WHITMAN-WALKER HEALTH
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May 27, 2014

Carolyn W. Colvin
Acting Commissioner of Social Security
Social Security Administration
6401 Security Boulevard
Baltimore, Maryland 21235-6401

RE: 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:

Whitman-Walker Health submits these comments on the Social Security Administration's (referred to herein as "SSA") Notice of Proposed Rulemaking in Docket No. SSA-2007-0082, published on February 26, 2014 in the Federal Register, 79 Fed. Reg. 10730 (referred to herein as the "Proposed Rule")[1]. Whitman-Walker Health also has signed on in support of the HIV Health Care Access Working Group and Lambda Legal's Joint Comments. We use this letter to supplement those comments, which include the following sections:

I. About Whitman-Walker Health and Its Legal Services Program
II. Overview of Whitman-Walker Health's Goals for Its Recommendations
III. SSA Should Allow for Methods for Diagnosis of HIV-Related Symptoms and Co-Existing Diseases in Addition to Those Specifically Enumerated, to Accommodate the Rapidly Changing Nature of HIV And Its Management
IV. SSA Should Defer to the Treating Medical Provider's Opinion of Severity Instead of Using Absolute Rules Governing The Length of Each Hospitalization Stay
V. SSA Should Expand the Role of Evidence from "Other Sources" in Determining a Claimant's Functional Limitations, as Recommended in The IOM Report
VI. SSA Should Train Its Claim Examiners to Correctly Evaluate Repeated Manifestations of HIV
VII. Conclusion

[1] Leora Gabry and Elizabeth Kaplan, Staff Attorneys, and Sara Kim Keller, Volunteer Attorney, contributed to these comments.

ELIZABETH TAYLOR MEDICAL CENTER ADMINISTRATION
1701 14th Street, NW
Washington, DC 20009
202.797.3500

MAX ROBINSON CENTER
2301 M L King, Jr. Avenue, SE
Washington, DC 20020
202.678.8877

CALL CENTER
202.745.7000
www.whitman-walker.org

I. About Whitman-Walker Health and Its Legal Services Program

Whitman-Walker Health (referred to herein as "WWH") is a community-based nonprofit medical center committed to bringing high-quality, culturally sensitive care to the area, including those individuals who face barriers to accessing health care. We offer a number of services, including primary medical care, HIV specialty care, mental health and addiction treatment services, dental care, medical adherence case management, and legal services. In its two sites – the Elizabeth Taylor Medical Center in Northwest DC and the Max Robinson Center in Southeast DC – WWH served 14,184 unique patients in 2013; 6,016 of these individual patients called WWH their medical home. For the past four decades, WWH has been a major player in the fight against HIV/AIDS in the DC metro region. In fact, approximately 25% of DC residents diagnosed with HIV now use WWH as their primary medical home.

In 1986, WWH established the Legal Services Program to provide *pro bono* legal assistance to people living with HIV on matters related to their diagnosis. One major area of our practice focuses on securing access to healthcare for our clients through public benefits programs such as Social Security Disability Income (SSDI), Supplemental Security Income (SSI), Medicare, and Medicaid. As a result, WWH represents hundreds of clients each year in matters before SSA, from initial applications for benefits to all levels of appeals. WWH also works in collaboration with the local SSA offices to secure quality service for our clients. We participate in national efforts in improving access to benefits to our clients and the community alike, working with advocates and SSA representatives across the country.
WWH has been involved been with SSA's efforts to revise the HIV disability criteria since 2003, presenting expert information at public forums in 2003 and 2004 and offering written comments for proposed regulations in 2003, 2006, and 2008. WWH also participated in the public meetings as part of the Institute of Medicine's (IOM) report to SSA on HIV Listings. We, therefore, are pleased to see that substantial revisions to the Listing of Impairments for disability claims involving HIV are finally underway. HIV detection, treatment practices, medical options, patient demographics, presentation of symptoms, and common co-morbidities have dramatically changed since 1993 when the last substantial revision occurred. Given the lack of timely revisions, many parts of the current Listings are outdated and not consistent with current HIV medical treatment.

