



**GBS | CIDP**  
Foundation International

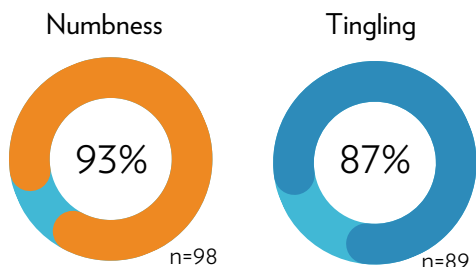


# GBS Patient Registry Report

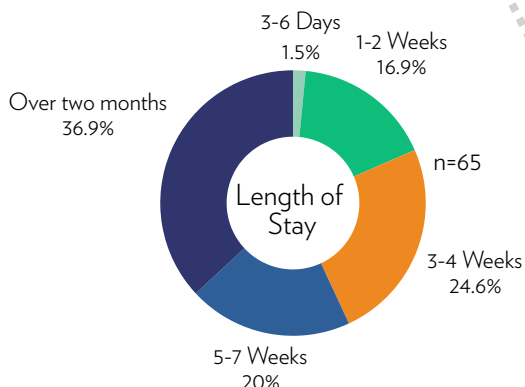
# Mapping the GBS Journey

## Symptoms/Diagnosis/Treatment

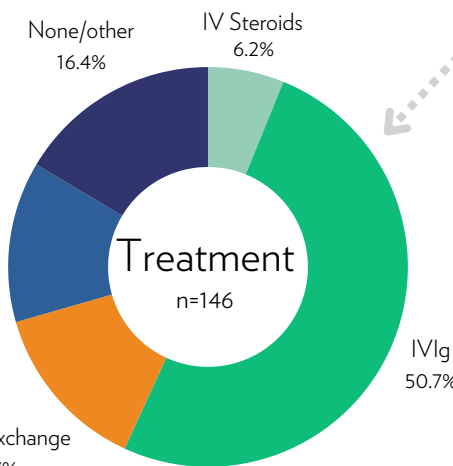
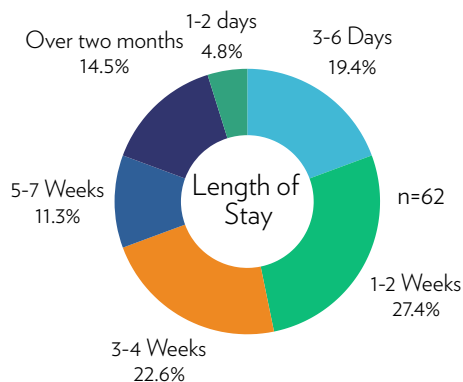
**A patient experiences symptoms of GBS**



**2 in 3 GBS patients will need rehab**  
n=96



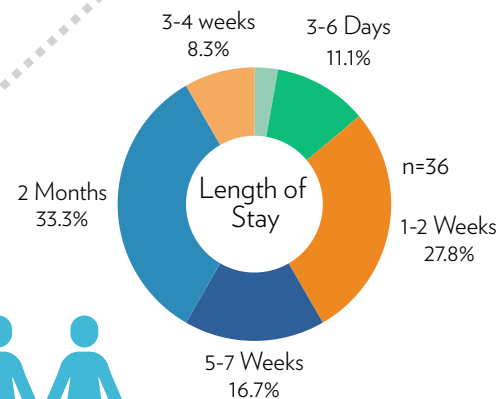
**65% of GBS patients will need to go to the ICU**  
n=96



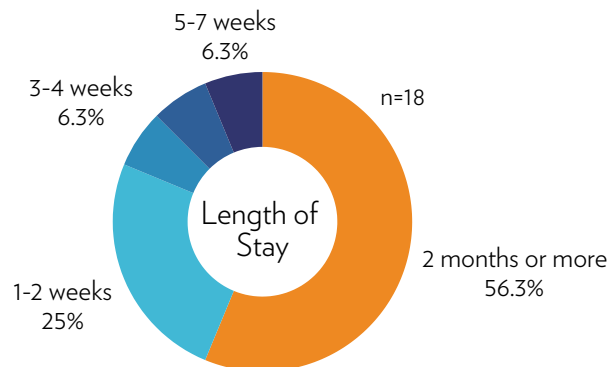
**About 50.7% will use IVIg to overcome their illness**



**1 in 3 GBS patients will need ventilators**  
n=96



**About 1 in 5 GBS patients will be readmitted into the hospital**  
n=95



# After the Hospital

## Pain



of GBS patients experience pain ranging from 1 to 10 (from a scale of 0-10)

n=84

\*In this section of the registry, patients are able to answer each question from a range of not all all, a little bit, somewhat, quite a bit, to very much. The data presented below includes answers ranging from a little bit to very much.



