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December 20th, 2017

Dear Association for Creatine Deficiencies (ACD),

This past August, we shared with you some updates on the progress of our Vigilan Study, an observational study of males with Creatine Transport Deficiency (CTD) and the development status of LUM-001, a potential therapeutic for CTD. Since then, we have advanced on this course and have news to share with the Cerebral Creatine Deficiencies Syndrome (CCDS) community.

Regarding the Vigilan study, we now have 7 sites open and 3 more scheduled to be part of the Vigilan program in 2018. Increasing the number of Vigilan study sites throughout North America, in order to ease patient participation in this invaluable study and broaden the knowledge of this disease to many centers, is paramount to our commitment to document and clinically characterize patients with CTD. Hence, as of this date, the CTD community can now participate at these Vigilan centers:

- Childrens Hospital of Philadelphia, Philadelphia, PA
- National Institutes of Health, Bethesda, MD
- Duke University Medical Center, Durham, NC
- Rush University Medical Center, Chicago, IL
- University of California San Diego, San Diego, CA
- Boston Children's Hospital, Boston, MA
- Texas Children's Hospital, Houston, TX

https://clinicaltrials.gov/show/NCT02931682

We have also moved forward with the continuation of the pre-clinical studies of our LUM-001 program. After productive interactions with regulatory authorities since our last update, we have a defined path forward to inform the non-clinical findings previously observed. We are steadfast in establishing the safety and effectiveness of LUM-001 and are working diligently to focus and resolve any and all issues. We will continue to update the CCDS community on the status of LUM-001 development in the Summer of 2018.

For many years, Lumos Pharma has been committed to developing a potential oral treatment for CTD and we are honored to be part of your special CCDS family. We have seen how the awareness of the CCDS has expanded and are thrilled to see efforts to add GAMT testing to various state newborn screening programs. Likewise, we are very excited for the ACD, in their continued development, in organizing their 1st Family and Patient Workshop scheduled for July 2018.

We at Lumos Pharma wish the CCDS community a peaceful holiday season and we are looking forward to another important CCDS awareness day- Feb 1st 2018!

Respectfully,

Rick Hawkins, CEO

