

September 4, 2024

Dear Lafora Community,

We are pleased to inform you that we have finalized an agreement to license ION283, our investigational medicine for the treatment of Lafora disease, to Noventia Pharma, a privately owned European specialty pharmaceutical company committed to advancing research to bring hope to those living with serious diseases. Noventia will now assume full responsibility for the development and evaluation of ION283.

This licensing agreement represents the culmination of an extensive process undertaken by Ionis to identify a partner for the ION283 program. In seeking a partner, Ionis was looking for an organization who had the commitment and capability necessary to execute a global development program to evaluate ION283 in Lafora disease. We believe that Noventia has the right knowledge, expertise, and passion to advance the ION283 program.

Over the coming weeks, Ionis will transfer materials and data related to ION283 to Noventia. Noventia, together with other stakeholders, will then determine the feasibility of clinical development and the next steps with the program.

We are grateful for the support, collaboration, and perseverance of the Lafora community. We look forward to working with Noventia to expedite this transition and facilitate the continuation of ION283 development activities.

Sincerely,

Ionis