

# ACTIVE AND PASSIVE SURVEILLANCE METHODS TO INFORM PATIENT PROGRAMS AND PATIENT-FOCUSED DRUG DEVELOPMENT FOR RARE, PERIPHERAL NEUROPATHY COMMUNITY

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GBS|CIDP Foundation International



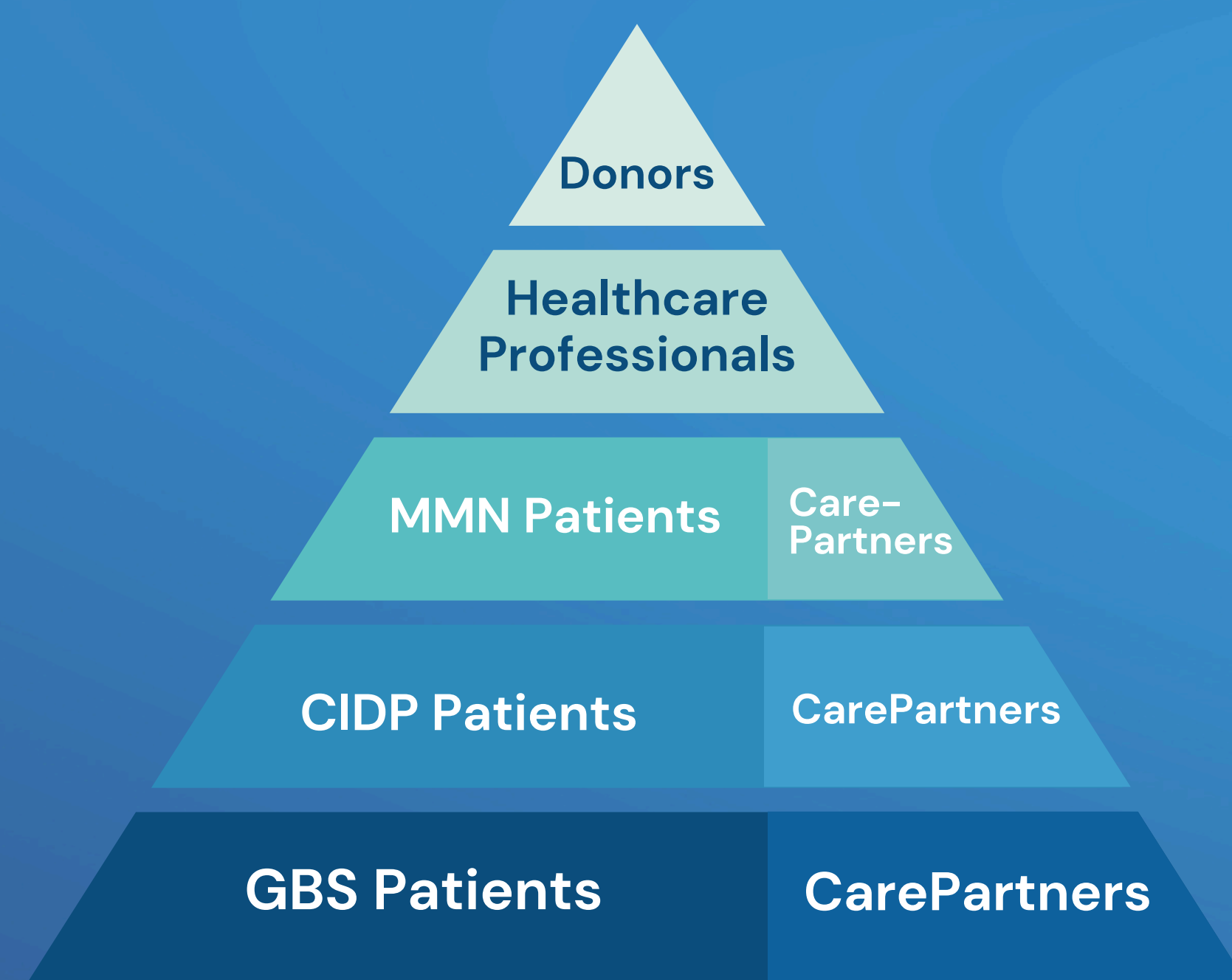
## PURPOSE/BACKGROUND

Guillain-Barre Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and Multifocal Motor Neuropathy (MMN) are rare conditions of the peripheral nervous system. These conditions, and other variants, cause patients to experience weakness, numbness, severe fatigue, paralysis (more common and acute in GBS patients), and varying levels of disability. These conditions have nuanced differences in how they impact a person, but a common need amongst these debilitating conditions is for support and education. The GBS|CIDP Foundation International has been serving the community through a mission of support, education, research, and advocacy for more than forty years.

## METHOD

The Foundation recently broadened its philosophy on data so that every interaction with a member becomes an opportunity for data collection and utilization. Using Salesforce and Salesforce integrated products, we have expanded our methodology to collect more precise information about our patient demographics.

