

May 19, 2008

BY FACSIMILE

Michael J. Astrue Commissioner of Social Security Social Security Administration P.O. Box 17703 Baltimore, Maryland 21235-7703 Via telefax: 410-966-2830

Re:

Comments re Revising Medical Criteria for Evaluating HIV Infection: Response to Advance Notice of Proposed Rulemaking, Docket No. SSA-2007-0082

Dear Commissioner Astrue:

Set forth below are suggestions for revision of the Social Security Administration (SSA) listings for evaluating HIV infection, as requested in the Advance Notice of Proposed Rulemaking published in the Federal Register on March 18, 2008 (Docket No. SSA 2007-0082). The undersigned organizations and individuals believe that further revisions to the HIV infection listings – beyond those made by the Final Rule also published on March 18, 2008 – are needed in order to reflect advances in medical knowledge, treatment, and methods of evaluating HIV infection and to address problems that individuals disabled by HIV infection have faced in having their disability claims evaluated by SSA.

Most of the organizations and individuals submitting these comments have been involved since 2003 with SSA's efforts to revise the criteria it uses for evaluating disability claimants living with HIV infection. Comments related to the criteria for evaluating immune system disorders generally and HIV infection specifically were submitted to the Commissioner by many of us on July 8, 2003, and on October 3, 2006. Our ongoing involvement in this matter stems in large part from our concerns about the great difficulties that disabled individuals living with HIV continue to encounter when seeking approval for Social Security disability benefits.

The organizations and individuals submitting these comments have extensive expertise in the area of HIV-related treatment and representation of HIV-positive claimants at every stage of the Social Security Administration's disability determination process. Through our many years working in legal and medical programs and multidisciplinary agencies specializing in the needs of people living with HIV, we have learned the common difficulties faced by HIV-

¹ We have told organizations and individuals who desire to reference this letter in separate comments that they may refer to our work as the "HIV-Legal Joint Comments."

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positive claimants and the typical responses of disability examiners and adjudicators to claims of disability based on HIV infection. In addition, many of us have become very familiar with advances in medical understanding of HIV infection. That background informs the comments provided below.

We request a continuing dialogue with the Social Security Administration as it considers revising the listings for HIV infection. We desire response to our input and participation in meetings and discussions with Social Security Administration representatives involved in the review process, prior to and following the anticipated Notice of Proposed Rulemaking. Such an interactive process will help ensure that the complicated area of HIV-related disability law reflects the experiences of the thousands of clients and patients we assist each year.

I. General Comments on the Listings for HIV Infection

We are pleased to see that important changes to 20 CFR Part 404, Subpart P suggested by many of the undersigned in comments submitted in July 2003 and October 2006 are reflected in the Revised Medical Criteria for Evaluating Immune System Disorders; Final Rule published on March 18, 2008, Docket No. SSA 2006-0070 ("Final Rule"). However, we have some very significant general concerns related to evaluation of claimants with HIV infection that we believe are not adequately addressed in the Final Rule and which should be reflected within the listings for HIV infection and in the written guidance to and training of SSA disability examiners and adjudicators.² Also, as set forth in the next section of this letter, we believe that additional revisions are needed in the listings for evaluating HIV infection (listings 14.08 and 114.08).

² We are glad that SSA already plans to address the issue of difficulty of adhering to HIV treatment regimens in training. See Revised Medical Criteria for Evaluating Immune System Disorders, 73 Fed. Reg. 14570, at 14597 (Mar. 18, 2008). We urge SSA to include written guidance on that issue in its internal instructions also. The guidance and training should include discussion of the difficulty of adhering to HIV treatment regimens and directly acknowledge that there are many valid reasons why individuals with HIV disease do not adhere perfectly to their prescribed treatment regimen, such as the individual's mental illness or young age; logistical difficulties (e.g., lack of access to refrigeration) precluding exact compliance; debilitating side effects from the medication (e.g., diarrhea, nausea, vomiting, neuropathy, fatigue); and inability to afford the prescribed treatment. See, e.g., Stone, V.E., Strategies for Optimizing Adherence to Highly Active Antiretroviral Therapy: Lessons Learned from Research and Clinical Practice, Clin. Infect. Dis. 2001; 33:865-872; Trotta, M.P. et al., Treatment-Related Factors and Highly Active Antiretroviral Therapy Adherence, J. Acquir. Immune Defic. Syndr. 2002; 31:S128-131.

