NATIONAL ORGANIZATION OF SOCIAL SECURITY CLAIMANTS' REPRESENTATIVES (NOSSCR)

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Executive Director
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Commissioner Andrew Saul
Social Security Administration
6401 Security Boulevard
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Submitted via www.regulations.gov

Re: Notice of Proposed Rulemaking on Revised Medical Criteria for Evaluating Digestive Disorders and Skin Disorders, 84 Fed. Reg. 35936 (July 25, 2019), Docket No. SSA-2017-0042

Dear Commissioner Saul:

These comments are submitted on behalf of the National Organization of Social Security Claimants' Representatives (NOSSCR).

The National Organization of Social Security Claimants' Representatives (NOSSCR) is a specialized bar association for attorneys and advocates who represent Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) claimants throughout the adjudication process and in federal court. Founded in 1979, NOSSCR is a national organization with a current membership of more than 3,000 members from the private and public sectors and is committed to the highest quality representation for claimants and beneficiaries. NOSSCR's mission is to advocate for improvements in Social Security disability programs and to ensure that individuals with disabilities applying for SSDI and SSI benefits have access to highly qualified representation and receive fair decisions.

<u>Digestive Disorders, 5.00 and 105.00</u>

Change to Time Periods

NOSSCR supports the proposed change to the period during which the criteria in listings 5.02, 5.05, 5.06, 5.08, and their childhood equivalents must occur. A "12-month period" is more appropriate than a "6-month period" because it is more consistent with the timeframe criteria in all other body systems within the listings, and with the Social Security Act's durational

requirement for severe impairments. It will also lead to more efficient adjudication for claimants whose symptoms were present or recorded more than six, but no more than 12, months apart.

Chronic Liver Disease

We encourage SSA to allow pulse oximetry as well as arterial blood gas (ABG) testing, contrast-enhanced echocardiography, or macroaggregated albumin lung perfusion scan to demonstrate hepatopulmonary syndrome in the final version of listing 5.05E and its childhood equivalent. Pulse oximetry may be performed because it is less painful, less expensive, and quicker than other types of testing, and it can identify the same patients. For example, in a study of patients with hepatopulmonary syndrome (https://www.cghjournal.org/article/S1542-3565(06)01271-7/pdf), "a pulse oximetry value of ≤94% detected all patients with a partial pressure of oxygen <60 mm Hg," which is listing 5.05E's standard at and near sea level. If pulse oximetry is not permitted as a substitute, 5.00C2e(ii) and its childhood equivalent should indicate that SSA will purchase ABG testing for claimants with hepatopulmonary syndrome who have pulse oximetry values below 96%. ABG testing is less expensive than the specialized imaging techniques described in 5.05E2, and paying for ABG testing will reduce the need for claimants to pursue time-consuming and costly appeals.

We note that proposed listing 5.05E requires a PaO2 level that is in some cases higher and in other cases lower than that required to meet listing 3.02C2 (table IV) for chronic respiratory disorders. If a specific PaO2 level is indicative of disability when it is caused by chronic respiratory disease, it would seem to be equally disabling if caused by chronic liver disease, and vice versa. One way to resolve this disparity is to include a statement in listing 5.05E and its childhood equivalent that the listings can also be met with test results that would lead to a finding of disability under any of the tables in listing 3.02C2 and its childhood equivalent. This would accommodate the various ways that pulmonary function is tested and provide parity between the pulmonary and hepatopulmonary listings.

We support SSA's proposal that SSA-CLD and scores of "at least 20" should meet listing 5.05G and its childhood equivalent for children 12 and older, but believe that if the final listing requires two such scores at least 60 days apart, it should include the current listing's direction to "Consider under a disability from at least the date of the first score" or a reworded direction to "consider under a disability no later than the date of the first score."

Inflammatory Bowel Disease

NOSSCR supports the additional language in proposed 5.00D noting that "you need not be totally precluded from performing an activity to have marked limitation, as long as the degree of limitation interferes seriously with your ability to function independently, appropriately, and effectively. The term 'marked' does not imply that you must be confined to bed, hospitalized, or in a nursing home." The descriptions of marked limitations in several areas of functioning are also useful, because too often, claimants are considered to have less than marked limitations simply because they at some point socialize, perform household chores or childcare, leave the house, participate in worship or hobbies, etc.—even if their ability to do so is reduced, causes pain or fatigue, or requires significant breaks or accommodations. The proposed language in

5.00D would help confirm that such claimants do meet or equal a listing, leading to more accurate and efficient decisions. It also comports with some of the functional limitations caused by inflammatory bowel disorder that are discussed in the comments on the 2008 proposed digestive listings from a coalition of impairment-specific organizations and medical providers (https://www.regulations.gov/document?D=SSA-2007-0065-0005) and patients and family members of people with digestive disorders (https://www.regulations.gov/document?D=SSA-2007-0065-0013).

However, we question why "perineal disease" was removed from the list of signs and symptoms of IBD in proposed 5.00D2 and urge its inclusion in the final rule. We also recommend that the final version of the listing include the language from the current 5.00E3 about extraintestinal manifestations of IBD.