II. Overview of Whitman-Walker Health's Goals for Its Recommendations

The revisions in the Proposed Rule constitute a substantial improvement and we are pleased that the Proposed Rule incorporated so many of the IOM recommendations, as we believe that IOM's inquiry and its resulting report was led by HIV experts and reflected more current medical treatment and understanding of the complexities of HIV. In addition to the Proposed Rule, we recommend some additional changes, based on our considerable experience, over many years, with treating HIV patients and representing them in SSDI and SSI cases. We respectfully submit that our recommendations:

(1) allow for continued advancement in medical science without rendering the Listings obsolete in a short period of time;

(2) allow for medical professionals to use sound judgment without risking the patient's chances at obtaining disability benefits due to inflexible or arbitrary rules;
(3) promote clearer language in the Listings to affirmatively direct SSA claims examiners to defer to treatment providers' diagnoses, observations, and medical opinions and provides flexibility from arbitrary rules when it comes to evaluating severity; and
(4) provide for additional training for claims examiners in evaluating a disability claim with an allegation of HIV disease.

We applaud SSA's goal of revising the evaluation criteria for HIV, "to reflect [the SSA's] program experience, advances in medical knowledge, recommendations from a commissioned report and comments from medical experts and the public."[2] We particularly commend SSA's inclusion of absolute CD4 counts and in the alternative, CD4 percentage values, in the Proposed Rule.[3] We believe this additional criterion for determining disability under the HIV Listings will be particularly beneficial to individuals who are seriously ill and to those individuals who are responding poorly to anti-retroviral treatment as a short-cut through the disability process. A low CD4 count remains a key indicator of susceptibility to opportunistic infection.

While finding objective methods for evaluating disability is important, the Listings need to better incorporate other opportunities for flexibility that allows for continued advancement in medical science, defers to claimants' HIV treating medical practitioners' sound judgment on functionality, and eliminates arbitrariness. With the continuing medical advancements, the heavy reliance on strict and arbitrary definitions will likely be outdated quickly without some guidance or language permitting evaluators alternate methods of diagnosis or equivalence arguments.

III. SSA Should Allow for Methods for Diagnosis of HIV-Related Symptoms and Co-Existing Diseases in Addition to Those Specifically Enumerated, to Accommodate the Rapidly Changing Nature of HIV And Its Management

SSA should reconsider its proposal to eliminate language in the existing Listings allowing for alternate means of documenting HIV symptoms and co-morbidities. Removal of language that allows for flexibility in documentation and evaluation of HIV infection and other related symptoms and/or diseases is contrary to SSA's own stated goals. In fact, the revised Listings should be more inclusive of other possible methods of detecting HIV symptoms or co-morbidities and include clearer guidance permitting SSA to consider medical evidence beyond the specific evidence identified in the Listings. The Proposed Rule does not account for those individuals whose HIV disease effectively accelerates the onset of such conditions as diabetes, heart disease, or kidney disease. There now exists a substantial population of HIV-infected patients whose HIV may be clinically stable but will die from these other co-morbidities accelerated by the inflammation associated with HIV and its treatment. Clinical research on this issue continues and the science and recommendations remain relatively new. Treating physicians should be given more flexibility to provide more patient-specific diagnoses and treatment, and the current Proposed Rule remains too restrictive to achieve this goal.

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[2] *See* Proposed Rule Summary, 79 Fed. Reg. 10731 (February 26, 2014).[3] Proposed Rule, Listing 14.11.
[3] Proposed Rule, Listing 14.11.