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We continue to be very concerned about the insistence of SSA disability examiners and adjudicators on objective evidence of manifestations of HIV infection. Advances in medical diagnostic procedures and progress in understanding clinical manifestations of HIV disease have commonly eliminated the need for laboratory evidence of certain HIV-related conditions. Moreover, claimants may experience a combination of symptoms which render them disabled, but which cannot be established by objective data. Treating physicians necessarily evaluate how credible their patients' subjective symptoms are and how those symptoms affect patients' functional abilities. Yet SSA disability examiners and adjudicators typically discount treating physicians' evaluations based on subjective symptoms and rarely find a claimant disabled in the absence of objective findings. As a result, adjudicators are denying benefits to people whom the criteria are designed to cover and we fear that SSA disability examiners and adjudicators will continue to insist on objective findings in situations where practicing HIV specialists would consider other evidence sufficient to establish the severity of manifestations of HIV infection.

This problem needs to be addressed both in additional language in the Rule and in training of SSA's disability examiners and adjudicators. The current version of the Rule states that both HIV infection and manifestations of HIV infection may be established without laboratory evidence if there is other documentation "consistent with the prevailing state of medical knowledge and clinical practice," Sections 14.00(D)(3) & (4). The same language appears in the Final Rule scheduled to go into effect on June 16, 2008 – in Sections 14.00(F)(1)(b), (F)(3). Because that language has proved insufficient, it needs to be strengthened. The Rule should state specifically that manifestations of HIV infection may be established in the absence of objective findings based on the claimant's treating physician's assessment of the impact of impairments and manifestations of impairments on the claimant.

Updated written guidance and training will be needed to ensure that SSA adjudicators properly credit evidence – subjective as well as objective – presented by claimants and their treating physicians. HIV disease is still a relatively new disease and the standards for identifying it and its associated conditions, and for treatment, will change more rapidly than will the language of the Rule. Continuing guidance and training needs to be provided to SSA disability examiners and adjudicators on the topics of what symptoms and signs HIV specialists consider to be reliable evidence of impairments and manifestations of impairments; what other evidence – not specified in the listings – HIV specialists consider to be equivalent to the evidence specified in the listings; and what other combined manifestations of impairments – not specified in the listings – impact claimants' functional abilities comparably to the combined manifestations set forth in the listings.

As another example, written guidance and training are needed on the topic of people who are non-responsive to treatment. Some individuals with HIV have persistent resistance, with no new treatment options. The fragile and tenuous position of a person with HIV who has

experienced persistent resistance to a medication regimen needs to be considered as a factor in the case-by-case analysis of whether that claimant meets the disability listings. If an individual fails to respond to a particular combination of medications, either because he or she is naturally resistant, because the virus mutates in the body or for some other reason, that individual has fewer options for relief in the future. With fewer available treatment options, the person is more susceptible to complications, illness and disabling conditions. With this increased susceptibility to opportunistic infection and other medical complications come additional mental health implications, as stress, fear, depression and anxiety compound the claimant's physical fragility. In many such cases, physicians instruct their patients to reduce their exposure to infection by limiting their contact with other people, stress and adverse weather conditions. A claimant with few treatment options is likely to have created a very structured environment to reduce his or her risk of infection and illness. Whether the claimant avoids subsequent infection at the expense of his or her relationships, mobility, freedom and mental health is itself a manifestation of HIV disease and the direct result of the damage to his or her immune system caused by HIV.

