

# **A.C.C.E.S.S.**

## ***Advocating for Chronic Conditions, Entitlements, and Social Services***

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Thank you for extending this opportunity to address you on the issue of disability determinations for people with rare diseases. Since 1995, I have represented hundreds of claimants with rare chronic conditions before the Social Security Administration. ACCESS provides this representation at no cost to members of certain specific disease communities. My comments and suggestions are based on this experience and are focused primarily on the disorders in which our program specializes. I should emphasize that both Kim Bernstein and I are speaking here today in our capacity as advocates for the disabled and not on behalf of the company that funds our program.

I would begin by noting that for the relatively small number of our clients with rare diseases who are eligible for presumptive disability payments or special processing due to terminal illness (TERI) the results are certainly beneficial. However, many of them do not qualify for these initiatives, so I would like to discuss some of the challenges that they encounter in the disability process.

In my experience, individuals with rare diseases who unquestionably qualify under SSA's Listing of Impairments can have widely divergent outcomes. One of the things I frequently tell our clients is that I could present the same facts to two different adjudicators and get two different results. Some claims are approved quickly and some take longer than anticipated but there is no reliable way to determine how long a given claim will take. Moreover, the lack of predictability in outcomes leads to a perception that the process is not always fair.

Part of the disparity arises from the fact that some of the Listings for rare conditions are open to interpretation; people can reasonably differ over how the Listing should be applied. An example that comes to mind is Listing 14.07 (114.07 A1 for children), which looks for documented, recurrent severe infections in people with primary immune deficiency. There is no definition of "severe", and an argument can be made that a person with a seriously impaired immune system never has a "minor" infection. What may be a three-day bout of bronchitis for me may be two weeks' worth of antibiotics and bed rest for someone subject to this Listing. Recent efforts to clarify these particular Listings will hopefully make their application more consistent.

Occasionally we confront a problem determining *which* Listing has been met. Listing 11.10 provides that the diagnosis of amyotrophic lateral sclerosis (ALS) alone establishes disability. SSDI due to ALS results in Medicare eligibility without the 24-month waiting period. We have gotten quite a few calls from people who were found disabled for other reasons before their ALS was finally diagnosed. They are now being told that have to wait 24 months for Medicare after all.

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There needs to be an easier way to amend a favorable determination to relate this later diagnosis back to their onset date as most of these patients have an immediate need for medical care and typically won't live long enough to satisfy the 24-month wait for Medicare. Using the compassionate allowance process to amend favorable determinations to include later-diagnosed ALS might be one avenue for helping these claimants.

In some instances, the delay in allowing claims arises from issues of translating medical terms into regulatory language and vice versa. For example, Listing 3.09A addresses cor pulmonale secondary to pulmonary vascular hypertension. This Listing provides for disability when the mean pulmonary artery pressure is greater than 40 mm Hg as measured by right-heart catheterization, yet a surprising number of claimants who meet this Listing get denied.

The problem is that the terms "cor pulmonale" and "pulmonary vascular hypertension" are not used much in treating records. The medical community generally refers to this condition as pulmonary hypertension or pulmonary arterial hypertension. Cor pulmonale is simply enlargement of the right ventricle of the heart due to disease of the lungs or of the pulmonary blood vessels (typically as shown by echocardiogram); the term "right ventricular hypertrophy" is far more common in that context (and is actually referenced in the explanatory preamble at 3.00G).

It would help if adjudicators had access to a database of rare conditions like pulmonary hypertension and the associated ICD-9 diagnostic codes used in most medical records. This would eliminate the confusion as to which disorders are covered by a particular listing. This could also be used to cross-reference common co-morbidities, such as arthritis for people with hemophilia (the result of frequent spontaneous bleeding into the joints). Finally, these codes could be linked to questionnaires developed in conjunction with medical professionals with specialized knowledge of a particular rare chronic condition. These questionnaires could be specifically tailored to develop evidence particular to each rare condition. The DDS adjudicator could then submit the relevant questionnaire to the treating physician and use the responses to identify cases where compassionate allowance would be appropriate. Such a process would assist adjudicators who have a frame of reference for evaluating common disorders but may not have ever heard of most rare conditions.

