GeneDx and Beren Therapeutics Launch NPC GenomeComplete to Improve Diagnosis of Niemann-Pick Disease Type C

September 9, 2026

NPC GenomeComplete to identify children who might otherwise remain undiagnosed through broad NPC-specific eligibility criteria, comprehensive genomic testing and expert diagnostic support

GAITHERSBURG, Md.--(BUSINESS WIRE)--Sep. 9, 2026-- GeneDx, the leader in rare disease diagnosis and improving health through the power of genomic data, today announced a collaboration with Beren Therapeutics P.B.C. to launch the NPC GenomeComplete Sponsored Testing Program. The program provides no-cost comprehensive genome sequencing for eligible pediatric patients with clinical findings, family history, or biomarker evidence suggestive of Niemann-Pick Disease Type C (NPC), helping address barriers to diagnosis and identify children who are currently undiagnosed.

NPC is a rare, progressive, genetic, neurodegenerative disorder that results in progressive neurological decline and premature death. Heterogeneous clinical presentation and age of onset vary widely, making diagnosis challenging and leaving approximately two-thirds of patients in the United States undiagnosed. The most severe form, infantile-onset NPC (I-NPC), presents with neurological signs before age six. In the U.S., approximately 475 children are believed to have I-NPC, yet only approximately 175 are currently diagnosed.[1]

In a progressive disease like NPC, where lost neurological function cannot be regained, early diagnosis is crucial. NPC GenomeComplete is designed around the heterogeneous ways NPC presents in clinical practice, without requiring a classic presentation or prior specialist diagnosis. The program gives eligible healthcare providers access to genome sequencing and targeted NPC1 and NPC2 variant testing with rapid sequencing available for eligible children requiring urgent medical decisions. Rapid genome sequencing can provide preliminary results in as soon as 48 hours.

"Nearly every family we speak with in the NPC community describes a long diagnostic journey full of uncertainty," said Jason Camm, Founder and Chief Executive Officer of Beren Therapeutics. "Beren designed NPC GenomeComplete to change that through broad comprehensive genome sequencing, family testing and genetic counseling at no charge. GeneDx brings the genomic expertise and infrastructure needed to make that approach available nationally and help find children who might otherwise remain undiagnosed."

“For children with suspected rare disease, an accurate diagnosis can be life-changing,” said Lisa Gurry, Chief Business Officer at GeneDx. “By combining GeneDx's diagnostic expertise with the power of our genomic data and Beren’s deep understanding of NPC, this collaboration can help more patients get answers sooner and accelerate the path to appropriate care.”

Testing is fully sponsored by Beren Therapeutics and does not require a patient to have insurance, helping reduce financial and insurance-related barriers to comprehensive genomic testing.

Healthcare providers and families interested in learning more about patient eligibility, available testing options, and ordering can visit https://www.genedx.com/providers/genetic-testing-programs/beren-npc.

About GeneDx

GeneDx’s (Nasdaq: WGS) mission is to empower everyone to live their healthiest life through genomics. GeneDx combines unmatched clinical expertise, advanced technology, and the power of GeneDx Infinity ™ – the world’s largest rare disease genomic dataset. This unparalleled foundation powers GeneDx’s ExomeDx ™ and GenomeDx® tests – ranked #1 by expert geneticists and granted FDA Breakthrough Device designation – enabling clinicians to deliver precise, fast, and actionable diagnoses. GeneDx Infinity also fuels discovery for biopharma, with the most powerful AI-driven genomic intelligence. A genomics pioneer over the last 25 years, diagnosing more than 4,800 genetic diseases and publishing more than 1,000 research publications, GeneDx is building the network that will drive the future of genomic precision medicine. For more information, visit **genedx.com** and connect with us on **LinkedIn**, **Facebook**, and **Instagram**.

About Beren Therapeutics P.B.C.

Beren Therapeutics P.B.C.® is a founder-led, clinical-stage biotechnology company pioneering the discovery, development, and commercialization of cyclodextrin-based therapeutics for conditions characterized by defective cholesterol trafficking. Beren and its subsidiary Mandos LLC® are committed to the development of adrabetadex for individuals living with Niemann-Pick disease, type C (NPC) and have supported the NPC community by providing access to adrabetadex through an Expanded Access Program (EAP). Adrabetadex is investigational and has not been approved by the FDA or any other health authority at this time.

Beren's public benefit purpose is to discover, develop, and deliver novel therapies that provide optimal benefit for patients, and to

do so by integrating the needs of patients, caregivers, clinicians, and health systems from the beginning of the development process and maintaining a long-term focus on delivering meaningful therapies and access.

Beren is headquartered in Thousand Oaks, Calif. To learn more, visit the company's website or Beren's LinkedIn channel.

Forward Looking Statements

This press release may contain “forward-looking statements” within the meaning of Section 21E of the Securities Exchange Act of 1934, as amended, and the U.S. Private Securities Litigation Reform Act of 1995. These forward-looking statements generally are identified by the words “believe,” “project,” “expect,” “anticipate,” “estimate,” “intend,” “strategy,” “future,” “opportunity,” “plan,” “may,” “should,” “will,” “would,” “will be,” “will continue,” “will likely result,” and similar expressions. Forward-looking statements are predictions, projections and other statements about future events that are based on current expectations and assumptions and, as a result, are subject to risks and uncertainties. Many factors could cause actual future events to differ materially from the forward-looking statements in this press release, including but not limited to: (i) our ability to implement business plans and strategic partnerships, (ii) the risk of downturns and a changing regulatory landscape in the highly competitive healthcare industry, (iii) the size and growth of the market in which we operate, and (iv) future expansion of insurance coverage for exome and genome testing. The foregoing list of factors is not exhaustive. A further list and description of risks, uncertainties and other matters can be found in the “Risk Factors” section of our Annual Report on Form 10-K for the fiscal year ended December 31, 2025 and our Quarterly Report on Form 10-Q for the fiscal quarter ended March 31, 2026, filed with the SEC on May 4, 2026, our Quarterly Report on Form 10-Q for the fiscal quarter ended June 30, 2026, filed with the SEC on August 3, 2026 and other documents filed by us from time to time with the SEC. These filings identify and address other important risks and uncertainties that could cause actual events and results to differ materially from those contained in the forward-looking statements. Forward-looking statements speak only as of the date they are made. Readers are cautioned not to put undue reliance on forward-looking statements, and we assume no obligation and do not intend to update or revise these forward-looking statements, whether as a result of new information, future events, or otherwise. We do not give any assurance that we will achieve our expectations.

1. Burton BK, Ellis AG, Orr B, Chatlani S, Yoon K, Shoaff JR, Gallo D. Estimating the prevalence of Niemann-Pick disease type C (NPC) in the United States. *Mol Genet Metab.* 2021 Sep-Oct;134(1-2):182-187. doi: 10.1016/j.ymgme.2021.06.011. Epub 2021 Jul 1.

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