Disallowing flexibility in documenting HIV disease and its related symptoms and co-morbidities ties the Listings to today's medical realities without allowing for any progress. SSA historically has based the HIV Listings too rigidly to the medical standards at a particular point in time, without considering the rapidly-changing nature of HIV disease and its treatment.
The clearest example of this past SSA practice is the current Listing for toxoplasmosis, an opportunistic infection that commonly was linked to HIV. Current Listing 14.00F3b(iii) explains "[a] definitive diagnosis of toxoplasmosis of the brain is based on brain biopsy, *but this procedure carries significant risk and is not commonly performed* [emphasis added]. This condition is usually diagnosed presumptively based on symptoms or signs of fever, headache, focal neurologic deficits, seizures, typical lesions on brain imaging, and a positive serology test." We appreciate the written warning of the dangers of a brain biopsy in SSA's own rules as an acknowledgement that presumptive diagnosis of this condition is more common. However, without clear guidance to evaluators that presumptive diagnosis of a condition is acceptable and meets the Listing itself, we believe that these cases will not be approved. Our belief is based on anecdotal evidence of other conditions where claims examiners often insisted on the specific biopsies to document a specific condition, including toxoplasmosis of the brain, before approving the claim. Another example from the current Listings is the requirement for a bronchoscopy to diagnose Pneumocystis Carinii Pneumonia (PCP). Presumptive diagnosis has been the common standard for a decade. Yet, approval of claims on the basis of PCP were not routinely approved unless the bronchoscopy results were provided.

We, therefore, encourage SSA to eliminate language that would bind treating physicians to a specific method of diagnosis, and affirmatively allow for alternate means of diagnoses of HIV related symptoms and co-morbidities. The Proposed Rule should contain broader guidelines on acceptable documentation to account for changing medical standards as well as unanticipated or rapid developments in the field of HIV. In addition, SSA should add stronger language directing claims examiners to consider alternative forms of evidence, and provide training to ensure that examiners are indeed following the agency's own rules. The current Listing allows for alternate means of documenting HIV so long as "such documentation is consistent with the prevailing state of medical knowledge and clinical practice and is consistent with the other evidence in [the] case record."[4] However, this language is so vague that SSA's own claims examiners often ignore the possibility of alternate means of documenting HIV and its related symptoms, and insist on one preferred method of diagnosis even if this preferred method is outdated or contrary to current medical practice.

Physicians do not approach the treatment of their patients with the primary goal of establishing a case for disability. A medical professional may often diagnose a condition presumptively, in lieu of performing a more painful, time-consuming or expensive test that might be specifically identified in SSA rules. The specification of one test or other diagnostic method as required or preferred, therefore, places an unrealistic burden on physicians and penalizes claimants. This is especially true for terminal conditions that usually qualify for Compassionate Allowances, where time is of the essence. Doctors may opt for alternative diagnostic tools if a more conventional test is too time-intensive or resource-intensive given the patient's situation. The face of HIV and

[4] *See* Current Listings 14.00E2, Immune System Disorders - Adult.

the scope of treatment options continue to change at a breakneck pace. Without such flexibility in the Listing and adequate training, claims examiners will continue to apply the Listing too literally and in turn too harshly.

IV. SSA Should Defer to the Treating Medical Provider's Opinion of Severity Instead of Using Absolute Rules Governing The Length of Each Hospitalization Stay

Proposed Listing 14.11H requires hospitalization stays to occur "at least 30 days apart" and requires each hospitalization to last "at least 48 hours, including hours in a hospital emergency department immediately before the hospitalization."[5] These requirements should be eliminated or additional guidance language added to ensure deference to the treating physician's opinion as to the medical severity of the patient's condition. The length of each hospital stay and the frequency of the visits are not necessarily indicative of the level of severity of a specific condition; too many variables can make those simple indicators unreliable as objective tools for evaluation. Hospital stays are becoming shorter, as better medicines, equipment, and techniques are developed. More efficient treatments are now employed even for very serious conditions, often right in the emergency room. In addition, many doctors opt to treat many serious conditions on an outpatient basis if the option is available. Some patients with serious complications of HIV infection are treated in the emergency room. The treating medical provider possesses the best ability to assess her or his patient's medical status. SSA should not make rules that incentivize patients and medical providers to opt for longer hospital stays to meet a minimum time requirement to prove the severity of a condition. Likewise, a Listing should not encourage patients to abstain from medical care to ensure that each hospitalization is at least 30 days apart to qualify for benefits.

