

Dear families, rare disease communities and healthcare providers,

On behalf of the entire team at Lysogene, let me start by extending my warmest wishes to you and yours during this unprecedented and challenging time. We appreciate that the COVID-19 pandemic is causing unique and greater burden on families caring for children with chronic diseases and on healthcare providers who are dealing with increased demands and pressures.

I am writing today to let you know that despite the new hurdles we face from the current circumstances, our commitment to patients and their families does not change. We remain entirely focused on our different development programs. We are constantly assessing the rapidly changing healthcare landscape and trying to minimize disruption to our programs.

Lysogene remains operational and is coping with its distributed team and reliance on virtual connections.

For families participating in our MPS IIIA clinical trial, we are actively and continuously working with our clinical trial sites, regulatory authorities and ethics committees to reduce families' potential exposure to COVID-19, whilst continuing to provide medically necessary study care. We are planning for a bespoke response to the needs of every family.

We continue to push forward our clinical trial for GM1 gangliosidosis children and will do everything to set this up as fast and safely as we can.

The ongoing natural history video study in GM1 gangliosidosis (NCT04310163), expected to start very soon, was set up to address methodological challenges in clinic-based assessments that are not always well suited to capture all the disease features of GM1 gangliosidosis. This study is home-based and will collect patient-specific video data. Please let us know if you are interested in participating ([patientadvocacy@lysogene.com](mailto:patientadvocacy@lysogene.com)).

I would like to extend my gratitude to the exceptional support from our investigators and collaborators around the world. They are all doing their absolute best to mitigate potential delays and implement continuity plans. At this time, we remain confident that our development programs will continue to proceed as planned to meet the needs of patients and families.

Yours sincerely

Samantha Parker

Lysogene Chief Patient Access Officer