

Dear Batten community,

On behalf of the entire Amicus team, it is a privilege and an honor to have been able to learn from and support the Batten community over the past 5 years. We established many valued relationships and gained so much from our interactions.

I have been engaging and leading the Patient & Professional Advocacy Batten program for the past four years and am always amazed at the strength and grace of all the families affected by this very devastating rare disease.

Today I am able to share an important update about the CLN3 clinical development program. After careful consideration and open dialogue with NCH, and with mutual agreement, Amicus has returned the rights to all Batten programs to NCH, which includes the CLN3 clinical development program. NCH is now solely responsible for determining next steps in the development of AT-GTX-502 and for all follow-up with the CLN3 clinical trial participants and their families. This also includes all CLN3 study related communications with the Batten disease community, including individuals and Patient Advocacy Organizations (PAOs).

Amicus Patient & Professional Advocacy is making available all Batten disease educational resources to the Batten community through the PAOs. Amicus also has submitted for publication the manuscript ***The parent and family impact of CLN3 disease: an observational survey-based study*** and is expecting acceptance very soon. We are very pleased to have supported Care Beyond Diagnosis in developing the first CLN3 disease monitoring guidelines which should be available by the end of the year. For more information please visit: <https://carebeyonddiagnosis.org/>

In recent years it has been our honor to support the family services and educational activities of the community's non-profit organizations when requested. We will continue to consider requests for support of Batten's organizations through 2025.

If you would like a copy of the educational materials, please contact me at npatel@amicusrx.com.

I thank you for allowing me and my colleagues to be inspired by your children and by you.

Thank you,

Nita Patel, RN

Executive Director, Patient & Professional Advocacy

Amicus Therapeutics

T: 609.662.2047 | M: 732.823.2496

Amicus Therapeutics, Inc.

47 Hulfish Street, Princeton, NJ 08542

Phone: 609.662.2000 | Fax: 609.662.2001 | www.amicusrx.com