II. Comments on Specific Subparts of Sections 14.08 (Part A) and 114.08 (Part B) of Appendix 1

As a general principle, it is very important that the specific listings for HIV infection continue to be part of the listings for evaluation of immune system disorders. Even though evaluation of an individual situation cannot be limited to consideration of the disabling impairments specified in Sections 14.08 and 114.08 – as properly recognized in sections 14.00 and 114.00 – the "stand-alone" diagnoses for people living with HIV infection are an important part of the Rule. Diagnosis with a condition listed in those sections demonstrates that an individual has a severely compromised immune system and serves as a useful and sensible indicator of the inability to work. Therefore, the specific listings of impairments facilitate determinations of disability where an individual does meet one of the "stand-alone" listings.

We believe that the specific revisions to Sections 14.08 and 114.08 discussed below will result in listings that more accurately reflect the nature, course and treatment of HIV at this time and in the years ahead.

- A. The descriptions of some conditions currently listed in Sections 14.08 and 114.08 should be modified to better account for the variety of disabling impairments experienced by people living with HIV.
 - 1. Section 14.08(C)(1) and 114.08(C)(1): Protozoan or helminthic infections

Subsection (1) of 14.08(C) and 114.08(C) should be modified to read "cryptosporidiosis, isosporiasis, or microsporidiosis, with diarrhea lasting two-and-a-half weeks or longer despite

treatment." Where those infections are susceptible to successful treatment, that will be apparent after approximately two weeks and therefore the requirement that the diarrhea last one month is excessive.³

2. Sections 14.08(D) and 114.08(D): Viral infections

We suggest that Subsection (3) of 14.08(D) and 114.08(D) be re-worded to state "Herpes or Varicella zoster." These terms are sometimes, but not always, used interchangeably. Whether infected by the "herpes zoster virus" or the "varicella zoster virus," the infected individual experiences recurring, severe, disabling pain.

Also, this section should include medical criteria for co-infection with Hepatitis C ("HCV") or Hepatitis B ("HBV"), because for many individuals being co-infected is a significant contributing factor to their being disabled. The references to hepatitis in Sections 14.08(K), 14.00(G)(1)(f), and 114.00(G)(1)(f) do not adequately address the complicated medical realities faced by people who are co-infected. The listings need to specify that the interplay of the two infections needs to be considered on an individualized, case-by-case basis. Individuals who are co-infected will not do as well on any kind of treatment as monoinfected individuals and that must be taken into account.

People who are infected with both HIV and HCV or HBV need to start treatment earlier, have more limited treatment options, and will be less responsive to treatment and therefore less able to function. Although simultaneous treatment of both HIV and hepatitis is critical for people who experience co-infection, the two treatment regimens can work against one another. Treatment options for individuals co-infected with HCV are extremely bad: drugs used to treat HIV can undercut the benefits sought through treatment for HCV because the HIV drugs are toxic to the liver. HCV-related liver disease has been found to accelerate among people infected with HIV and similar complications occur in HIV-positive people with HBV. Further complicating matters for individuals co-infected with HIV and hepatitis is that the individual may suffer from symptoms that are typical of both conditions, such that the medical records may not clearly distinguish manifestations as HIV-specific or hepatitis-specific. If the listing does not consider these viral infections in combination, SSA may fail to accord proper significance to the noted symptoms. Therefore, Sections 14.08(D)

³ See, e.g., Farthing, M.J.G., Treatment Options for the Eradication of Intestinal Protozoa, Nat. Clin. Pract. Gastroenterol. Hepatol. 2006; 3:436-445.

⁴ See, e.g., Braitstein, P. et al., Special Considerations in the Initiation and Management of Antiretroviral Therapy in Individuals Coinfected with HIV and Hepatitis C, AIDS 2004; 18:2221-2234.

⁵ See, e.g., Braitstein, P. et al. (2004), supra; Sherman, K.E. et al., Hepatitis C Virus Prevalence among Patients Infected with Human Immunodeficiency Virus: a Cross-Sectional Analysis of the US Adult AIDS Clinical Trials Group, Clin. Infect. Dis. 2002; 34:831-837.

