The Duchenne Registry: Your Data Visualized

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1. Parent Project Muscular Dystrophy

Introduction

The Duchenne Registry (formerly DuchenneConnect) began in 2007, when a group of thought leaders in the Duchenne muscular dystrophy community began discussing the need for a new kind of resource that would connect and serve the needs of the entire community. What they envisioned was a central hub that would bring together those living with Duchenne or Becker, along with their families and caregivers, to connect them with medical research, clinical care, clinical trials, and each other. At the same time, it would also be a resource for researchers and industries with an interest in Duchenne, allowing access to aggregate, de-identified data provided by patients and their families — information that could prove vital to advances in care and treatment. Today, the result of this endeavor is The Duchenne Registry, the largest, most comprehensive registry for Duchenne and Becker muscular dystrophy and women who are carriers. The Duchenne Registry (Registry) is a patient-report registry. Participants in the Registry complete surveys about various health and daily experiences living with Duchenne/Becker or being a carrier. They can complete a total of 12 surveys, and we ask that they complete most surveys at least annually. We also ask participants to share a copy of their genetic test report. Participants can provide as much or as little data as they want. However, the more data we have, the more we can share with researchers and the better we can tailor information to a specific participant.

Benefits of participating in The Registry

- Receive clinical trial information specific to you/your family member
- Contribute to research from home!
- Gain a better understanding of EVERYONE with dystrophinopathies

Methods

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The Registry contacts participants, usually at least once a month, through app notifications and emails. Contact may be to complete a survey, share an educational newsletter, or notify registrants about new research studies and clinical trials or upcoming activities such as webinars and conferences.

Demographic Information

5632 individuals with dystrophinopathy have provided data to the Registry, and 1361 participants are currently active on the app.