Taking pulmonary hypertension as an example, the questionnaire could be used to identify claimants who use medications that require a continuous infusion pump through an implanted catheter or frequent daily use of a special inhalation device, who need oxygen to function, who suffer from chronic pulmonary or heart failure or who have been placed on a heart/lung transplant list. The doctor's

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replies could then be used to determine whether a TERI assessment or a compassionate allowance is in order for that claimant.

Finally, it seems that some adjudicators apparently just don't believe that certain listings actually mean what they say. For children with an inherited coagulation disorder, such as hemophilia or von Willebrand's disease, Listing 107.08A provides for disability where there is repeated inappropriate or spontaneous bleeding. Yet I have represented many children with a documented history of such hemorrhages who had to appeal the denial of their claim. In fact, I recently did a hearing for a child in New York where the medical expert essentially admitted that my client had repeated bleeding but didn't meet the Listing because she had not been hospitalized recently, despite the lack of any mention of such a criterion in the Listing.

One of the problems is that people with coagulation defects (both adults and children) frequently treat at home rather than in a hospital or clinical setting. However, treating physicians routinely rely upon home treatment records to prescribe for their patients. Allowing adjudicators to rely on home treatment records just as informed medical professionals do would help expedite favorable outcomes for people who are often approved on appeal.

In denying a claim for a rare condition, adjudicators frequently note that the claimant is undergoing some form of treatment that lessens the impact of their disease. However, they hardly ever address the *extent* of the relief provided by such therapy. Very often, these treatments take a horribly debilitating condition and make it marginally less horrible. They are by no means a cure and their benefits are usually offset to some degree by the impact of the therapy itself.

The frequency, duration and side effects of these treatments rarely enter into their evaluation of the claimant's functional capacity. It is very difficult to maintain regular work attendance when you are going to require a six-hour infusion every three weeks for the rest of your life and the treatment leaves you feeling ill for a day or so. People on such a treatment regimen should be considered for compassionate allowance. This would include claimants with primary immune deficiency who use intravenous immunoglobulin (as do people with certain neurological disorders, such as polymyocitis). Another group with a similar pattern of infusion includes people with a genetic form of emphysema known as alpha-1 antitrypsin deficiency.

Nor is there much discussion about the functional limitations that claimants endure while waiting for their therapy to take effect. People with coagulation defects may suffer extreme pain and restricted range of motion in the affected area for days before a bleeding episode is finally controlled. The sporadic and

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unpredictable occurrence of such episodes has a huge impact on their ability to function. People with bleeding disorders such as hemophilia and von Willebrand's disease should be considered for compassionate allowance when their records demonstrate spontaneous bleeding episodes that require treatment six times or more over the course of a year.

SSA needs to continue working with medical professionals who specialize in rare disorders to improve the Listings. Again taking hemophilia as an example, adult Listing 7.08 for coagulation defects looks for transfusions of whole blood despite the fact that the prevailing treatment for this condition today consists of infusions of blood-clotting factor. As a result, the current Listing is rarely met.

From a process standpoint, my feeling is that the pre-effectuation review by the regional offices of half of all SSDI allowances discourages complete claim development, particularly since the odds of having a denial reviewed are slight. I question the value of these reviews and I would recommend substantially reducing them if not eliminating them outright.

We all know that it costs more to approve a claim after an appeal to ODAR than to approve it on an initial application, but that added cost is not borne by the responsible DDS. There needs to be some sort of disincentive that makes the denial of claims that are eventually paid as dreaded as the pre-effectuation review. This ought to include some sort of feedback to the adjudicator that denied the subsequently approved claim.

In closing, I want to give credit where it's due. Many of the initiatives that the Social Security Administration has undertaken as part of its Disability Service Improvement plan should help to speed up the process. However, I do have some concerns that a quick decision is not always a good decision. I often tell our clients that it is better to spend a few extra weeks at reconsideration than to wait two years for a hearing.

In my view, the primary reason why the disability process takes so long and is so frustrating for claimants is the persistent lack of adequate funding for the personnel and resources needed to handle an ever-growing case load. With the large number of Americans now entering the years when disability is most likely to occur, it is more urgent than ever that we address the administrative needs of the one federal agency (besides the IRS) that touches the lives of all of us.

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I would like to thank the Social Security Administration and the Office of Compassionate Allowances and Listing Improvement for your interest in people with rare diseases. Anything that can be done to help speed up disability awards for these individuals would be greatly appreciated. I would also like to thank you for giving me this opportunity to share my comments with you on this important issue.