⁶ See, e.g., Khalili, M., Coinfection with Hepatitis Viruses and HIV, HIV InSite Knowledge Base Chapter (March 2006), http://hivinsite.ucsf.edu/InSite?page=kb-05-03-04, (last visited May 19, 2008).

and 114.08(D) should reference hepatitis, where co-infection with both HIV and HCV or HCB complicates treatment of both conditions.

3. Section 14.08(E) & 114.08(E): Malignant neoplasms

Central Nervous System (CNS) lymphoma, a very severe lymphoma of the brain that is difficult to treat, should be added to Subsection (3) of Sections 14.08(E) and 114.08(E), which list various types of lymphoma which can cause disability in people with HIV.

4. Section 14.08(F) & 114.08(F): Conditions of the skin or mucous membranes

Limiting qualifying lesions in Sections 14.08(F) and 114.08(F) to "extensive fungating or ulcerating lesions" is too restrictive. The listing should be revised to include rash, itching, and burning as symptoms to consider in evaluating the condition. All of these symptoms can cause severe insomnia and are disabling on their own.

5. Section 14.08(H): HIV wasting syndrome

Section 14.08(H)'s listing of HIV wasting syndrome should be revised to reflect more current medical knowledge about this condition. In subsection (1), the requirements with regard to diarrhea should be changed to add "or chronic diarrhea with two or more loose stools daily lasting for two weeks or longer plus lean body mass (documented by BMI)." Fever is no longer considered a factor for documenting HIV wasting syndrome and therefore Subsection (2) should be revised to read "chronic weakness or chronic fatigue."

6. Sections 14.08(I) and 114.08(I): Diarrhea

Sections 14.08(I) and 114.08(I) (unchanged in the Final Rule from their predecessor sections in the Rule adopted in 1993) fail to take into account the extent to which some individuals with HIV are prevented from leading a normal life due to diarrhea. HIV infection can be associated with diarrhea in any of the following three ways: (1) diarrhea associated with parasitic co-infection; (2) diarrhea as a side effect of medication; or (3) generalized condition of malabsorption. Diarrhea in any of those three contexts can cause instability in the patient – if the patient is not able to control his or her bowels despite use of available modalities, the patient will be unable to perform his or her regular activities of daily living or will have functional limitations or restrictions due to incontinence issues. However, individuals disabled as a result of diarrhea are likely to lack objective indicators of the severity of their diarrhea. It is in the very nature of diarrhea that it can be severe and disabling without meeting objective criteria and without needing the treatments required to meet the listing.

⁷ See, e.g., Mangili, A. et al., Nutrition and HIV Infection: Review of Weight Loss and Wasting in the Era of Highly Active Antiretroviral Therapy from the Nutrition for Healthy Living Cohort, Clin. Infect. Dis. 2006; 42:836-842 (noting problems with using defining criteria of weight loss plus diarrhea or fever).

Evaluation of the impact of diarrhea on the individual is likely to be based on subjective evidence and SSA disability examiners and adjudicators should defer to the clinical opinion of treating physicians, who are in the best position to evaluate the credibility of a patient's assertions with respect to persistent diarrhea. Therefore, the listing needs to specify clinical indicators, not just objective indicators.

In addition, the listing needs to be revised to reflect current medical views regarding the treatment of diarrhea. Many patients with disabling diarrhea do not require hydration and therefore are not treated with intravenous hydration. "Tube feeding" also is not a useful indicator of diarrhea; it is rarely used now to treat diarrhea and, in fact, diarrhea has been identified as a complication associated with tube feeding.⁸

For these reasons, the requirement for "intravenous hydration, intravenous alimentation, or tube feeding" should be removed from the listing and replaced with the following indicators of disabling diarrhea "and indicated by inability to maintain weight, discomfort, abdominal pain, and unpredictability of the diarrhea."

