Opening Remarks

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Commissioner of Social Security

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Good morning, my name is Michael Astrue and I am the Commissioner of Social Security. Welcome to this outreach hearing on Compassionate Allowances for people with rare diseases. I appreciate your joining us at this critical time as we try to improve the way we make decisions about disability claims.

My top priority is to reduce the backlog of disability cases. This is America, and it simply is not acceptable for Americans to wait years for a final decision on a claim. We are overdue for a change, and we are committed to a process that is as fair and speedy as possible. To achieve this goal, we have taken or will take soon, a number of steps to better manage our workloads. The program includes four components:

- Accelerating review of cases likely or certain to be approved;
- Improving hearing procedure;
- Increasing adjudicatory capacity; and
- Increasing efficiency through automation and improved business processes.

Today's hearing focuses on the first of these components: accelerating the review of cases likely or certain to be approved.

When Congress first enacted Title II, to a large extent it viewed the program as a fairly limited one directed primarily at a fairly small number of middle-aged workers who needed a bridge to early retirement. Today, our disability programs are far larger and more diverse than Congress initially envisioned. Title II and Title XVI are critical to

such people from all walks of life, including children born with serious defects, wounded warriors returning with traumatic physical and psychological injuries and the homeless.

By comparison, the way that we process medical information to define disability has not changed in any fundamental way for decades. We divide our listings into fourteen "body systems," and we only update those listings when we do comprehensive overhauls, which sometimes wait decades. Our recent release of updated digestive regulations – which includes diseases of the liver and colon – were last revised in 1985. We have also tended to focus on large diseases and conditions.

This model worked in 1970, but it doesn't work today, and it surely will not work in the coming decade as we process 26 million disability claims. We need to be more efficient and more accurate. When people don't receive their benefits in as timely manner a possible it undercuts the contributions they have made and can continue to make to our society. Getting people benefits quickly is the right thing to do—especially since claimants are often in medical and financial distress. Recognizing distress and wanting to alleviate it is how the dictionary defines compassion. Many of you know from personal experience – I know I do – that uncertainty during the long wait for a decision on your case can make a bad situation even worse.

We're trying to change our business model based on some very simple propositions. First, we need to update our listings much more often and we need to expand the number of diseases and conditions. Guidance for one rare disease affecting 50,000 Americans

will not be sufficient to improve the process, but if over time we can do it for between 100 to 500 rare diseases, we can make a difference. These are precisely the kinds of cases where examiners are uncertain what to do. This uncertainty leads to requests for time-consuming and expensive consultations often performed by doctors that are unfamiliar with our rules and regulations. In part, this is why our first hearing focuses on rare diseases. If the process can be improved for children and adults with rare diseases, it can be improved for everyone.

Second, we need to fast-track the cases that are certain or near-certain to be allowed, and with our new electronic systems we can automatically and with precision pull those cases out of the queue for fast processing. Our initial test of this concept in New England was highly successful even though the model only included a handful of cancers, ALS and low birth weight babies. If we do the hard work of identifying the hundreds, perhaps thousands of similarly situated diseases and conditions – which is what you're all here to help us with – then we may be able to process up to 15% of our cases in days or weeks instead of months or years.

Our Quick Disability Determination system – which is one method we are using to fast-track cases – has helped us decide cases in the New England region in an average of 11 days. That system has just gone national and we're going to drive the current 3% threshold for likely allowance up – with your help – in 2008.

QDD deals with cases that are extremely likely – more than 90% - to be allowed. We are also moving to create a category of conclusively presumptive disabilities called "compassionate allowances" – in other words, diseases and conditions where we know, by definition, that the patient will be unable to work for at least 12 months.

Third, we need to tap into medical advances of the past decade to make some of our current high-volume cases automatic and easy. There have been stunning developments with imaging and biomarkers that should help us correlate objective information with the functional capacity determination necessary to make decisions regarding disability. Can we measure progression of MS by measuring neuronal scarring with MRI? Can the newest imaging machines help us tie blood flow to the heart with functional capacity? We have never investigated the answers to these types of questions, but we're going to start.

As you listen to today's witnesses, you will hear testimony from medical experts at the National Institutes of Health. Over the past several months, SSA has been working with the NIH to lay the foundation for a partnership designed to provide our adjudicators with modern up-to-date tools and the cutting–edge medical information needed to expedite disability claims.

Dave Rust, Glen Sklar and Diane Braunstein in ODISP and many other SSA and DDS staff across the nation have been working hard to move our disability initiatives from concepts to realities by the middle of next year. As terrific as their work has been, we

cannot do it alone. Already we have received tremendous support from our partners in the state DDS's, advocacy groups, NIH, OMB and many others. We will continue to need this help as we move forward.

A few minutes ago, I mentioned a partnership with the National Institutes of Health. As part of that effort, joining me on the panel is Stephen Groft, Director of the NIH Office of Rare Diseases. Steve is taking a great deal of time out of his busy schedule to attend the hearing. Also, on the panel are David Rust, Acting Deputy Commissioner for Disability and Income Security Programs and Frank Cristaudo, Chief Administrative Law Judge.

Over the course of the day, we are going to examine how Compassionate Allowances can be implemented for individuals with rare diseases. This examination will include the perspectives of the advocacy, adjudicatory and medical technology communities

So, thanks again for coming to today's public hearing. Whether you are here in person or listening in over the phone, I invite you to submit your thoughts about today's proceedings to the Compassionate Allowances mailbox at Compassionate.Allowances@ssa.gov.

Again, we appreciate your choosing to be a part of this important step towards improving disability service.