



January 20, 2023

Dear CLN7 Batten Disease Community,

The purpose of this letter is to share an important update about Neurogene's research program for CLN7 Batten disease. Neurogene has made the difficult decision to discontinue the CLN7 Batten disease research, and is therefore discontinuing the CLN7 portion of the natural history study entitled, *A Natural History and Outcome Measure Discovery Study of Variant Late Infantile Neuronal Ceroid Lipofuscinosis Type 5 (CLN5) and Variant Late Infantile Neuronal Ceroid Lipofuscinosis Type 7 (CLN7)*. Neurogene is making a conscientious effort to identify potential industry and scientific partners to continue the work on CLN7, however, we have not yet been able to identify a research partner to continue this work.

We recognize the deep disappointment the CLN7 community may feel upon hearing this update. We want the community to know this decision was not made lightly; the decision was only made after rigorous discussion with, and at the direction of, the Board of Directors. Today's biotechnology landscape is extremely challenging, and requires difficult decisions to be made about the programs that move forward in a company's development pipeline.

The efforts of the community have resulted in critical data being collected on the natural history of CLN7. Currently we are collaborating with the University of Rochester, the study site, on plans for how the natural history data may be used to further the scientific knowledge about CLN7. Additionally, we aim to help researchers access these data in the future.

We extend our sincere appreciation to the many patients, families, advocates, and researchers who have contributed to Neurogene's work in CLN7, which would not have occurred without your efforts. The CLN7 community rose to the occasion when we sought insight to help design the natural history study. In addition, these insights provided invaluable information used to help develop content for our websites and CLN7 educational materials. These efforts were supportive of families seeking a diagnosis. The importance of the input from the community that led to these initiatives cannot be overstated.

Over the coming weeks, the information on LivingBatten.com and Neurogene.com focused on CLN7 will be removed. This is to ensure that families affected by CLN7 searching for information are not led to believe Neurogene is actively pursuing research in CLN7. Neurogene will communicate with the CLN7 patient advocacy organizations to address questions that may arise. We close this letter by acknowledging the families, the patient advocacy organizations, the researchers, and the entire CLN7 community that have made such incredible contributions to CLN7 research. We sincerely thank you.

Gratefully,

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