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Before the
Social Security Administration
Hearing on Compassionate Allowance Recommendations
For Rare Diseases

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On behalf of the Cystic Fibrosis Foundation, thank you for inviting me to discuss the impact of the medical listings in assessing the eligibility of people with cystic fibrosis (CF) for benefits from the Social Security Administration (SSA) under the compassionate allowance guidelines. We are pleased that the agency is planning to make changes to ensure that individuals who clearly meet the Listings of Impairments for CF are approved for benefits in the most timely fashion.

This is a serious issue for people with CF. Living with a chronic, progressive disease all of their lives means that most individuals with CF are hesitant to give up working as this makes them feel most normal. Some are so reluctant that they take their laptops and projects into the hospital to work from their hospital bed, until their physician literally tells them to stop working and encourages them to apply for disability. Yet, there are still cases today when individuals with CF who meet the listings must wait as long as two years for a hearing to appeal a denial of benefits for which they are clearly eligible. With the relatively short and uncertain life expectancy of people with CF, a two year waiting period can be an extreme and unnecessary hardship. We appreciate the agency's commitment to rectify the situation for people with CF.

Medical Background

As a result of better medical care, survival for people with CF has improved, and most people are enjoying longer, healthier lives. However, 46 percent of children with CF under age 18, and 41 percent of adults with CF receive Medicaid and/or Medicare benefits, in conjunction with Social Security benefits, according to the 2006 CF Foundation National Patient Registry. The median age of survival has increased from early childhood in the 1960s to age 36 today. The median age of the population, however, is only 16 years. Thus, most applicants with CF are much younger than the average age of Social Security applicants, further raising skepticism by SSA staff.

Along with increased survival comes more intensive daily treatments to enable individuals to stay as healthy as possible. To maintain lung function alone, individuals must endure burdensome treatments of antimicrobial inhalations, which is the use of aerosolized antibiotics to combat chronic lung infections; inhaled mucolytics to thin the mucus that clogs the CF airways and provides a breeding ground for infections; airway clearance to vigorously remove and cough out mucus; frequent home IV antibiotics to treat more stubborn infections, and other measures to keep the airways free of mucus and virulent pathogens. In addition, these individuals must work hard to maintain adequate weight to combat the extra energy expenditure of breathing and performing treatments to fight the progression of CF. People with CF can achieve a higher lung function with these treatments, but only through hard work that takes energy and time which impedes their ability to work full time.

CF is a multi-system disorder, which is not well characterized by the listings. The disease is best known for its impact on the respiratory system, as it causes chronic, disabling and life-threatening lung infections. However, respiratory health is compounded by nutritional impairments, as

people with CF have trouble gaining or maintaining weight. There is a strong correlation between poor nutrition and decreased lung function for people with CF. Using Body Mass Index (BMI), a well-accepted medical criterion used by the Centers for Disease Control and Prevention (CDC) to assess nutritional health, it has been shown that low BMI is associated with increased mortality risk. In our response to SSA about the compassionate allowance notice, we urged the agency to include BMI in its assessment of CF nutritional health.

In addition, people with CF have many more complications which can include diabetes, liver problems, sinusitis, arthritis, osteoporosis and depression. We urge the agency to clarify in the listings the impact that CF has on multiple systems.

SSA Disability Review Process and CF

There are estimated to be 700 approvals for benefits of CF individuals every year. Yet, the average Administrative Law Judge (ALJ) will only see one application for benefits from individuals with CF every few years. Thus, the ALJs, as well as SSA field staff and medical experts who determine disability status, do not become familiar with the disease itself or the CF listings to make a clear judgment upon seeing the rare case.

Some aspects of the respiratory listings for CF are not well-understood by SSA field staff, medical experts, or ALJs. These individuals deny benefits to someone with CF, despite meeting the listings, because they do not understand the severity of the illness as described by the listings. It is necessary to explain how the respiratory listings for CF properly characterize the severity of the disease. For instance, at a recent meeting to review the respiratory listings for CF, SSA senior staff readily admitted that they had not fully realized the severity and complexity of CF and how it differs from other lung diseases until that meeting. As a result of this better understanding, senior staff reiterated their support for the CF respiratory listings. To help other SSA staff also understand the true impact of CF, SSA should provide to its field offices more medical and lay information about CF, its burdensome treatment requirements, and its impact on multiple body systems. This type of information would be extremely helpful for more equitable and timely review of CF applications.

Problems with Interpreting the Respiratory Listings for CF

People with CF who clearly meet Part A of the CF respiratory listings (103.04A and 3.04A) regarding specified levels of forced expiratory volume over one second (FEV_1) are typically found eligible for benefits. These are the types of cases that would be most readily approvable under the compassionate allowance guidelines, as noted in the regulation itself.