88% have a hard time starting tasks because of their fatigue



85% says fatigue interferes with their physical functioning



88% have a hard time finishing tasks because of their fatigue

## Fatigue



of GBS patients experience fatigue ranging from a little bit to very much

n=84



74% say pain interferes with their day-to-day activities



73% say pain interferes with their ability to do house work



67% say pain interferes with their ability to participate in social activities



72% say pain interferes with their ability to complete chores



72% say pain interferes with their ability to enjoy social activities

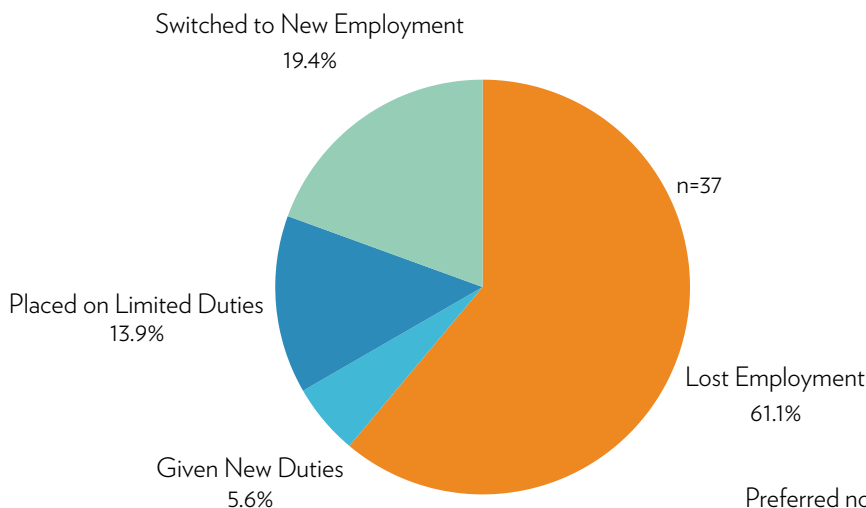


72% say pain interferes with their enjoyment of life

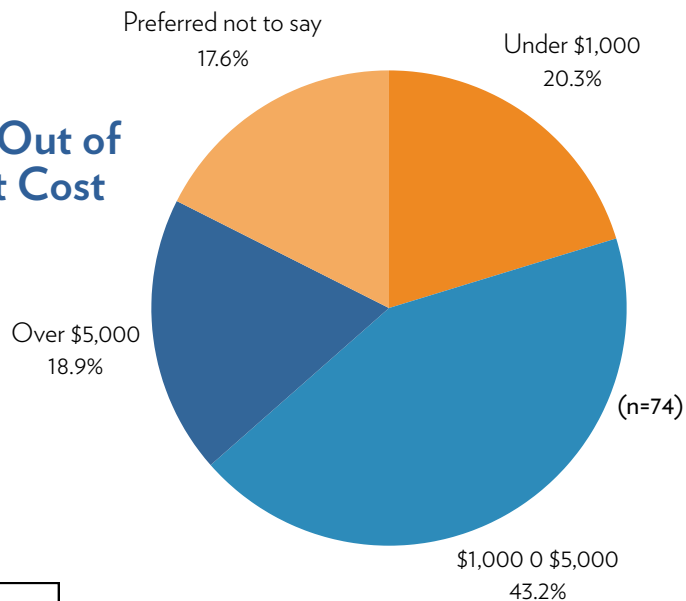
# After the Hospital

## Employment

40% of GBS patients will experience changes in their employment n=83

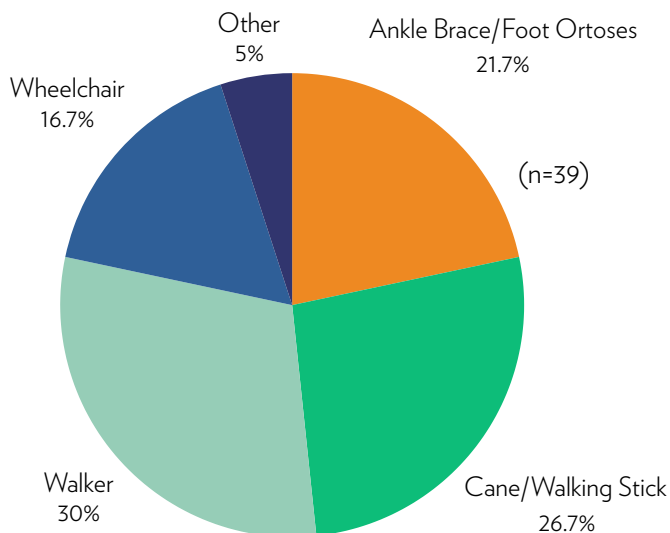


