

GBS|CIDP FOUNDATION INTERNATIONAL PATIENT-REPORTED REGISTRY



Launched on Rare Disease Day
February 28, 2019

1,026
Enrolled!

GBS|CIDP FOUNDATION INTERNATIONAL PATIENT-REPORTED REGISTRY GBS-CIDP.IAMRARE.ORG

The screenshot shows the homepage of the GBS|CIDP Registry. At the top, there is a navigation bar with the site name and links for Home, About, News, and Contact. A 'Register' and 'Log in' link are also present. Below the navigation is a welcome message: 'Welcome to the Guillain-Barré Syndrome | Chronic Inflammatory Demyelinating Polyneuropathy, MMN, Anti-Mag Registry'. A large photograph shows a group of people, some wearing blue and purple t-shirts with 'GBS|CIDP' and 'SYMPOSIUM SAN DIEGO' printed on them. Below the photo are three main sections: 'Rare Disease Research' with a 'Researchers' button, 'Participating in This Study' with a 'Patients' button, and 'Join the Registry' with a 'Register' button. A large red arrow points to the 'Register' button. The browser's address bar shows 'https://gbs-cidp.iamrare.org'. The Windows taskbar at the bottom shows the time as 3:38 PM on 4/3/2019.

WHAT IS A PATIENT REGISTRY?

- A patient registry is a collection of standardized information about a group of patients who share a common condition.
- Surveys
- The de-identified data is used for a variety of purposes such as:
 - Conducting natural history studies
 - Building a library of patient resources
 - Supporting disease specific clinical trial recruitment



GOALS & OUTCOMES OF GBS|CIDP REGISTRY DATA

- A natural history study to help us understand GBS|CIDP and variants of the condition, and its progression over time.
- Characterize and describe the GBS|CIDP population as a whole.
- Assist the GBS|CIDP medical community with the development of recommendations for standards of care.
- Support the design of clinical trials for new treatments.

SPECIAL ANALYTICS REPORT FEATURE

Graph Results Example

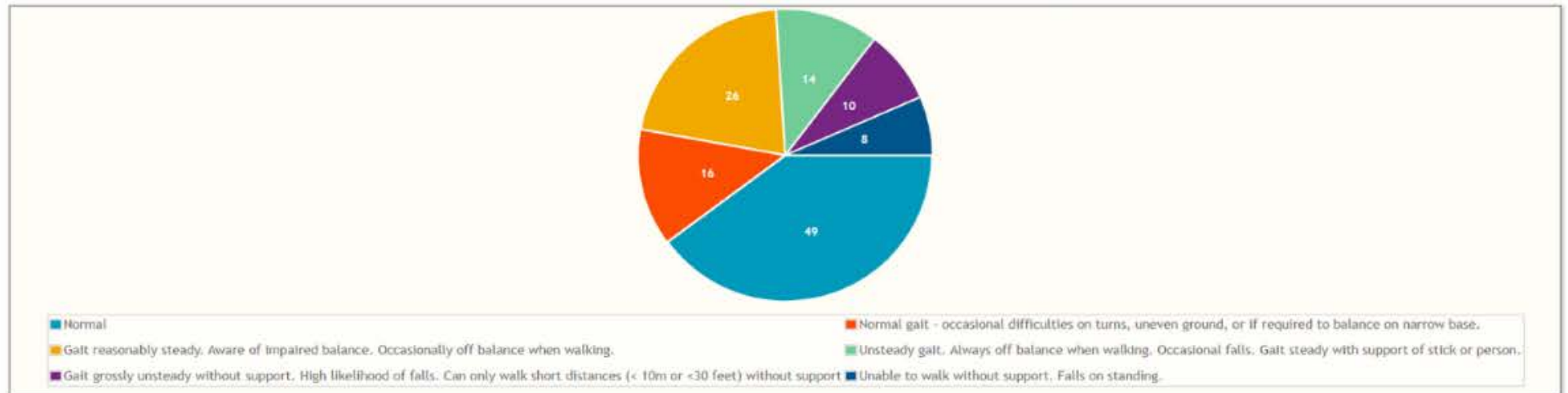
1. Muscle Weakness

- 16% shoulders/arms
- 22% hands/fingers
- 21% hips/legs
- 27% just legs
- 21% feet/toes

2. Numbness & tingling sensations

- 60% in hands
- 63% in feet
- 77% hand tremors
- 56% chronic fatigue

Rate function over the 4 week period preceding diagnosis. Gait stability: (Responses: 123)

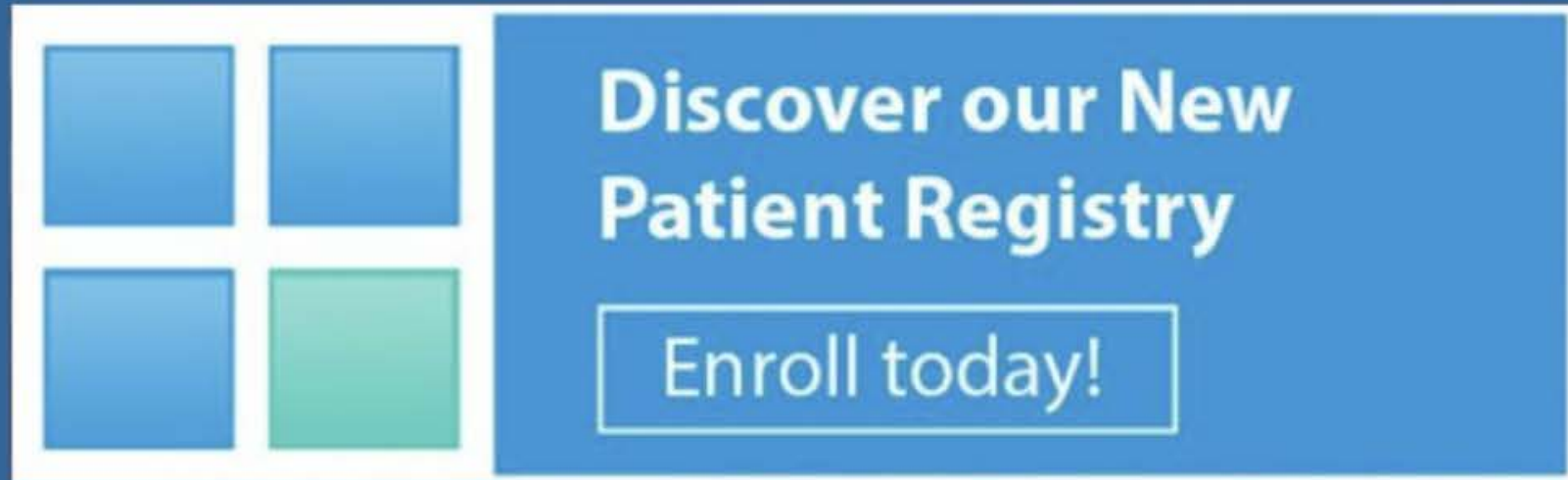


FAQS

- ✔ How long will it take to complete?
- ✔ Is it de-identified
- ✔ When will we see results?

Check out registry flyer at your seat for more info or visit:
<https://www.gbs-cidp.org/research/faq-patient-registry-study/>

SO MUCH MORE TO LEARN
YOU CAN ASK, WE CAN HELP!

A graphic consisting of a 2x2 grid of squares on the left and text on the right. The top-left, top-right, and bottom-left squares are blue, while the bottom-right square is green. The text on the right is white on a blue background.

**Discover our New
Patient Registry**

Enroll today!