Uncovering Periodic Paralysis

Genetic testing to shorten the diagnostic journey

Patients should speak with their healthcare providers to request a genetic test for periodic paralysis.

For more information, please visit:

www.UncoveringPeriodicParalysis.com

No-cost Periodic Paralysis gene panel testing program

Strongbridge Biopharma™ has partnered with Invitae to offer a Periodic Paralysis gene panel test for those who have episodic muscle weakness or temporary paralysis provoked by common triggers for primary hyperkalemic or hypokalemic periodic paralysis.

A Periodic Paralysis gene panel test can bring you closer to uncovering the genetic cause behind the attacks of paralysis and muscle weakness caused by hyperkalemic or hypokalemic periodic paralysis. It can help shorten the diagnostic journey and expedite management of the disease.

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Periodic Paralysis Panel

- The Invitae Periodic Paralysis Panel includes analysis for both hyperkalemic and hypokalemic periodic paralysis.
    - Testing with the Invitae Periodic Paralysis Panel includes analysis of the following three most common associated genes: **SCN4A, CACNA1S, and KCNJ2**
- Turnaround time for the panel is rapid: Once Invitae receives the sample, your doctor will receive results within 10 to 21 calendar days (14 days on average).
- Invitae's board-certified genetic counselors are available on-demand Monday through Friday, 5 am to 5 pm Pacific Time.

Family Variant Testing

- Strongbridge Biopharma and Invitae offer no-cost family variant testing to any first-degree relative of a patient newly diagnosed through the *Uncovering Periodic Paralysis* genetic testing program.
- Requirements:
    - Known genetic variant was found on the Uncovering Periodic Paralysis gene panel test for original patient
    - A doctor must place the order within 90 days of the original test report

Program Eligibility

- 18+ years of age
- Episodic muscle weakness/paralysis attacks or episodic pain after attacks (more than one occurrence)
- Episodes are provoked by at least one of the common triggers for hyperkalemic or hypokalemic primary periodic paralysis

Utilizing the *Uncovering Periodic Paralysis* program imposes no obligation to prescribe or use Strongbridge Biopharma products or services.

Convenient Sample Collection

To order a test, please speak with your healthcare provider.

Resources Offered:

1. Kits for either blood or saliva sample collection
2. Blood draw services at no additional cost within the US
3. Ability to schedule a blood draw appointment at a physician's office or at a patient's home

About Primary Periodic Paralysis (PPP)

- Primary Periodic Paralysis is very rare, affecting ~4,000 to 5,000 diagnosed individuals in the US.[1]
- This condition causes attacks that affect your muscles, resulting in extreme weakness or temporary paralysis—most often the inability to move the muscles of the arms and legs.[2]
- The most common forms are hyperkalemic and hypokalemic periodic paralysis; however, other forms exist.[3-7]
- Primary Periodic Paralysis is usually inherited from a parent and may affect multiple people within a family.[8]

Although genetic testing can help confirm a suspected diagnosis, the absence of a genetic alteration does not preclude diagnosis[9-10]

References:

1. Data on File. Available from Strongbridge Biopharma plc. **2.** Charles G, Zheng C, Lehmann-Horn F, Jurkat-Rott K, Levitt J. Characterization of hyperkalemic periodic paralysis: a survey of genetically diagnosed individuals. *J Neurol.* 2013;260:2606-2613. **3.** National Institutes of Health. Hyperkalemic periodic paralysis. Available at: https://ghr.nlm.nih.gov/condition/hyperkalemic-periodic-paralysis. Accessed December 5, 2016. **4.** National Institutes of Health. Hypokalemic periodic paralysis. Available at: https://ghr.nlm.nih.gov/condition/hypokalemic-periodic-paralysis. Accessed December 5, 2016. **5.** National Institutes of Health. Anderson-Tawil syndrome. Available at: https://ghr.nlm.nih.gov/condition/andersen-tawil-syndrome. Accessed December 5, 2016. **6.** National Institutes of Health. Potassium-aggravated myotonia. Available at: https://ghr.nlm.nih.gov/condition/potassium-aggravated-myotonia. Accessed December 5, 2016. **7.** National Institutes of Health. Paramyotonia congenita. Available at: https://ghr.nlm.nih.gov/condition/paramyotonia-congenita. Accessed December 5, 2016. **8.** Fontaine B, Phillips LH 2nd. A newly approved drug for a rare group of diseases: dichlorphenamide for periodic paralysis. Neurology. 2016;86:1366-1367. **9.** Weber F, Jurkat-Rott, Karin, Lehmann-Horn F. Hyperkalemic Periodic Paralysis. NCBI Bookshelf. A service of the National Library of Medicine, National Institutes of Health. 2016. **10.** Vicart S, Sternberg D, Arzel-Hezode, M, et al. Hypokalemic Periodic Paralysis. NCBI Bookshelf. A service of the National Library of Medicine, National Institutes of Health. 2014.

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CareConnection

Strongbridge CareConnection offers a wide range of services for patients and their families

One-on-One Support

- A dedicated case manager is assigned to every patient
- Treatment support from highly trained specialized healthcare professionals

Treatment Access Assistance

- Support in understanding insurance coverage
- Information on co-pay and financial assistance programs
- Access to a patient assistance program
- Convenient, free specialty pharmacy services
    - Home delivery of prescriptions and refills
    - 24/7 support

Patient Education

- Information about Primary Periodic Paralysis
- Information about a treatment option

Community Connection

- Links to events sponsored by advocacy organizations
- Online patient communities

Genetic Testing

- *Uncovering Periodic Paralysis*: No-cost Periodic Paralysis gene panel testing program
- Visit www.UncoveringPeriodicParalysis.com for more information

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