We do appreciate that the language governing "Complications of HIV Infection Requiring at Least Three Hospitalizations" in the Proposed Rule is sufficiently broad to cover many complications of HIV, including both common and opportunistic infections. Unlike the current Listings,[6] the Proposed Rule does not limit claimants to a specific list of infections but instead give examples of the kinds of situations that may lead to a hospitalization.[7] We recommend guidance language for the entire rule that this (and other) provision is a guideline, not an all-inclusive or inflexible list.

V. SSA Should Expand the Role of Evidence from "Other Sources" in Determining a Claimant's Functional Limitations, as Recommended in The IOM Report

We are pleased that the SSA intends to retain "[r]epeated… manifestations of HIV infection" as a disability listing,[8] as this listing applies to many individuals who suffer from multiple HIV-related symptoms and infections, none of which meet the specific requirements of another Listing when taken individually, but which are disabling when occurring together. However, we

[5] Proposed Rule, Listing 14.11H.
[6] Listing 14.08J.
[7] Proposed Rule, Listing 14.00F6. See also Listing 14.11H.
[8] *See* Proposed Rule, Listing 14.11 (formerly Listing 14.08K).

wish to highlight the practical challenges that many HIV-positive individuals face when gathering enough functional evidence to seek disability benefits under this listing. We encourage SSA to take steps to reduce this barrier, specifically by expanding the role of evidence of a claimant's functional limitations that comes from sources other than "acceptable medical sources," as currently defined in SSA's rules.

Under current guidelines, a successful application for disability benefits under the "repeated manifestations of HIV" listing requires detailed medical evidence that documents the claimants' functional limitations due to his or her HIV-related symptoms. Based on our experience assisting numerous applicants for disability under this listing, and working closely with physicians who are frequently tasked with completing functional assessments for disability applicants, we are concerned that this process places an unnecessary and at times insurmountable burden on physicians. In today's climate of increasing demand for primary care physician services, with pressures on physicians to see increasing numbers of patients during shorter appointments, physicians often express to us that they have difficulty finding enough time to complete functional assessments with the level of detail that is required in order to document all of the patient's functional limitations. In addition, although primary care physicians or HIV specialists may be highly qualified to diagnose symptoms such as HIV-related peripheral neuropathy, fatigue, or depression, the doctor's limited amount of face-time with the patient can sometimes make it challenging for that doctor to quantify the exact level of functional impact of these symptoms on a patient.

For this reason, we thoroughly endorse the IOM Committee's recommendation that "SSA should consider including a wide array of licensed health professionals as acceptable medical sources (e.g., nurses, dentists, allied health professionals) for determining the functional effects of impairments" such as HIV infection.[9] As the Committee report observes, professional sources other than those that SSA considers "acceptable medical sources" under the agency's rules often have the most complete and accurate information about an HIV-positive individual's functional limitations.[10] These observations are in line with our experience serving HIV-positive clients, who often receive a significant amount of their care from nurse case managers, social workers, physician's assistants, and other professionals who interact closely with the individual on a more frequent basis than a doctor can provide. Due to their more frequent and lengthy interactions with patients, these other professionals are sometimes better positioned than the individual's doctor to identify all of ways in which the patient experiences limitations in their activities of daily living, social functioning, or ability to complete tasks in a timely manner. Also, licensed professionals have been vetted by the state through the licensing procedure and their professional credentialing. Therefore, the integrity of the information can be assured. We therefore recommend that SSA consider adopting further recommendations that expand the role of medical evidence from other professional sources in determining a claimant's functional limitations.

SSA already recognizes the importance of expanding acceptable medical sources. It has come to our attention that the agency has been reviewing program rules on acceptable medical sources

[9] *HIV and Disability: Updating the Social Security Listings*, Committee on Social Security HIV Disability Criteria; Board on the Health of Select Populations; Institute of Medicine, at 8-6.
[10] *Id.* at 8-5.

through a workgroup since June 2013. We urge SSA to immediately adopt the IOM Committee's recommendation to expand acceptable medical sources to a wide array of licensed health care professionals and move to finalize the workgroup efforts on broadening the acceptable medical sources rule and guidance.

