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Dear Association for Creatine Deficiencies (ACD),

Lumos Pharma would like to take this opportunity to share some updates with you and the Cerebral Creatine Deficiency Syndromes (CCDS) community on the development of our Vigilant Study, an observational study of males with Creatine Transport Deficiency (CTD) and the development status of LUM-001, a potential therapeutic for CTD.

Regarding the Vigilant study, current sites are open for enrollment today, and the study is continuing towards its goal to document and clinically characterize patients with CTD. Lumos Pharma is actively increasing the number of Vigilant study sites throughout North America, for ease of patient participation in this invaluable study. The data collected are crucial to understanding the natural history of CTD.

<https://clinicaltrials.gov/show/NCT02931682>

Along with the Vigilant Study, Lumos Pharma remains fully committed to the LUM-001 development program. First and foremost, the primary objective of the LUM-001 program is to establish the safety and effectiveness of this potential therapy in CTD patients. At this time, the program has experienced a temporary delay based on outcomes from recent pre-clinical testing. With this new information, we now must gather additional pre-clinical data before proceeding in the clinic. When the new pre-clinical studies are complete, we will be able to determine how and when the clinical program will proceed. Again, safety and effectiveness remain our utmost concern. We will continue to update the CCDS community on the status of LUM-001 developments later this year.

We thank the ACD and the patient community for being outstanding rare disease advocacy partners. Along with our research, we have been building programs like ScreenCreatine.org that will help raise awareness of CCDS. It is our hope that educational programs, like this one, will speed up the identification process and diagnosis of CCDS.

Working together, with shared goals and objectives, helps to fuel the passion and commitment that Lumos Pharma has towards the CCDS community. Patients and families are in our daily thoughts as we strive to advance our LUM-001 development program to help those with CTD.

Respectfully,

A handwritten signature in blue ink that reads "Rick".

Rick Hawkins

Chief Executive Officer

