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Thursday, March 29, 2018
To Whom It May Concern (NIH Grant Review Section):

In my role as Director of the Rare Disease Institute at Children's National Health System, I am privileged to be aware of many initiatives and programs for rare disease, often in their infancy. Over the past year, I have been in communication with Rare STRIDES and discussed the functionality of their program and its benefits. In this Phase 1 Grant Submission, they are proposing the development of their Risk Assessments for age-stratified groups, which will have the ability, when implemented, to identify patients who may demonstrate signs of rare disease early enough to shorten the diagnostic odyssey and improve the lives of many. I have no doubt that what they are proposing can change the landscape of the rare disease community.

The team at Rare STRIDES understands the root of the issues facing rare disease communities today in a way that many other companies in diagnostics do not seem to fully grasp. In regard to the risk assessment, I appreciate their perspective on seeing the value of looking for the common factors that many individuals with rare diseases demonstrate, independent of symptoms, and they have a well-researched perspective on a range of related factors.

Rare STRIDES has requested an informal collaboration with me and my Diagnostic Team at Children's National on this project, and I can say that we are delighted to work with them on this ambitious effort. Furthermore, I discussed with them that I will also connect Rare STRIDES with clinicians from Rare Disease Centers of Excellence across the country to assist with the development of the item pools in this Phase 1 grant. Forging these relationships will also allow for us to create and eventually implement a data collection strategy, when the planned Phase 2 grant moves forward with testing the item pools.

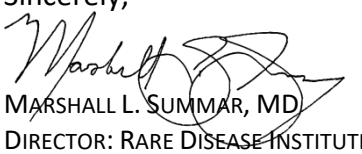
Through the process of our discussions, I see some key benefits to what Rare STRIDES is proposing:

1. Patients will be identified sooner, and therefore we will be able to intervene in the disease process at earlier stages
2. Patients with undiagnosed diseases will be directed to appropriate resources, which will aid in identification and research
3. Insurance companies will have empirical justification for supporting medical necessity for evaluative procedures and treatment, something we currently spend approximately 35% of our man power and resources on at CNHS.

I fully support the strategic plan they have laid out and look forward to collaborating with them on their grant. We anticipate that this will be the beginning of a mutually beneficial strategic partnership for CNHS, NORD and the rare community.

My hope is that the NIH will support their passion and efforts. Thank you for your attention to this very important project.

Sincerely,



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