specific manifestations appropriately.

Thank you for your consideration of the above as you work to finalize the updated HIV listing. If we can be of assistance, please contact Alison Yager with HIV Law Project at ayager@hivlawproject.org or 347.473.7490.

Respectfully Submitted,

30 for 30 Campaign Member Organizations, Affiliates, and Allies:

African Services Committee, New York, NY

Afiya Center, Dallas, TX

AIDS Alabama, Birmingham, AL

AIDS Alliance for Children Youth & Families, Washington, DC

AIDS Foundation of Chicago, Chicago, IL

AIDS United, Washington, DC

Bailey House, New York, NY

Center for Health and Gender Equity (CHANGE), Washington, DC

Center for HIV Law and Policy (CHLP), New York, NY

Christie's Place, San Diego, CA

Community Healthcare Network, New York, NY

Women with a Vision, New Orleans, LA

HIV Law Project, New York, NY

International Community of Women Living with HIV/AIDS (ICW), Washington, DC

Memphis Center for Reproductive Health, Memphis, TN

National AIDS Housing Coalition (NAHC), Washington, DC

National Black Leadership Commission on AIDS, Inc. (NBLCA), New York, NY

National Black Women's HIV/AIDS Network (NBWHAN), Houston, TX

National Health Law Program (NHeLP), Carrboro, NC

National Women and AIDS Collective (NWAC), Washington, DC

Positive Women's Network USA (PWN-USA) Oakland, CA

Sisterhood Mobilized for AIDS Research & Treatment (SMART), New York, NY

Sisterlove, Atlanta, GA

South Carolina HIV/AIDS Council, Columbia, SC

The Well Project, Oakland, CA

The Women's Collective, Washington, DC

Women Organized to Respond to Life-threatening Diseases (WORLD), Oakland, CA