Testimony Prepared by Kathy Hunter, Founder & President
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Mr. Astrue, Mr. Groft, Mr. Cristaudo, Mr. Rust and fellow panel members, thank you for this opportunity to participate in this Compassionate Allowances Outreach Hearing on Social Security benefits for those with rare disorders. I deeply appreciate your consideration of seeking ways to better serve this population.

My comments today are based on my experience as founder and President of the International Rett Syndrome Association for the last twenty-three years. By way of background, Rett syndrome is a genetic neurological disorder which affects 1:15,000 females. It is seen primarily in girls, who develop typically for the first 12-18 months of life, after which a devastating regression leads to loss of speech, mobility and hand function. Seizures, breathing problems, gastric difficulties and loss of muscle tone and ambulation are common. Rett syndrome results in severe to profound disability by the age of three years. Individuals with Rett syndrome need assistance for every aspect of daily living for the remainder of their lives. They will never be self-supporting wage earners.

While it is not the label, but the extent of the disability, which frames eligibility with social security, in Rett syndrome it can be assumed that any individual with the label should qualify unquestionably. However, as a rare and relatively newly discovered disorder, Rett syndrome is not widely recognized, even in the medical community at large. This makes a particular problem for families advocating for their loved ones when making application for social security benefits. Adjudicators and even the allied medical community more often than not have never heard of Rett syndrome and may even have difficulty locating printed resources on the disorder. This prolongs the processing of claims not only in terms of establishing basic eligibility but also in understanding the impact of Rett syndrome on the child and the family. Maintaining evidence of the diagnosis may be further delayed because the biological marker for Rett syndrome, a mutation on the MECP2

gene of the X chromosome, is now found in only 90 percent of known cases, leaving the remaining ten percent to a clinical diagnosis.

It would be very helpful to have a list of rare disorders in which disability would be assumed. Hopefully this would alleviate the huge backlog at Social Security by moving the simple cases much more expeditiously. The problem is that the state disability determinations personnel make the first decision. This is the level at which Rett Syndrome should be considered. Interviewers should be familiar with the list; Rett syndrome is often confused with Tourette syndrome and they are two very different syndromes.

The Residual Functional Capacity Questionnaire for physicians is easily and quickly completed by hand. The problem is that they are not widely used until an appeal is in process. Interviewers should be afforded some basic sensitivity training to understand the overwhelming nature of the application process for families of children with disabilities. Families on the income edge find their financial lives become an open book where every penny is counted even when the monthly income stream is unstable. Some interviewers can be very intimidating. Sensitivity, empathy, understanding and kindness are what are needed by parents who are already stressed. Parents should not be made to feel inadequate or greedy for seeking services that will help their children. They should be given information openly, instead of reluctantly, on how to determine maximum benefits, to "play the game" so to speak, without having to go "underground" to learn the secret formula for increasing the amount to which they are entitled. Parents should not be "punished" for providing financial support for their loved ones and for keeping them at home and out of institutions.

Social Security programs have an immense potential to enhance the lives of individuals with rare disorders. Your attention to streamlining and improving these programs are deeply commended.