

YEAR ONE DATA REPORT

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introduction

The GBS|CIDP Patient Registry, consisting of patient reported standardized questionnaires, will allow healthcare professionals access to critical, de-identified patient data and a more in-depth understanding of the patient experience. This unique collection of data can be critical for the pursuit of medical advancements and development of patient resources. The registry is hosted in partnership with the National Organization for Rare Disorders (NORD), an independent non-profit patient advocacy organization dedicated to individuals with rare diseases and the organizations who serve them. Studies of these conditions may take years to finish, but patient reported registries provide power in numbers!

The Foundation is pleased to report on the data that we have collected during the one year time period since launching this registry! So far, more than 1,200 people have created a profile in the GBS|CIDP Patient Registry. The data reported below represents the responses collected from the 518 people who have taken surveys within the registry, though not every person responds to every question. Also, people who have joined the registry are from all over the world; almost 60 respondents in the registry come from countries other than the United States, including Australia, Germany, Greece, Israel, Japan, Nicaragua, Kenya, and more!

Finally, the data summaries presented below only include responses from people who have taken surveys in the GBS|CIDP Patient Registry. If you don't see yourself represented in these surveys, please visit gbs-cidp.iamrare.org to learn more.

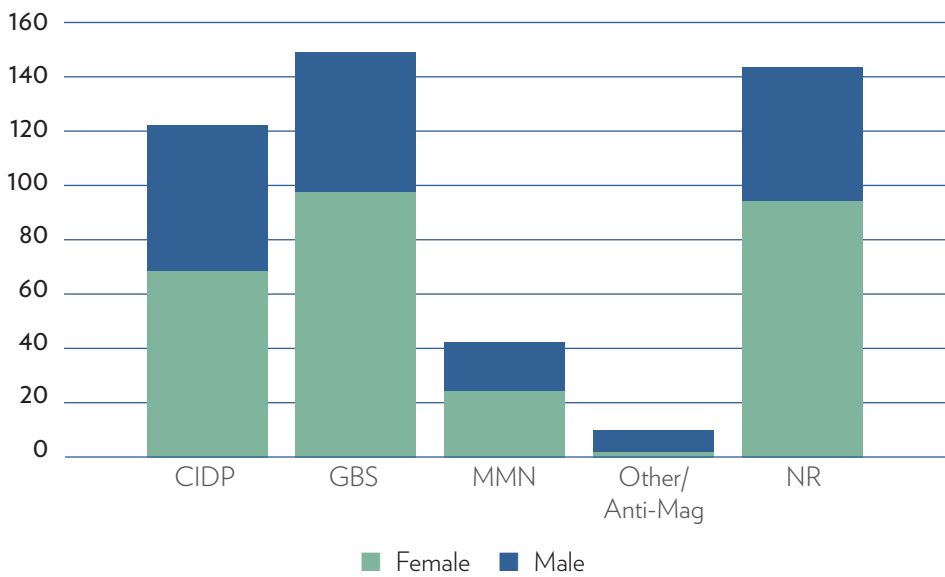
The Foundation is pleased to report on the data that we have collected during the one year time period since launching the GBS|CIDP Patient Registry!

Demographics

Who is in the GBS|CIDP Patient Registry?

The registry starts by asking some basic information about the patient living with GBS, CIDP, or a variant. As shown here, patients in the registry most often reported that they had GBS, are female, and are approximately 53 years old.

GENDER



AVERAGE AGE

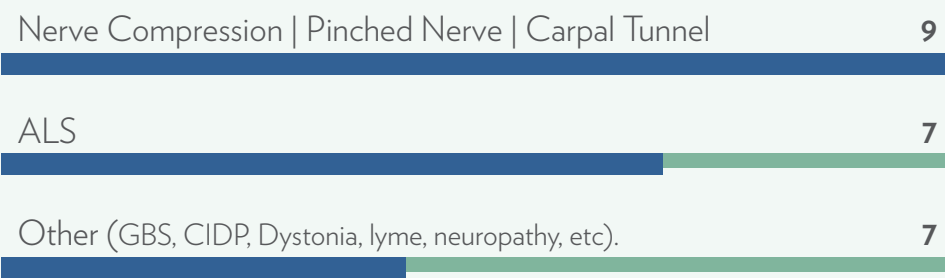


We are also interested in learning more about the diagnosis process. Rare diseases often face many barriers when seeking a diagnosis, including living with a misdiagnosis for years. Here, we see that people living with MMN often waited a year or more for a correct diagnosis.

