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Congress of the United States  
House of Representatives  
COMMITTEE ON WAYS AND MEANS

WASHINGTON, DC 20515

SUBCOMMITTEE ON SOCIAL SECURITY

July 28, 2015

The Honorable Carolyn Colvin  
Acting Commissioner of Social Security  
Social Security Administration  
6401 Security Boulevard  
Woodlawn, MD 21207

Dear Acting Commissioner Colvin:

We have long been concerned that it has taken Social Security decades to update the medical listings. While some progress has been made, there is still a lot of work to do. The Huntington's Disease (HD) listing was last updated in 1979, even though most of what we know about this disease has been discovered by scientists since then.

On March 20, 2012, Commissioner Michael Astrue announced before the Subcommittee on Social Security the addition of juvenile onset HD to the list of Compassionate Allowances (CAL). Adult onset HD was added later that year. Based on conversations with constituents, however, we are concerned that the CAL system is not working as intended for individuals with HD.

Though CAL status is designed to expedite decisions for those with the most serious illnesses, those we spoke with believed that Disability Determination Service staff do not often give expedited review to HD claims and inconsistently apply Social Security's CAL policies.

We would like to better understand how well Social Security is adjudicating HD claims. Specifically, we would like to know:

1. When do you expect to complete an update of the HD listing?
2. What quality assurance measures are in place to determine if the system is correctly flagging all cases eligible for CAL processing?
3. How do the allowance rates for cases alleging HD differ between Single Decision Maker pilot states versus the rest of the country?
4. What percentage of claims alleging HD are denied based on a lapse in insured status?

Additionally, please find enclosed a copy of the letter Social Security Subcommittee Chairman Sam Johnson received from the HD Society of America. It outlines many of the concerns we mentioned in greater detail.

Thank you for your attention to this important matter. Please contact Ted McCann, Staff Director of the Social Security Subcommittee, at (202) 225-9263 if you have any questions concerning this letter.

Sincerely,



SAM JOHNSON  
Chairman  
Subcommittee on Social Security



PATRICK J. TIBERI  
Chairman  
Subcommittee on Trade



CHARLES W. BOUSTANY JR.  
Chairman  
Subcommittee on Human Resources



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Member of Congress