

RYR1-Related Diseases



Dr. Tokunbor A. Lawal and his team at the National Institutes of Health (NIH) are conducting a research study to describe the clinical manifestations and course of Ryanodine receptor type 1-Related Disorders (RYR1-RD) in children and adults.

Study Information:

- Annual visits for three years, with an option to extend participation for an additional two years
- Ambulatory participants will be seen at the NIH clinic and non-ambulatory participants will be seen remotely, via telehealth
- Annual visits consist of a physical assessment, sample collection, questionnaires, and activity tracking for all participants
- Participants seen at NIH will have physical therapy testing, breathing tests, an eye muscle assessment, and muscle imaging
- Domestic travel and accommodation expenses will be covered
- All study-related tests are provided at no cost

You may be eligible if you:



- Are at least seven years of age with a confirmed genetic diagnosis of an RYR1-related disorder
- Live in the United States

You may not be eligible if you:

- Have other neuromuscular diseases resulting in muscle weakness

To participate or receive more information, please contact the Office of Patient Recruitment



800-411-1222
TTY users dial 7-1-1



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Refer to research study #001737-CC



Location: The NIH Clinical Center,
America's research hospital, is located in
Bethesda, Maryland