B. Chronic pancreatitis should be added as a "stand-alone" listing in Sections 14.08 and 114.08.

Although pancreatitis is now referenced in 14.00(G)(5)(a) – as a side effect of antiretroviral drugs – and in 14.08(K), the Final Rule fails to acknowledge the seriousness of residual chronic pancreatitis among people with HIV disease. Chronic or relapsing pancreatitis among people with HIV disease severely impairs those individuals' abilities to function. Serious, life-threatening pancreatitis can develop as a side effect of medications used to treat HIV disease. The condition may cause severe abdominal pain, nausea, vomiting, fever, chills, and shortness of breath, and can result in admission to a hospital's intensive care unit for two to three weeks at a time. Also, it may result in profound weight loss and long-term food intolerance. These manifestations may recur continually when the cause of the pancreatitis persists or when lasting damage has been done to the pancreas. The affected individual may suffer numerous painful and debilitating relapses. Unfortunately, there is no cure for the condition.

⁸ See, e.g., Bliss, D.Z. et al., Acquisition of Clostridium Difficile and Clostridium Difficile-Associated Diarrhea in Hospitalized Patients Receiving Tube Feeding, Ann. Intern. Med. 1998; 129:1012-1019; Finucane, T.E. et al., Tube Feeding in Patients with Advanced Dementia: a Review of the Evidence, JAMA 1999; 282:1365-1370.

⁹ See, e.g., Dragovic, G. et al., Incidence of Acute Pancreatitis and Nucleoside Reverse Transcriptase Inhibitors Usage, Int. J. STD AIDS 2005; 16:427-429; Gan, I. et al., Pancreatitis in HIV Infection: Predictors of Severity, Am. J. Gastroenterol. 2003; 98:1278-1283.

¹⁰ See, e.g., Dragovic, G. et al. (2003), supra; Gan, I. et al. (2003), supra.

¹¹ See, e.g., Dragovic, G. et al. (2003), supra.

Because the presence of pancreatitis can be an important marker of HIV-related drug toxicities that could also limit life-saving treatment options or of complications of HIV-related opportunistic infections, we recommend that Sections 14.08 and 114.08 include chronic pancreatitis as a "stand-alone" listing, satisfied by evidence of one or more episodes of pancreatitis from which clinical recovery is incomplete after three months and is accompanied by ULN (upper limits normal) lipase or amylase laboratory values, and disabling symptoms (such as, but not limited to, persistent abdominal pain, diarrhea, significant weight loss, nausea, anorexia, or glucose intolerance requiring frequent monitoring or treatment). These criteria would apply to individuals who suffer more than a transient episode of pancreatitis that resolves after a change in medication.

C. Sections 14.08(K) & 114.08(L) should be revised to specifically reference additional disabling manifestations of HIV.

Sections 14.08(K) and 114.08(L) state that HIV-positive claimants may be disabled by repeated manifestations of HIV-related conditions and provide some examples. It is clear that these sections do not contain exhaustive lists of the "other manifestations" of HIV infection that may satisfy the listing and the agency's comments accompanying the Final Rule re-iterate that fact. However, additional language should be added to these sections to help ensure that SSA decision makers properly apply these Sections when they evaluate claims. Unfortunately, SSA decision makers often conclude that a particular claimant does not meet or equal current Section 14.08(N) – Section 14.08(K) in the Final Rule – because the manifestations, symptoms, or signs that the claimant experiences do not rise to the level of another "stand-alone" listing. Referencing some of the additional manifestations that, when recurrent or in combination with others, impair the functional capacity of a person with HIV may help reduce such incorrect evaluations. To that end, we suggest that the parenthetical after "or other manifestations" in Section 14.08(K) be expanded to refer to the conditions listed below and that comparable changes be made in Section 114.08(L).

In addition, we request that the following general language be added to 14.08(K) and 114.08(L): "Special consideration should be given to other conditions, signs and symptoms deemed by the primary care provider as contributing to substantial functional limitations." Such language will reinforce the fact that these sections are not intended to provide an exhaustive listing of the manifestations and documented symptoms or signs that may meet the criteria of these sections.

¹² See, e.g., 73 Fed. Reg. at 14592.