In listing 5.06, we applaud the removal of the phrase "that is not completely controlled by prescribed narcotic medication," because IBD patients and others should not be encouraged to try narcotic treatments or penalized if they or their providers choose alternative medications that carry lower risks of addiction and other side effects. The final rule should also explain that a lack of opioid/narcotic prescriptions or attempts to reduce or avoid use of such medication should never be considered indicative of the severity of an impairment. Nor should it affect an adjudicator's decision about whether such impairments can reasonably be expected to produce a claimant's symptoms (including pain), or about the intensity and severity of such symptoms.

Short Bowel Syndrome

We agree that in listing 5.07 and its childhood equivalent that requiring "surgical resection of any amount of the small intestine" is more appropriate than "surgical resection of more than one-half of the small intestine" both for SSA's stated reason that "measurement of the total length of remaining intestine within the abdominal cavity is rarely obtained during surgery" and because the functional limitations caused by surgical resection of the small intestine exist even if less than half of the intestine has been removed.

Malnutrition

Malnutrition caused by an impairment other than a digestive disorder (for example, cancer and its treatment, HIV, tuberculosis, cystic fibrosis, Alzheimer's disease and other dementias, etc.) that includes BMI and hemoglobin or serum albumin as low as the levels in proposed listing 5.08 and 105.08 result in similar functional limitations regardless of which disorder caused them. Therefore, it would be useful to omit the words "due to any digestive disorder" from the titles of these listings and simply focus on the malnutrition or growth restriction. Alternatively, the final listings could indicate that sufficiently low BMIs and serum albumin or hemoglobin, regardless of the severe impairment that caused them, should be considered to equal these listings.

Transplantation

NOSSCR supports the addition of adult and child listings for small intestine transplantation (proposed 5.11 and 105.11) and pancreas transplantation (proposed 5.12 and 105.12). These

transplants cause significant functional limitations. Providing listings for them will allow for more efficient adjudication for claimants who have undergone such transplants.

Skin Disorders, 8.00 and 108.00

Definitions

The proposed listings, in 8.00B2 and its childhood equivalent, define an assistive device as "any device used to improve stability, dexterity, or mobility. An assistive device can be hand-held, such as a cane(s), a crutch(es), or a walker; or worn, such as a prosthesis or an orthosis." The definition should also include wheelchairs, adaptive/special needs strollers, and scooters. Although these are not hand-held or worn, they improve stability and mobility, and claimants with a documented medical need for these devices have functional limitations at least as significant as those with a need for other assistive devices.

We support the proposed rule's statement in 8.00B4 and its childhood equivalent that a prescription is not required for assistive devices. Disability claimants have a variety of financial and insurance situations that in some cases make prescribed devices unobtainable or more expensive. Whether a device is obtained via a prescription or "over the counter" does not affect a claimant's need for it.

The definition of "fine and gross movements" in 8.00B5 and its childhood equivalent should include feeling as a fine movement, in keeping with SSR 85-15.

Evidence and Evaluation

It is unclear why 8.00C3d and its childhood equivalent require information about the claimant's "history of familial incidence" of a skin impairment. This information may be unobtainable (family members may be absent, deceased, not receiving medical treatment, or reluctant to share medical information) and does not affect the claimant's level of functioning. Information about familial incidence is not required by any other listings.

Current 8.00C says SSA generally bases its assessment of severity on, among other things, "the extent of your treatment, and how your treatment affects you." Proposed 8.00D says instead "how your prescribed treatment affects you." The final rule should omit the word "prescribed" from the listing or clarify that "prescribed" treatment does not literally require a prescription, because some medically necessary treatments recommended by medical providers for skin conditions (e.g. medicated baths, frequent bandage changes, or over-the-counter ointments) do not require a prescription. This change would better comport with the proposed statement in 8.00B4 that assistive devices do not need to be prescribed in order to be considered by adjudicators.

Functional Limitations

The current 8.00C describes "extensive skin lesions that result in a very serious limitation" as including, but not being limited to:

"a. Skin lesions that interfere with the motion of your joints and that very seriously limit your use of more than one extremity; that is, two upper extremities, two lower extremities, or one upper and one lower extremity.

b. Skin lesions on the palms of both hands that very seriously limit your ability to do fine and gross motor movements.

c. Skin lesions on the soles of both feet, the perineum, or both inguinal areas that very seriously limit your ability to ambulate."

But the proposed 8.00D2b, as well as proposed listings 8.07, 8.08, 8.09, and their childhood equivalents, require:

"(i) Inability to use both upper extremities to the extent that neither can be used to independently initiate, sustain, and complete work-related activities involving fine and gross movements;

(ii) Inability to use one upper extremity to independently initiate, sustain, and complete work-related activities involving fine and gross movements due to chronic skin lesions or contractures, and a documented medical need for a one-handed assistive device that requires the use of your other upper extremity; or

(iii) Inability to stand up from a seated position and maintain an upright position to the extent you can independently initiate, sustain, and complete work-related activities due to chronic skin lesions or contractures affecting at least two extremities (including when the limitations are due to involvement of the perineum or the inguinal region); or

(iv) Inability to maintain an upright position while standing or walking, to independently initiate, sustain, and complete work-related activities due to chronic skin lesions or contractures affecting both lower extremities (including when the limitations are due to involvement of the perineum or the inguinal region)."