However, even though these applications are usually approved, we are aware of two pending cases, a child and an adult, who meet Part A, but are still awaiting benefits since their initial applications nearly 2 years ago. Both were denied benefits at the time of their initial applications, for which they waited 5 months, then again at their reconsideration hearings, which occurred 5 months later. Both have now been awaiting dates for hearings for more than 12 months. It is inexplicable why these individuals, who clearly meet Part A of the respiratory listings for CF, are still waiting for benefits 2 years after they applied. We hope that discussions today will help these individuals and many others like them obtain benefits for which they are clearly eligible.

It is more difficult for individuals with CF to be approved by SSA if they meet one of the other two criteria for CF in Parts B and C (see 103.04 B & C or 3.04 B & C), but do not meet Part A. Parts B and C ask for information on how the disease is impacting the individual's respiratory health, and require documentation of treatments for chronic lung infections. Part B requires evidence of respiratory complications documented by a requirement of physician intervention,

occurring at least once every two months or at least six times a year. Part C requires evidence of a persistent pulmonary infection accompanied by superimposed, recurrent, symptomatic episodes of increased bacterial infection as evidenced by the use of intravenous or nebulization antimicrobial therapy at least once every six months (*paraphrased from listings*).

Despite the specificity of the listings, few of the disability determination staff at SSA know what an “inhaled antimicrobial treatment” is, or recognize the level of disability its use represents for the individual. Also, few will accept as evidence of a “physician intervention” anything short of a hospitalization. New technology has enabled people with CF to receive intensive intravenous antibiotic therapy at home, avoiding the need for hospitalization. Once the full impact of the procedures outlined in B and C are explained to SSA representatives, most individuals with CF are approved for benefits. Unfortunately, in some parts of the country, obtaining an approval for someone who must go through each level of evaluation can take up to 36 months. This is a travesty.

Qualification under TERI

To our knowledge, people with CF are not currently accessing benefits using guidelines for cases for those with terminal illness (“TERI” cases). In examining the TERI guidelines, changes could be made to add criteria relevant to CF, such as those outlined in the listings above. In addition, the guidelines mention that someone who is awaiting a heart/lung transplant should be considered eligible to be reviewed under TERI. Many individuals with CF now receive lung transplants, but the frequency of heart/lung transplant procedures are very rare. We urge you to add “lung transplant” to these guidelines (I-4-3-43 Part C). In addition, we encourage you to provide more information about ways to access TERI so that people with CF and their physicians can better assess the individual’s eligibility to apply under these criteria when appropriate, thereby helping to better target these cases to avoid increasing SSA’s workload of regular cases.

Improving the Process for Those with Rare Diseases

To address the difficulties with the application process, the CF Foundation has taken great strides to educate the CF care centers around the country who provide medical care to the majority of people with this disease. As a result, we believe that individuals with CF who would not be eligible for benefits are deterred from applying when they consult their CF medical team who are educated on the process. We also support a legal information hotline to handle direct inquiries from people who are struggling with SSA applications or appeals. According to experts at the hotline, it is estimated that only about 10 percent of people with CF who seek benefits would be ineligible. Another reason that so few ineligible people with CF apply for benefits is that most have lived with this chronic disease and its intense treatment burden all of their lives and greatly resent the need to stop working and obtain government benefits. Very few accept the progression of their disease, as working makes them feel most normal and not a victim of their disease. Applying for Social Security benefits changes that and is hard to accept – but often necessary.

We believe that people with CF are not being approved for benefits currently because SSA disability determination staff do not always understand the severity of the disease, its impact on multiple organ systems, and how the listings represent the full disabling impact on the person. We believe that the agency can complement our education efforts by providing more explanations and narrative language for SSA staff, medical experts, and ALJs to better understand the complete picture of life with CF and more readily approve for benefits people with CF who meet the medical listings in a more timely fashion. Specifically, topics on which SSA’s disability determination staff should be trained include: 1) understanding the importance of lung function and how to interpret test results and CF medical information, 2) understanding the nature of CF as

a multiple organ disease, and 3) recognizing how the changing nature of care for CF does not suggest the disease and its effects are less serious.

To better facilitate the process, SSA staff should be required to consult with CF physicians as experts in evaluating the application, if they are considering denying an application of someone who meets the listings. If applications from individuals with CF who meet the listings continue to be denied by SSA staff and require hearings, it would be very useful to have specific ALJs become experts in CF and be assigned to handle cases for CF.

Finally, we believe it is in SSA's best interest to approve for benefits under compassionate allowance anyone with CF who clearly meets the listings. Given the limited survival of people with CF who are disabled by the disease, approving applications under compassionate allowance would be very compassionate and helpful for these young people. Receiving benefits at such a critical time when their health is declining would enable these folks to take better care of themselves and stay alive, rather than face a rapid health decline as they struggle to work, obtain care, and perform hours of daily treatments just to breathe.

We would be happy to take questions.

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