1. Morphological abnormalities

Morphological abnormalities – including lipodystrophy, lipohytrophy, and lipoatrophy – are serious conditions that often result from HIV and HIV therapies. Changes in body composition resulting from significant fat loss or fat deposition negatively impact medication adherence. Some individuals infected by HIV who experience morphological abnormalities including lipid disorders are susceptible to elevated blood fat levels and cardiovascular disease – including higher coronary rates and resultant shortened life expectancy – as well as diabetes due to altered glucose metabolism. In addition, these disorders cause psychological trauma for some individuals, which subsequently affects their ability to continue working. Given these impacts, these abnormalities should be referenced in Section 14.08(K).

2. Metabolic abnormalities

Section 14.08(K) should mention the disabling potential of metabolic abnormalities resulting from a temporary or permanent loss of blood supply to the bones. Osteomalcia – or bone wasting – causes spontaneous fractures and horrific pain, and can be disabling. Similarly, avascular necrosis (AVN) resulting in bone erosion and collapse can cause disabling pain. Although the cause of these bone conditions is unknown, it appears that HAART may play a role. Although a metabolic condition is not necessarily disabling, any of these bone conditions – when recurrent – can seriously affect functional capacity.

3. Infarction and cardiac problems

HIV treatment has been associated with increased risk of myocardial infarctions, hyperglycemia, hyperlipidemia and even hypertension. ¹⁵ Additionally, research has established that HIV-positive individuals with lipodystrophy have significantly greater risk of

¹³ See e.g., Tien, P.C. et al., Antiretroviral Therapy Exposure and Incidence of Diabetes Mellitus in the Women's Interagency HIV Study, AIDS 2007; 21:1739-1745 (discussing links between long-term use of some HIV medications and development of diabetes).

¹⁴ See, e.g., Currier, J. et al., Regional Adipose Tissue and Lipid and Lipoprotein Levels in HIV-infected Women, J. Acquir. Immune Defic. Syndr. 2008; 48:34-43; Wohl, D. et al., The Associations of Regional Adipose Tissue with Lipid and Lipoprotein Levels in HIV-Infected Men, J. Acquir. Immune Defic. Syndr. 2008; 48:44-52.

¹⁵ See e.g., The DAD Study Group, Class of Antiretroviral Drugs and the Risk of Myocardial Infarction, N. Engl. J. Med. 2007; 356:1723-1735; Holmberg, S. et al., Protease Inhibitors and Cardiovascular Outcomes in Patients with HIV-1, Lancet 2002; 360:1747-1748; Madden, E. et al., Association of Antiretroviral Therapy with Fibrinogen Levels in HIV-Infection, AIDS 2008; 22:707-715; Stein, J.H., Editorial: Cardiovascular Risks of Antiretroviral Therapy, N. Engl. J. Med. 2007; 356:1773-1775; Triant, V.A. et al., Increased Acute Myocardial Infarction Rates and Cardiovascular Risk Factors among Patients with Human Immunodeficiency Virus Disease, J. Clin. Endocrinol. Metab. 2007; 92:2506-2512.

cardiovascular disease than HIV patients without lipodystrophy. ¹⁶ While HAART-related heart conditions may not always rise to the level of the cardiac listings, evidence of medication-induced infarction or impaired cardiac capacity must be considered as a manifestation of HIV/AIDS.

4. Other common disabling manifestations of HIV

The important, disabling combination of impaired mental functioning and HIV infection still is not addressed adequately in the Final Rule. Mental and emotional functioning are often connected to HIV infection. Mental illness may precede HIV infection, as mental illness places people at risk of contracting HIV infection.¹⁷ Mental health issues may accompany HIV infection, as the initial diagnosis of HIV infection can trigger anxiety and depressive disorders. Reservoirs of HIV can accumulate in the brain and cause dementia.¹⁸ Not all current HIV medications effectively cross the blood-brain barrier, and many patients can become resistant to those that do.¹⁹ Additionally, HIV medications can themselves cause mental impairments such as significant memory loss, cognitive deficits, depression, anxiety, paranoia and hypervigilance.²⁰

For these and other reasons, mental illness frequently affects people who are living with HIV, and becomes more pronounced as the HIV disease progresses and becomes more severe. Mental health conditions can interfere with self-care, activities of daily living, and adherence to treatment regimens and appointment schedules.²¹ Stress, anxiety and depression weaken the immune system and speed disease progression, whether they stem from mental illness, the trauma of the diagnosis, or the rigors of treatment.²²

¹⁶ See e.g., Hadigan, C. et al., Metabolic Abnormalities and Cardiovascular Disease Risk Factors in Adults with Human Immunodeficiency Virus Infection and Lipodystrophy, Clin. Infect. Dis. 2001; 32:130-139.