The proposed standard is more onerous: for example, it does not allow for involvement of one upper and one lower extremity unless there is also the need for a one-handed assistive device used with the other upper extremity. In proposed 8.00D2b(i) and (ii), it is not clear whether both fine and gross movements must both be limited, but if they do that is a stricter standard than the "very seriously limit" standard in the current listing. Similarly, the current listing's "very seriously limit[ing] your ability to ambulate" is less stringent than the proposed listing's "Inability to maintain an upright position while standing or walking," because maintaining an upright position is not the only limitation someone could have on standing or walking—while posture is important, so are balance, stamina, speed, gait, and other aspects of standing and ambulating. As the Pennsylvania DDS noted in 2010 in response to proposed changes to the skin disorders listing (https://www.regulations.gov/document?D=SSA-2009-0037-0004), "What if one side of a groin, and one axilla was involved? Or a groin or arm-pit, an area under a breast or under an abdominal pannus? This disease may not potentially affect **both** upper extremity or **both** lower extremity limb use…The point is that systemic limb-affecting disease need not be present for listing level severity to be present" (emphasis in original).

SSA describes these significant changes as merely "a clearer explanation" of the existing rules, but this is not accurate. SSA does not explain or give any justification for the proposed change and should not adopt it, instead leaving the current language of 5.00C and its childhood equivalent, and the current language for burns, photosensitivity disorders, and chronic conditions of the skin or mucous membranes. People who meet the current listings have significant limitations and are extremely likely to be found disabled at steps 4 and 5 of the sequential evaluation process. This is why the current listings allow for a finding of disability at step 3 of the process: because it would be inefficient for adjudicators to continue to subsequent steps in the process when the outcome would ultimately be the same. The National Association of Disability Examiners' (NADE's) 2002 comments on proposed changes to musculoskeletal listings made this point in considerable detail:

> **We strongly dispute any suggestion by SSA that adjudicating claims at steps four and five in the sequential evaluation process can be done as quickly and as efficiently as claims decided earlier in the process.** It is far easier and less time consuming to process claims earlier in sequential evaluation when only medical factors are considered. Claims that require subjective consideration of functional abilities and other vocational factors will require more time to develop than claims that are decided on the basis of objective medical factors alone. SSA is ignoring reality to believe otherwise….**If, as expected, the revised listings result in more decisions at steps four and five of sequential evaluation, then this will clearly result in more development costs and increased processing time** (https://www.regulations.gov/document?D=SSA-2006-0112-0007**,** emphasis in original).

The proposed changes would make claimants less likely to meet a listing, and thus require decisionmakers to determine claimants' residual functional capacities, past relevant work and their ability to return to it, and their ability to perform other work in adult claims, and consider functional equivalence across several domains for child claims. SSA finalized a rule in 2017 that substantially limits the issues adjudicators must discuss in their disability determinations and reduces articulation requirements for other issues. The stated purpose for reducing the obligations placed on adjudicators was that "the increasing complexity of cases and voluminous files" meant "it is not administratively feasible" for adjudicators to do as much as they did in the past (See 82 Fed. Reg. 5856 (January 27, 2017) https://www.federalregister.gov/d/2017-00455/p-235). SSA has also planned to develop a "streamlined" fully favorable decision template to speed the processing of certain cases where the claimant is awarded benefits. It is therefore incongruous for SSA to propose regulatory changes here that will require adjudicators in many cases to proceed past the listing portion of the sequential evaluation process and make multiple additional findings.

Burns

SSA should remove the words "third-degree" from proposed listing 8.08 and its childhood equivalent. Fourth-degree burns, which go beyond the skin and underlying tissue to muscles and bones, are at least as detrimental to function as third-degree burns. Second-degree burns, especially but not only in combination with higher-degree burns, can also cause scarring that causes pain and limits function. Restricting the listing to third-degree burns could cause an adjudicator to ignore burns of a different or unspecified degree. SSA does not explain or justify the inclusion of the term "third-degree" and thus should not include it.

Lack of treatment

Proposed 8.00D6b states "If, for any reason, you have not received treatment, your skin disorder cannot meet the criteria for 8.09." This is contrary to the spirit of SSR 18-3p, which provides several reasons (including religion, inability to pay, incapacity, intense fear of surgery, risk of opioid addiction, etc.) why noncompliance with prescribed treatment could be excused. These same reasons might explain why a claimant has not received treatment and either 8.00D6b should be removed from the final listings, or the reasons from SSR 18-3p should be included as reasons a skin disorder could meet listing 8.09 without evidence of treatment, if, for example, a consultative examiner or medical expert opines that the listing criteria are met and adherence to medical treatment would not improve function to a point where the listing would no longer be met.

Thank you for the opportunity to comment on these proposed regulations.

Respectfully submitted,

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Executive Director