## Demographics Communicated With Regularly



## RESULT

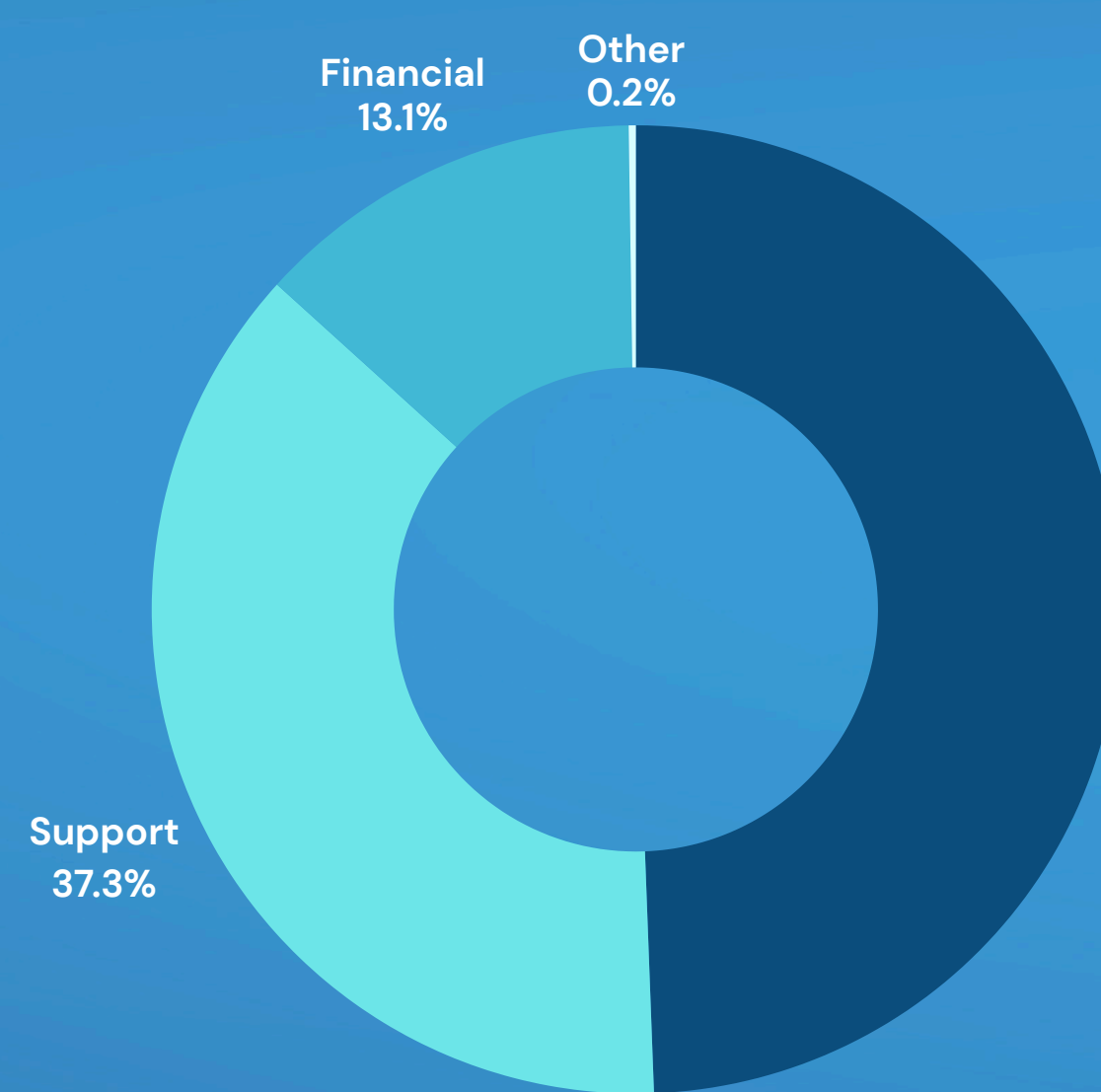
From more precise demographic information, the Foundation segmented email communications and created unique communication strategies for 8 (and increasing) different segments of our community.

## METHOD

Salesforce also facilitates passive epidemiological surveillance in the form of post-event surveys, a website inquiry form, and attendance tracking at virtual and in-person events



## Breakdown of Patient Inquiries



## RESULT

From the website inquiry tracking, the Foundation tracked 375 "support" inquiries in the past 365 days. As a result, the Foundation held a webinar in 2023 titled "Mental Health Checkup" to better serve the needs of the patient community and surveyed attendees after the event; 100% of attendees who completed the post-event survey reported an increase in feeling supported after attending the webinar; an average 81% of participants feel supported after all of our events with a post event survey.

Each post-event survey for all of our events also asks respondents to suggest a future topic. The most suggested topics is "Treatment Options", which inspired a recent webinar entitled "Treatment Options" with record registration of 527 people.

## METHOD

A Salesforce-linked form that collects contact information anchors a portal for healthcare professionals on the Foundation's website.



## RESULT

By tracking visits to the healthcare provider portal with a Salesforce-linked form, we identified 274 new healthcare professionals since the onset of the program add to a segmented communication strategy that includes condition-specific education, available resources for treating patients, and ways to engage with the Foundation.

