

NATIONAL ORGANIZATION OF
SOCIAL SECURITY CLAIMANTS' REPRESENTATIVES
(NOSSCR)

Government Affairs Office • 1025 Connecticut Avenue, NW Suite 709 • Washington, D.C. 20036
Telephone: (202) 457-7775 • Fax: (202) 457-7773 • email: nosscrdc@worldnet.att.net

Executive Director
Nancy G. Shor

February 11, 2010

Commissioner Michael J. Astrue
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235-6401

Submitted on www.regulations.gov

Re: Notice of Proposed Rulemaking on Revised Medical Criteria for Evaluating
Endocrine Disorders, 74 Fed. Reg. 66069 (Dec. 14, 2009); Docket No. SSA-2006-0114

Dear Commissioner Astrue:

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

Founded in 1979, NOSSCR is a professional association of attorneys and other advocates who represent individuals seeking Social Security disability or Supplemental Security Income (SSI) benefits. NOSSCR members represent these individuals with disabilities in legal proceedings before the Social Security Administration and in federal court. NOSSCR is a national organization with a current membership of more than 3,900 members from the private and public sectors and is committed to the highest quality legal representation for claimants. While our members represent claimants from the initial application through the Federal court appellate process, the majority of cases are hearings before Administrative Law Judges and appeals to the Appeals Council.

The preface to the proposed rule states:

Since 1985, medical science has made significant advances in detecting endocrine disorders at earlier stages, and newer treatments have resulted in better management of these conditions.

* * *

Because of advances in medical treatment and detection, most endocrine disorders do not reach listing-level severity because they do not become sufficiently severe

or do not remain at a sufficient level of severity long enough to meet our 12-month duration requirement.

* * *

The information we obtained from these experts [endocrinologists, diabetologists, and other medical experts consulted by SSA] and relevant medical references demonstrates that adequate glucose regulation is achievable with improved treatment options, such as a wider range of insulin products.

75 Fed. Reg. 66070. These reasons in the preface are provided in support of the proposed rule to remove all current endocrine listings (with one exception for children).

We are very concerned that the language in the preface and the proposed rule presumes that all claimants have full access to medical care. This presumption does not reflect the state of the current health care system in this country. It sets a dangerous, new precedent regarding the ability of claimants to access health care at a time when there is no universal health care. The current economic downturn has worsened the situation. Many more individuals are losing their health insurance when they become unemployed and they have lost their ability to obtain essential health care.

We urge SSA to reconsider the approach to delete all endocrine listings and to remove language from the preface that assumes all claimants have full access to health care and treatment.

Many individuals live with significant disabilities but they all do not have access to state-of-the-art medical advances. And unfortunately, many do not have access to *any* medical treatment. While there have been many advances in medical treatments, efforts to incorporate such changes into SSA's disability determination process, whether at Step 3 (Listing of Impairments) or Step 5, must be examined in the overall environment in which people with disabilities find themselves.

Has SSA determined the state of access to newer medical treatments or to any medical treatment? Are claimants who use public health care programs, e.g., Medicaid, VA, have access to these innovations? Should claimants who have no ability to pay for prescribed treatment be penalized? Current SSA policy states that benefits will not be denied because an individual is unable to afford prescribed treatment. See Social Security Ruling (SSR) 82-59.

A NOSSCR member in North Carolina who is the parent of an insulin dependent child has seen many treatment improvements over the past 20 years, such as fast-acting insulin and insulin pumps. He notes:

In this way, a properly trained patient can, knowing blood glucose levels and anticipated activity and food intake, judge how much insulin may need to be added as a bolus before meals, or whether additional glucose may need to be

added in order to avoid the possibility of a low blood sugar reaction. These pumps generally cost in the neighborhood of \$5,000 or more. Their availability depends upon wealth, or insurance, or the largesse of Medicaid or Medicare. Even the availability of a competent diabetes care team, without access to a pump, can be prohibitively expensive for many diabetics.

There also needs to be a recognition that access to newer medical treatments, or to any medical treatment, is likely to benefit those persons with disabilities who have a higher level of education and/or work experience. Further, the medical advances to which the preface refers may not necessarily work for those with severe cognitive or mental disabilities, multiple impairments, or other adverse factors.

There also is a need to recognize where individuals reside. SSA's current "failure to follow prescribed treatment" policy, embodied in SSR 82-59, recognizes this factor. The "good cause" exception to the rule for inability to afford treatment discusses the fact that free or subsidized treatment may not be reasonably available. An attorney who practices in rural southwest Georgia commented:

Many people that I see have diabetes that is untreated. Very few people in this area have health insurance. Diabetes is largely an uncontrolled problem for the majority of people that I see in disability cases.

To delete the listing for diabetes on the assumption that medical science has advanced and these problems are now treated is frankly very presumptuous. As many people are unable to afford even basic healthcare, the diabetes problem is rampant in this area Unfortunately, we are not living in an ideal world especially in areas such as southwest Georgia where people cannot afford treatment for even a deadly condition such as diabetes.

Another issue raised by our members is that their clients' diabetes is not controlled, even when there is access to treatment. This point was confirmed by October 2005 comments submitted by the American Diabetes Association (ADA) in response to an Advance Notice of Proposed Rulemaking regarding the endocrine listings. Notably, the ADA did *not* recommend that the diabetes listing be eliminated. While recognizing that many people with diabetes are able to work, the ADA noted that "diabetes can cause a range of short-term and long-term complications that, separately or together, can severely limit an individual's ability to work or function."

In contrast to the statements in the preface to the current NPRM, the ADA recommended that Listing 9.08 "should be revised to include episodes of severe hypoglycemia":

While most people with diabetes will rarely actually experience such an episode, some people with diabetes can experience them on a regular basis. Severe hypoglycemia is a medical emergency and can be life-threatening; it will render a person unable to work or function effectively until it is treated. Recurrent severe

hypoglycemia can render individuals unable to work because of the debilitating effects of the episodes.

Comments provided by NOSSCR members support the ADA's statements. The North Carolina attorney noted that "[s]ome diabetics seem to have more difficulty avoiding swings in blood glucose levels, despite their best efforts." Some of these problems are due to unexplained causes. Another attorney from Texas described a client with multiple emergency room trips and who could not bring his diabetes under control. Frequent medication and diet changes did not help. An insulin pump did not improve his condition. "For the last months, his life was a broken record of rushing to the hospital ER, being stabilized, and then being released. His condition got progressively worse and he finally died."

* * *

For the reasons stated above, we urge SSA to reconsider the approach to delete all endocrine listings and to remove language from the preface that assumes all claimants have full access to health care and treatment.

Thank you for consideration of our comments.

Sincerely,

Ethel Zelenske
Director of Government Affairs