



August 27, 2007

Commissioner of Social Security  
P.O. Box 11703  
Baltimore, MD 21235-7703

Re: **Docket No. SSA-2007-0045**  
**20 CFR Part 405**  
**RIN 090-AG53**  
**Proposed Suspension of New Claims to the Federal Reviewing Official Review Level,**  
**Changes to the Role of the Medical and Vocational Expert System, and Future Demonstration**  
**Projects.**

Dear Sirs:

We are delighted that the SSA is proposing to modify its disability administrative adjudication process as instituted since March 2006, in order to improve accurate and timely services to claimants for SSDI and SSI benefits based on disability and blindness.

The National Organization for Rare Disorders (NORD) is a non-profit voluntary health organization dedicated to the identification, treatment, and cure of rare disorders through programs of education, research, advocacy and services to patients and families. According to the National Institutes of Health (NIH) Office for Rare Diseases, there are an estimated 7,000 of these disorders cumulatively affecting over 25 million Americans. Under the *Orphan Drug Act of 1983*, a rare disease is defined as any disease or condition affecting fewer than 200,000 Americans. Because the number of people affected by each rare disease is small, there is often a lengthy delay in receiving an accurate diagnosis; patients have great difficulty finding medical experts who are familiar with their condition; there usually is no effective treatment available to change the course of the disease; and, if the disease is not included on SSA's Listing of Impairments, beneficiaries are commonly denied SSDI benefits and are forced to appeal.

1. Suspending OfedRO and MVES/reallocation of resources to the backlog

During the past 25 years we have noted that except for a very small number of rare diseases that have been added to SSA's Listing of Impairments, the chances of disabled people with rare diseases to obtain SSDI or SSI benefits without going through a lengthy and expensive appeals process has been practically nil.

When these patients apply for benefits it is often obvious that reviewers do not know the disease, or are relying on misinformation about the disease. For example, in the case of an infant born with recessive dystrophic epidermolysis bullosa, the parents were told that benefits were denied because the disease was a cosmetic skin problem that would have no effect on substantial gainful activity. The reviewers did not know it is a uniformly life-threatening disease causing external and internal blisters and infections, and is usually fatal in the first decade of life. With good medical care the child might live to the second decade, but without SSI he would have no medical benefits. The parents were forced through several years of appeals; retroactive benefits were ultimately awarded, but, in the interim, the child sustained increased permanent injury.

The Social Security Administration's changes to the administrative review process in the Spring of 2006 were particularly burdensome for people with rare diseases in the Northeast United States because the State agency reconsideration level was replaced by a Federal adjudication level (FedRO). Applicant beneficiaries had to deal with long-distance appeals rather than meeting face-to-face with an administrative law judge. Obviously, when an applicant is denied benefits because a reviewer does not understand an unusual disease, there should be an opportunity for a face-to-face meeting with the patient, or at the very least there should be accurate and understandable information about the disease available to the SSA employee.

When a person with a rare disorder becomes disabled and files for SSI Disability benefits, they are usually at the lowest point in their lives. The loss of income from a job often means they cannot afford to keep their health insurance through COBRA payments, and then they learn that they will only qualify for Medicare after they have been receiving disability benefits for two years. Nevertheless, this is the time of their life that they are most in need of medical care! One can only imagine their reaction when their disability claim is denied.

We believe that quick disability determinations (QDD) is a very good process that helps people with certain diagnoses by qualifying them quickly for benefits. The QDD System ought to be broadened to include additional life-threatening rare disorders that continue to be hopeless and untreatable. Unfortunately, patients with diagnoses that are not on the Listing of Impairments have to expect that their claim will be automatically denied, and with luck they may live long enough to survive the lengthy appeals process. Under the FedRO process they do not even have an opportunity to appear in person before a judge, so the March 2006 rule appears to stack the cards against people with unusual diagnoses. We heartily endorse SSA's willingness to revert the system back to the processes followed before August 2006. Hopefully this will clear up the current backlog and prevent heavy backlogs for future applicants.

## 2. National Registry of Experts

**SSA proposes to create and maintain a national registry of medical, psychological and vocational experts to assist disability adjudications in developing or clarifying information. We heartily endorse this effort, and we offer our assistance in finding the needed experts on unusual diseases who could help SSA to understand the disabling aspects of rare disorders. It is critically important that cases involving unusual diseases should use the expertise of physicians who are experts on that particular disease.**

For many rare disorders, non-profit patient organizations exist to help in this effort. Each of them has a medical advisory committee composed of experts on that disease and related conditions. When SSA needs an expert on a neuromuscular disease, for example, it is not right for you to call on any neurologist because they may be experts on seizure disorders, hypertension, etc., and know very little about rare neuromuscular diseases. Therefore, non-profit support groups can help SSA to find appropriate experts. If the disease has no patient organization devoted to that specific disease, NORD can help to find the experts.

What qualifications should they have? Experts on any disease can be identified by the number of peer-reviewed journal articles they authored on a disease (and related diseases). Once they have published, other patients with that disease will be referred to them. Therefore, a second qualification would be the number of patients with the specific diagnosis that they have seen during their medical career.

How much should they be paid? We cannot comment on this question. However, it is important to remember that some diseases may be so rare that there are only two or three experts in the United States who are knowledgeable about the disorder. These physicians are often willing to communicate and educate via phone or email, but it would likely be more difficult for them to travel to a meeting or hearing, and they may not be willing to do so. Thus, SSA should decide exactly what they would ask these experts to do before you decide on a fee schedule.

3. Clarity of the Proposed Rules

You asked for advice how to make the rules easier to understand. We suggest that publication of any rules should contain a “Definitions” section. This would help laymen to understand terms such as “Substantial Gainful Activity”, “FedRO”, “adjudication”, “reconsidered determinations”, etc.

We hope these comments are helpful. Again, NORD would welcome the opportunity to work in concert with the Social Security Administration to identify experts on specific rare diseases. Please feel free to contact us with any questions.

Very truly yours,

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