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Ultragenyx Pharmaceutical Announces the Start of a Phase 1 Clinical Trial for Hereditary Inclusion Body Myopathy (HIBM) - also known as Nonaka Myopathy or Distal Myopathy with Rimmed Vacuoles (DMRV)

(Novato, CA, July 20, 2011) -- Ultragenyx Pharmaceutical has announced that recruitment has begun for a first clinical study for HIBM patients. To be eligible, patients need to have their HIBM diagnosis confirmed with a genetic test. This first study is a short study to see how the investigational drug circulates in the body.

“People with this rare disorder previously had no compelling reason to undergo genetic testing to understand their genetic mutation or to obtain a definitive diagnosis,” said Emil Kakkis, MD, PhD, President and CEO of Ultragenyx. “As clinical trials are initiated patients will need a documented diagnosis of HIBM to be eligible, so we are helping them to get genetic testing.”

To obtain testing at no cost, patients should contact their doctor and ask them to *order sample collection kits from Ultragenyx for testing.*

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