For the past 13 years I have been privileged to serve as the director of the ACCESS Program, which offers representation to SSDI and SSI claimants with certain rare chronic conditions. Our services are provided free of charge and without regard to choice of medical provider. During those 13 years I have had the opportunity to travel throughout the country and to speak on the topics of federal disability programs and insurance issues for people who require very expensive medications to stay healthy and productive, or in some instances, just to stay alive. This has also given me the chance to listen to their concerns and questions about the disability determination process.

The concerns and fears that I have heard expressed by these people leads me to ask you to consider the impact of their condition on a personal level. People born with rare chronic conditions find many creative ways to cope with their limitations and work around them. It may take two days to finish a load of laundry, but they eventually get it done and say "at least I can still do the laundry". When someone with an attitude of "I can cope with this" hears the word "disabled", that doesn't sound like a label they want to wear. They put off finding out what Social Security means by that term, and then delay filing for benefits because in their minds "disabled" brings up images of being bedridden to the point that they can't do that load of laundry anymore and are virtually at death's door. No one can honestly see themselves that way and still find the courage to go forward with their lives as so many chronically ill people do.

For this reason, having an initial claim denied feeds into the feeling that disability is not meant for them. Many join the large number of applicants who do not appeal the denial of their claim. Those who do appeal must not only overcome their reluctance to focus on their limitations (both with the agency and with their doctor), but they must also emotionally prepare themselves to go through a lengthy and uncertain appeal process. For many of them, this causes them to relive the lengthy ordeal that they endured just getting an accurate diagnosis of their condition in the first place.

In particular, women with rare disorders often encounter difficulties in being diagnosed because skeptical doctors keep telling them that it's all in their head. They eventually stop working outside the home and scale back to work as homemakers until they just can't do it anymore. Finally, they get a diagnosis of

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their long-standing illness but they no longer have insured status for SSDI and don't quite qualify financially for SSI. My concern is that people in these situations should have their functional capacity evaluated as of the date when their complaints to their doctors actually began rather than when they were eventually diagnosed.

I feel that there is a real need to expedite determinations and fully consider functional limitations at the earliest possible stage of the process for those who live with rare chronic conditions. From the standpoint of available time and resources, I understand the difficulty of managing a large number of cases. Before I became the director of the ACCESS Program I was an assistant public defender, so I have also experienced pressures and constraints similar to those placed on the average DDS claims examiners.

I am convinced that there are solutions. I also believe that the savings realized from avoiding unnecessary appeals would at least partially offset the costs of implementing these new procedures. I would propose the following:

1. Transitioning to the use of ICD-9 diagnostic codes would make it easier to identify rare conditions that could qualify for compassionate allowances. Because it will take time to implement this, I would ask you to consider expanding and improving current methods for flagging rare disorder claims as an interim step.
2. Work with medical professional who specialize in rare chronic conditions to develop functional guidelines specific to that that disorder. This can be used to design questionnaires that are more appropriate for the treating physician than the "one-size-fits-all" residual functional capacity questionnaires being sent to them now. These questionnaires could then be sent to treating doctors or to the claimants to discuss with their doctor.
3. Establish a panel of consumer advocates for rare disorders either within SSA, or from another agency, such as the National Institute of Health's Office of Rare Diseases, or from an independent outside group, for example, the National Organization of Rare Disorders and its members. These advocates could be made available to any claimant whose case has been flagged as a rare disorder. They could assist in identifying functional limitations and developing compassionate allowance guidelines for disability claimants with rare diseases. These consumer advocates could also make sure that unrepresented claimants with rare conditions get full consideration of all relevant issues, including their last date insured.

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4. Every denial letter should include disclosure as to what percentage of claims on average are approved or denied at each stage of the appeal process and what the average processing time is for each stage of the appeal process. It should also make clear what the relevant waiting periods are for cash benefits and any associated medical coverage from the date of onset. My feeling is that every month of delay in approving a disability claim that is ultimately allowed should result in a corresponding reduction in these waiting periods.

We are very grateful to the Social Security Administration for inviting our participation in this effort to expand compassionate allowances. ACCESS has been privileged to work with SSA on efforts to revise the listings for the rare chronic conditions in which we specialize. We appreciate your efforts to reach out not only to the medical and patient communities but also to those of us who represent claimants before your agency. We look forward to working with you on future efforts to improve Social Security for everyone.

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