AVERAGE TIME BETWEEN FIRST SYMPTOMS AND OFFICIAL DIAGNOSIS, MEASURED IN MONTHS

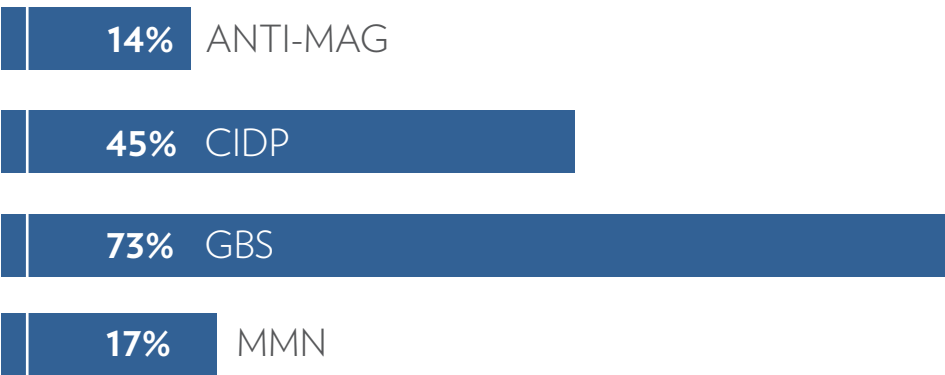


DIAGNOSIS BEFORE MMN



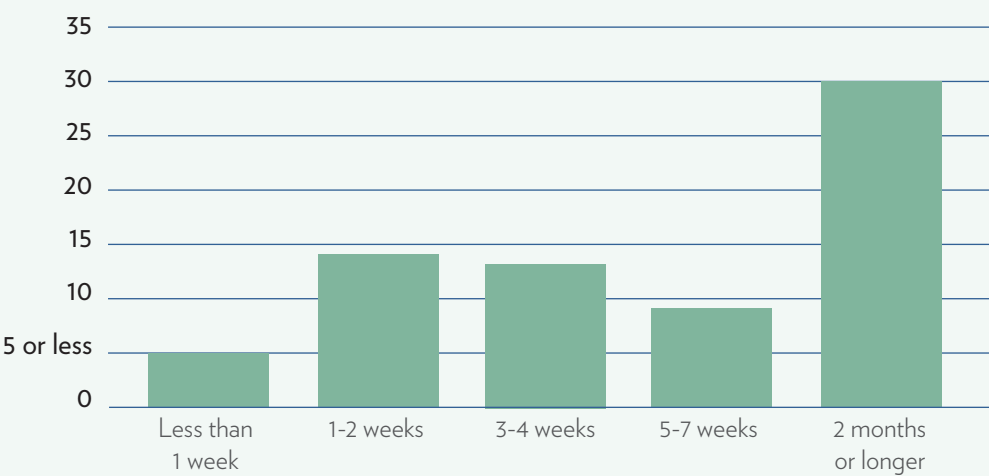
We are very interested in reporting on the typical treatment and outcome course of patients with GBS, CIDP, or variants. First, we wanted to know what percentage of patients with each of those conditions were hospitalized. Overwhelmingly (and unsurprisingly), most GBS patients were admitted to a hospital for some period of time.

% HOSPITALIZED



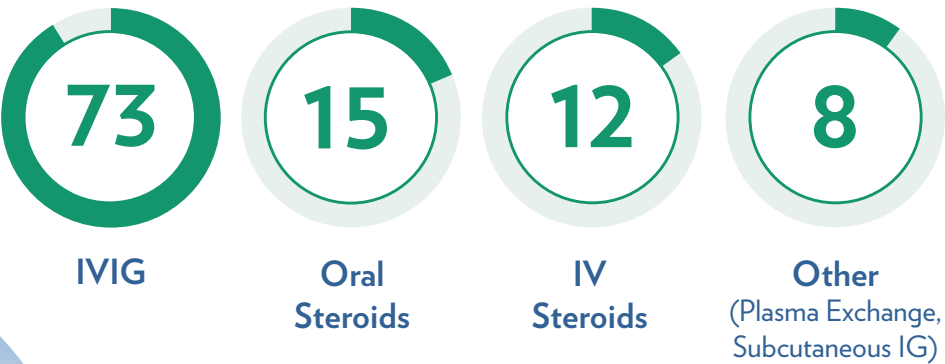
While most GBS patients spend time as an inpatient at a hospital, we also found that 60% of GBS patients spent time as an inpatient at a rehabilitation facility. Interestingly, we found that most GBS patients who needed an inpatient rehab program stayed there for at least 2 months. Types of activities at rehab can include speech therapy, physical therapy, occupational therapy, and aquatic therapy.

