



## Neurogene Joins Behind the Seizure® Program, Sponsors Genetic Testing for Children with Seizures

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*Neurogene joins Behind the Seizure program to support improved diagnosis for patients with rare forms of Batten disease  
Neurogene support helps expand no-cost genetic testing for children with unprovoked seizure from under 5 years to children under 8 years*

**NEW YORK, Feb 10, 2020** – [Neurogene Inc.](#), a company founded with a mission to bring life-changing medicines to patients and families affected by rare neurological diseases, today announced it has joined Behind the Seizure®, a cross-company collaboration established by BioMarin and Invitae that aims to provide faster diagnosis for young children with genetic diseases who experience seizures. With support from Neurogene, Behind the Seizure® will allow healthcare providers to order no-cost genetic testing for any child under the age of eight who has had an unprovoked seizure.

"Identifying patients is a critical step on the road to treating rare genetic diseases," said Rachel McMinn, Ph.D., Neurogene's Founder and Chief Executive Officer. "Increasing access to genetic testing may help increase diagnosis of CLN5 and CLN7, two types of Batten disease in which unprovoked seizures can present later than other forms of Batten Disease. By expanding the no-cost genetic testing from children up to five years of age to include children under the age of eight, we hope to improve the chances that patients with Batten disease have the chance to receive a diagnosis. We're thrilled to embark on our second collaboration with Invitae, and to partner with other companies to further Neurogene's mission of developing life-changing medicines for patients and families affected by rare neurological disorders."

Batten disease, also called neuronal ceroid lipofuscinoses (NCL), is a family of rare and fatal neurodegenerative diseases caused by pathogenic changes in one of a series of genes that result in the accumulation of toxic deposits across multiple organ systems, including the brain, eye, skin and other cells. CLN5 and CLN7 are rare, pediatric-onset and rapidly progressive diseases caused by defects in the *CLN5* and *MFSD8* genes, respectively. CLN5 or CLN7 diseases are characterized by seizures, progressive deterioration in intellectual and motor capabilities, loss of vision and death in childhood or adolescence. Diagnosis of the disease is confirmed through genetic testing. Neurogene has developed a disease state website [www.LivingBatten.com](http://www.LivingBatten.com) to support patients, families and care providers looking for more information on CLN5 and CLN7 forms of Batten Disease.

"For families trying to make sense of unexplained symptoms, having a definitive answer, even if that answer is Batten disease, can provide peace of mind and in some cases, options for treatment," said Elizabeth Berry-Kravis, M.D., Ph.D., Pediatric Neurologist and Professor, Rush University Medical Center. "In expanding the age range of the program, the sponsors of the Behind the Seizure program are allowing many more children with unexplained seizures to get the answers their families need so that they may focus on treatment for the disease."

Additional details, as well as terms and conditions of the program, can be found at <https://www.invitae.com/en/behindtheseizure>.

### About Behind the Seizure®

Behind the Seizure is an innovative, cross-company collaboration designed to increase access to genetic testing for children who experience unprovoked seizures in childhood in the United States and Canada. More than half of epilepsies have some genetic basis, and are often associated with rare, neurodegenerative conditions with non-specific symptoms. Early genetic testing may be the most direct, cost-effective, and accurate diagnostic tool. Participants in the Behind the Seizure program are diagnosed one to two years sooner than reported averages. The program was established by BioMarin and Invitae and now includes: Biogen, Encoded Therapeutics, Neurogene Inc., Praxis Precision Medicines, PTC Therapeutics, Stoke Therapeutics and Xenon Pharmaceuticals. To learn more about the Behind the Seizure program please visit <https://www.invitae.com/en/behindtheseizure/>.

### About Neurogene Inc.

Neurogene was founded to bring life-changing medicines to patients and families affected by rare neurological disorders. We partner with leading academic researchers, patient advocacy organizations and caregivers to bring to patients, therapies that address the underlying genetic cause of a broad spectrum of neurological diseases where no effective treatment options exist today. Our lead programs use AAV-based gene therapy technology to deliver a normal gene to patients with a dysfunctional gene. Neurogene is also investing in novel technology to develop treatments for diseases not well served by gene therapy. For more information, visit [neurogenestg.wpengine.com](http://neurogenestg.wpengine.com).

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