VI. SSA Should Train Its Claim Examiners to Correctly Evaluate Repeated Manifestations of HIV

Our experience with claims for SSDI and SSI is that many claims examiners do not adequately examine medical evidence of a claimant's repeated manifestations of HIV infection. Often, SSA incorrectly examines each manifestation of HIV infection separately to see whether it meets Listings 14.11A-H, or another body system Listing altogether. This is an incorrect application of the HIV Listings. The Proposed Rule clearly instructs SSA to look at those conditions that may not meet a separate listing and determine how they affect the claimant's functionality when considered together.[11] Because HIV infection usually involves co-morbidities and other medical complications, it is important that SSA provide additional training to examiners in evaluating claims of disability based on this Listing.

The Listing governing repeated manifestations of HIV infection requires the "repeated manifestations of HIV" to impact the claimant's ability to perform activities of daily living, his ability to maintain social functioning, and his ability to complete tasks in a timely manner (in looking at deficiencies in concentration, persistence, or pace).[12] However, we rarely see adjudicators willing to approve our claimants with HIV based on their repeated manifestations of the disease. These cases are usually rejected at Step 3 of the sequential evaluation as not meeting a Listing (despite ample evidence of repeated manifestations and severe impact as required.) Adjudicators wrongly subject these claimants to the vocational assessment process of Steps 4 and 5 reviewing their residual functional capacity. While we acknowledge that the listing requires impact on the claimant's ability to perform activities of daily living, his ability to maintain social functioning, and his ability to complete tasks in a timely manner, the imposition of the vocational assessment violates the Listing.

We believe that this error occurs because of the unclear language and lack of willingness to take into account symptoms and conditions self-reported to physicians by claimants. We want to reiterate that the specific Institute on Medicine (IOM) Recommendation 4 should be incorporated into 14.11I, specifically by making clear that disability is established with: Repeated manifestations of HIV, **or** significant, documented manifestations, symptoms, or signs of HIV, **or** adverse effects of HIV treatment; resulting in functional limitations at a marked level. This clearer language in the Listing as well as additional training will help guide evaluators to approve these claims at Step 3, alleviating errors. We also suggest adding language to the Proposed Rule, making it clear that the "repeated manifestations of HIV infection" Listing does not contain an exhaustive list of conditions that may qualify under Step 3 of the sequential evaluation process. In addition, until SSA can establish a proven record of correctly applying the "repeated manifestation of HIV infection" Listing, we encourage SSA to retain the specific

[11] Proposed Rule, Listing 14.11I.
[12] *Id.*

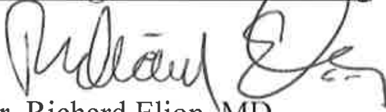
guidance on how HIV infection manifests in women, [13] as it highlights ways that the disease presents differently for women, which is useful guidance to evaluators.

VII. Conclusion

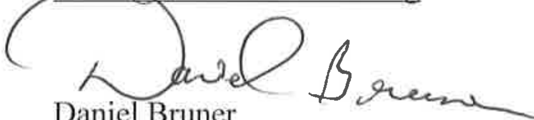
We urge SSA to incorporate our recommendations into the revised HIV Listings, which are based on WWH's expertise and extensive experience in HIV care. The disability benefits application process is arduous for most individuals, but especially for those people suffering from a life-long, chronic, and sometimes fatal disease that requires daily management of its symptoms. We respectfully submit that our suggestions will make the process both less arduous and more accurate.

Respectfully submitted,

Erin M. Loubier
Director of Public Benefits and Senior Managing Attorney
(202) 939-7662
eloubier@whitman-walker.org



Dr. Richard Elion, MD
Director of Clinical Investigations
(202) 745-6142
relion@whitman-walker.org



Daniel Bruner
Director of Legal Services
(202) 939-7628
dbruner@whitman-walker.org

Whitman-Walker Health
1701 14th Street NW
Washington, DC 20009
www.whitman-walker.org

[13] Listing 14.00F4.