GBS – LENGTH TIME SPENT IN A REHABILITATION FACILITY



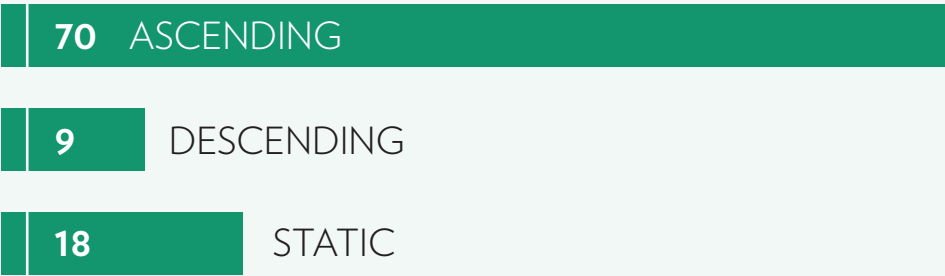
As treatment options expand for CIDP patients, we found that most CIDP patients still use IVIG therapy at some point during their treatment.

CIDP MEDICATIONS EVER TAKEN

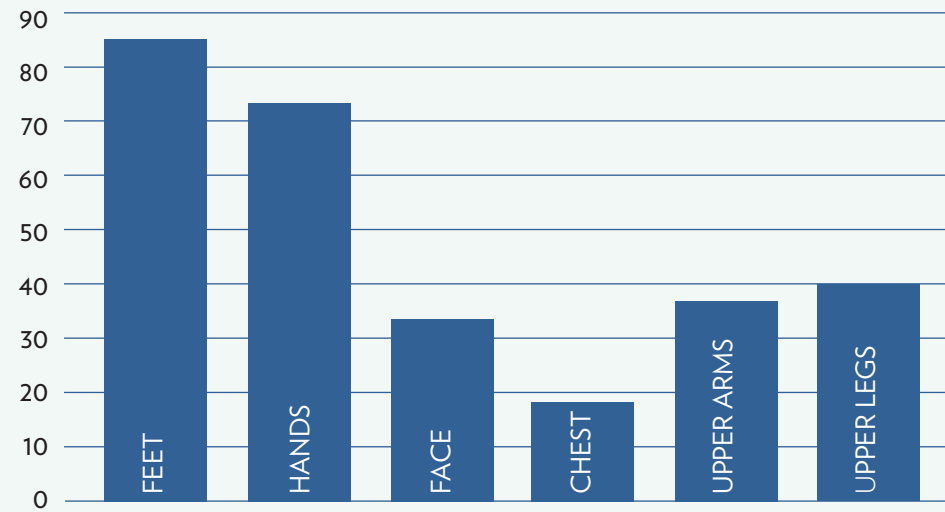


One symptom that crosses most GBS, CIDP, and variant patients is numbness. Here, we describe the type of numbness experienced by patients living with GBS, CIDP, and MMN.

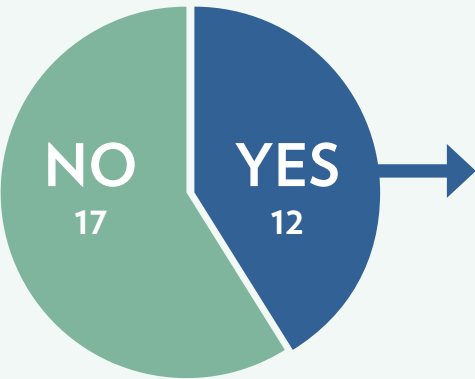
TYPE OF NUMBNESS EXPERIENCED BY GBS PATIENTS



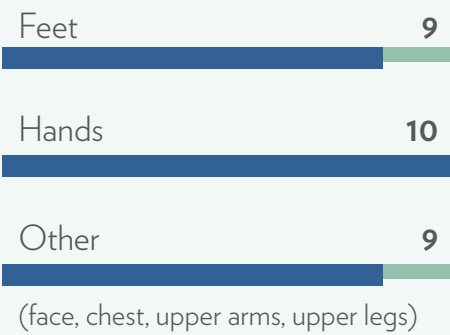
TYPE OF NUMBNESS EXPERIENCED BY CIDP PATIENTS



MMN PATIENTS, NUMBNESS SINCE DIAGNOSIS



TYPE OF NUMBNESS EXPERIENCED BY MMN PATIENTS





SPECIAL THANK YOU TO:

- GBS|CIDP Registry Staff
- NORD
- GBS|CIDP Registry participants
- Registry Committee

WE NEED YOU! LEARN HOW
TO PLAY AN IMPORTANT ROLE
IN GBS|CIDP RESEARCH AT
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