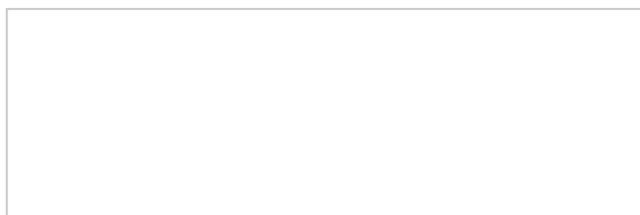


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From: NORD [orphan@rarediseases.org]
Sent: 16 December 2011 19:56
To: Shephard, Elizabeth
Subject: An Opportunity to Help Rare Disease Patients



Medical Advisory Committee

NORD Seeks Your Help in Identifying the Most Disabling Rare Diseases

Thank you for helping NORD by reviewing information on rare diseases being prepared for patients and families. Now, we have come to ask for your help in identifying some of the most disabling rare diseases.

Social Security Commissioner Michael Astrue has invited NORD to recommend severely disabling rare diseases for inclusion on the "Compassionate Allowances" list. This is a list of diseases so disabling that those who have them qualify for expedited review of applications for Social Security disability assistance.

As you all know, patients and families coping with rare diseases often experience significant financial issues. However, if they apply for assistance through the Social Security Administration (SSA), they often experience significant delays in qualifying because those making the decisions are not familiar with their diseases. A typical scenario is that applicants with rare diseases initially are denied assistance and later ... after much stress and a lengthy appeals process .. ultimately receive approval of their applications.

Because Commissioner Astrue has previous knowledge of what it's like to live with a rare disease, he created the Compassionate Allowances Program early in his tenure at SSA. Currently, there are 113 diseases on the list, and several are ones that NORD medical advisors have suggested. SSA has also gotten strong support and much input for this program from rare disease experts at NIH and elsewhere.

The Deadline for Input is January 13

Before Commissioner Astrue completes his six-year term at SSA, he would like to roll out one more expansion of the Compassionate

Allowances list, possibly adding enough diseases to bring the total list to 200 medical conditions. He and his staff are asking NORD (and others, including NIH medical experts) to suggest diseases for this expansion.

NORD would greatly appreciate your help in identifying rare diseases to suggest to SSA. Since we must submit our list to SSA by mid-January, we would need to receive your suggestions by January 13.

SSA will spend a period of several months vetting all input provided to them by NORD and others. They plan to announce their final decisions regarding diagnoses to add to the list in late 2012.

The SSA Criteria

SSA is really trying to focus in on the most universally devastating and disabling diseases and, therefore, not ones for which there is great variation in the patient experience. They are trying to identify the rare diseases that almost invariably would ultimately qualify patients for disability assistance.

The SSA team has asked us to share the following criteria and suggestions with you, as you think about this. They also asked that we include diseases from as many as possible of the 14 body systems for adults and children that you can view by clicking on the link below.

SSA's definition of disability is as follows:

Adults: You must be unable to do any substantial work because of your medical condition(s); and your medical condition(s) must have lasted, or be expected to last, at least 1 year or be expected to result in your death.

Children: The child must have a physical or mental condition(s) that very seriously limits his or her activities; and the condition(s) must have lasted, or be expected to last, at least 1 year or result in death.

[Read the description](#) of the Compassionate Allowances Program on the SSA website.

[View the list](#) of diseases currently approved for the Compassionate Allowances Program.

For adults: [View the list](#) of body systems SSA uses in its evaluations. The SSA team has asked NORD to submit one or more suggested diseases for each of these body systems.

For children: [View the list](#) of body systems SSA uses in its evaluations of pediatric diseases. As noted above, NORD is being asked to submit one or more diseases for each of these categories.

Your Help Will Truly Make a Difference for Patients and Families!

NORD receives many heartbreaking phone calls and emails from patients and family members who are experiencing extreme hardship, both financial and emotional, as a result of delays in the Social Security approval process. This is a wonderful opportunity to help those people.

We hesitate to ask you, knowing how busy you all are, but we would greatly appreciate any suggestions you could find time to make.

Please submit your suggestions to Mary Dunkle (mdunkle@rarediseases.org) anytime on or before January 13. Thank you so much for any help you are able to provide on this very important project!

You are receiving this because the email address e.shephard@ucl.ac.uk was subscribed to our email list.

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