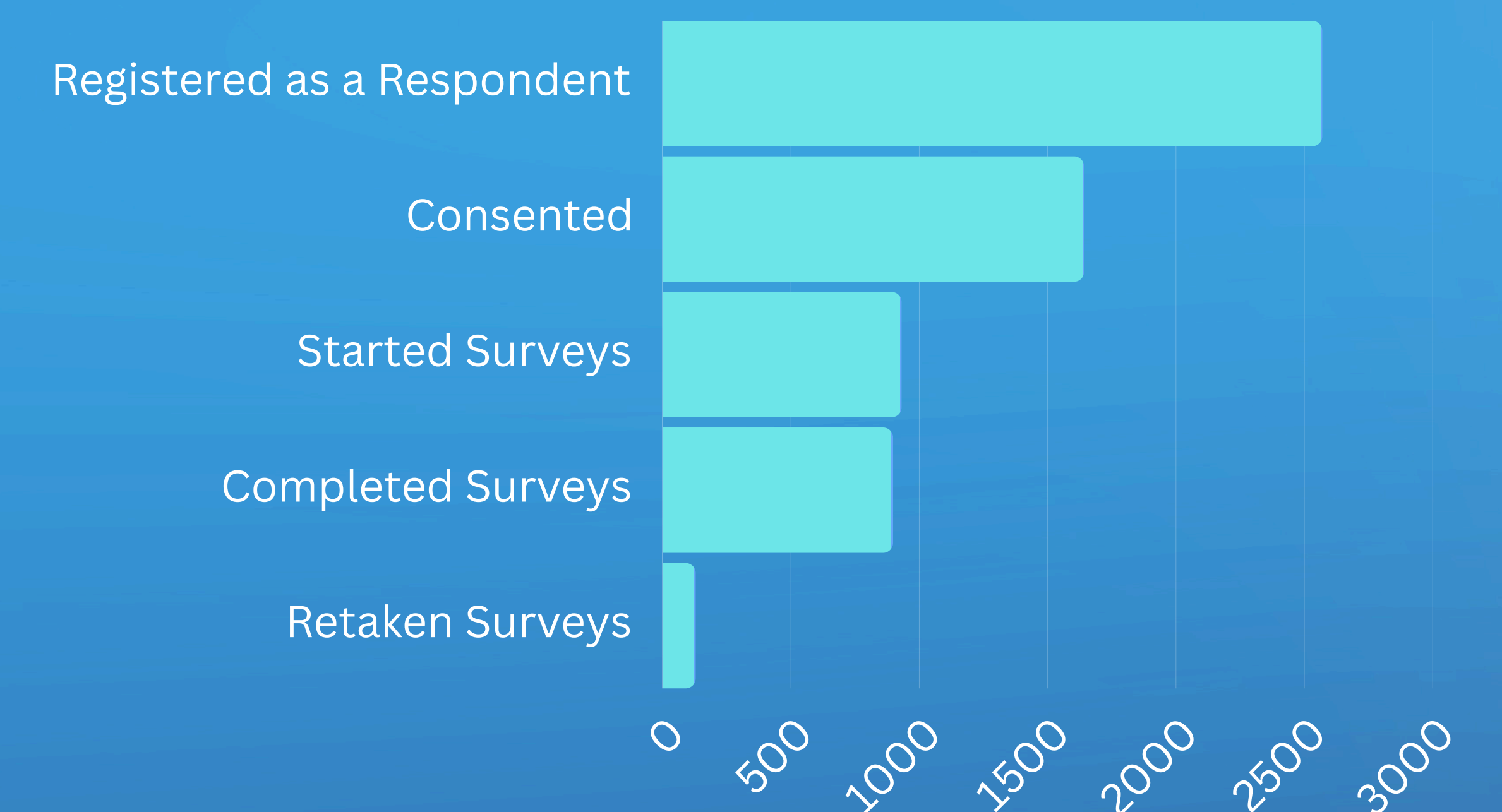
## DISCUSSION

Salesforce and our Registry have helped the GBS|CIDP Foundation International create more meaningful programs for the patient community; 90% of post-event survey respondents feel more empowered after attending an online event. These findings help us identify themes and volunteers for patient-focused drug development (PFDD) activities, such as externally led (EL) PFDD meetings and patient advisory boards for industry. The Foundation will be hosting an EL-PFDD meeting in May 2024 on GBS, MMN, and a variant known as Anti-Mag. The data collected from our technological improvements will be the backbone for the discussion and will also continue to inform patient programming.

## METHOD

The Foundation also hosts a patient-reported information registry, in partnership with NORD, to actively surveil the community on various healthcare needs. The patient registry is currently being revised, and survey categories include diagnosis and treatment, quality of life, recovery (condition-specific), etc. These surveys are designed in conjunction with the Foundation's Global Medical Advisory Board and actively monitor both medical and quality of life trends amongst the patient community.

## Patient Registry Survey Data



## RESULT

As of April 2024, 1,922 people have enrolled in the registry and 930 people have completed the surveys relevant to them.