¹⁷ See, e.g., Angelino, A.F. & Treisman, G.J., Management of Psychiatric Disorders in Patients Infected with Human Immunodeficiency Virus, Clin. Infect. Dis. 2001; 33:847-856; Thompson, A. et al., Psychotropic Medications and HIV, Clin. Infect. Dis. 2006; 42:1305-1310.

¹⁸ See, e.g., Tozzi, V. et al., Changes in Neurocognitive Performance in a Cohort of Patients Treated with HAART for 3 Years, J. Acquir. Immune Defic. Syndr. 2001; 28:19-27; Valcour, V. & Paul, R., HIV Infection and Dementia in Older Adults, Clin. Infect. Dis. 2006; 42:1449-1454.

¹⁹ See, e.g., Tozzi, V. et al. (2001), supra.

²⁰ See, e.g., Thompson, A. et al. (2006), supra, at 1306-1309.

²¹ See, e.g., Angelino, A.F. & Treisman, G.J. (2001), supra; Yun, L.W. et al., Antidepressant Treatment Improves Adherence to Antiretroviral Therapy among Depressed HIV-Infected patients, J. Acquir. Immune Defic. Syndr. 2005; 38:432-438.

²² See, e.g., Ickovics, J.R. et al., Mortality, CD4 Cell Count Decline, and Depressive Symptoms among HIV-Seropositive Women: Longitudinal Analysis from the HIV Epidemiology Research Study, JAMA 2001; 285:1466-1474; Tate, D. et al., The Impact of Apathy and Depression on Quality of Life in Patients Infected with HIV, AIDS Patient Care STDS 2003; 17:115-120.

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The link between HIV infection and mental illness is so strong, moreover, that often primary care providers and infectious disease specialists prescribe compensatory medications such as anti-depressants and anti-anxiety medications to their patients without referring them for psychiatric care or counseling.²³ Moreover, claimants with HIV and mental illness may have expense and other access issues that make it very difficult for them to obtain an evaluation from a mental health expert. In such cases, there is no longitudinal history of psychiatric care or assessment and no results from objective tests, as would be expected in the ordinary claim where the principal disabling impairment is a mental health condition. While such a patient may not have the history of signs and symptoms that document the severity required by SSA's mental health condition listings, these very real and often severe conditions must be recognized by SSA as a manifestation of HIV infection which contributes to the disabling nature of the disease.

The Final Rule does acknowledge some of these impacts in Sections 14.00(G)(1), 14.00(G)(5), and 14.00(J)(2), as well as by insertion of the phrase "cognitive or other mental limitation" in Section 14.08(K). However, the importance of this issue calls for additional language in Section 14.08(K). Therefore, we recommend that the listed examples of possible symptoms or signs in Section 14.08(K) be expanded to include memory loss, concentration problems, and cognitive processing difficulties. People disabled by HIV and related impairment of mental functioning commonly experience these symptoms. In addition, we recommend that the listed examples of "other limitations" include "anxiety" and "depression." Furthermore, the issues discussed above should be addressed specifically in the written guidance and training provided to SSA disability examiners and adjudicators.

If you have any questions or wish for clarification regarding any of the above comments, please contact, on behalf of the undersigned, Bebe J. Anderson, HIV Project Director, Lambda Legal, 120 Wall Street, Suite 1500, New York, New York, 10005, telephone (212) 809-8585, email banderson@lambdalegal.org. We look forward to a productive continuing discussion as the process moves forward.

Sincerely,

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 $^{^{23}\,}$ See, e.g., Thompson, A. et al. (2006), supra, at 1305.

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