## Annual Out of Pocket Cost



## Devices Needed after treatment

45% of GBS patients need devices (n=86)



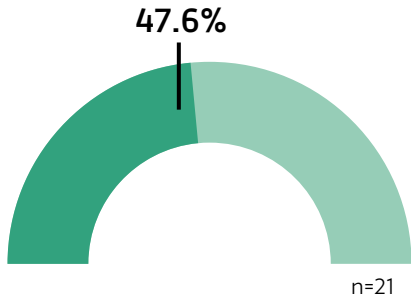
## Out of Pocket Cost can include

- Premiums (\$174 per month for Part B or Higher)
- Home Care Services
- Deductibles
- Co-insurances
- Adaptive Modifications (such as grab bars, ramps, lifts, and electric wheel chairs)
- Home Modifications (such as door knobs)

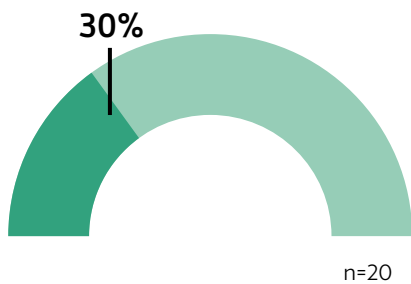
# After the Hospital

## Mental Health

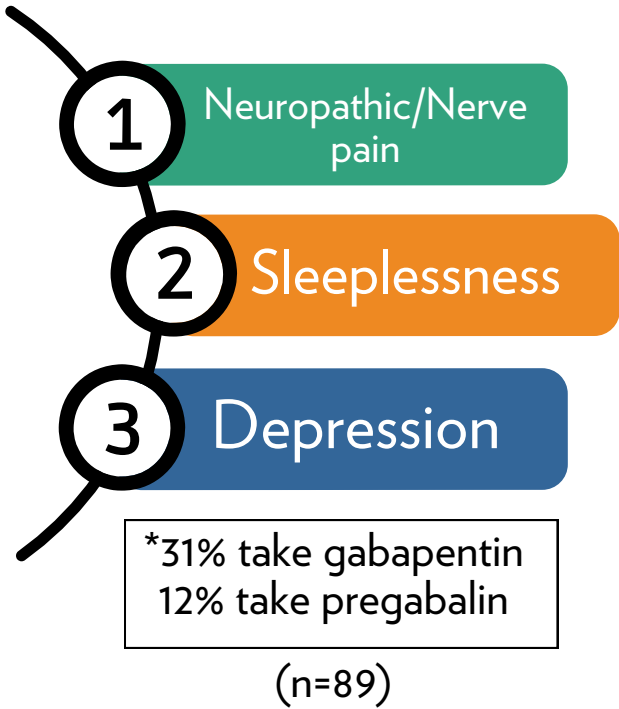
Patient diagnosis with Depression  
After experiencing their condition



Patient diagnosis with Anxiety  
After experiencing their condition



## Top 3 Reasons why patients take non-immune medication\*



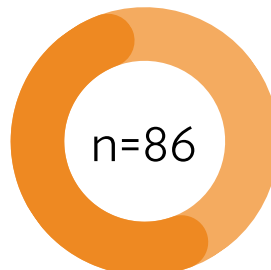
\*In this section of the registry, patients are able to answer each question from a range of never, rarely, sometimes, often, to always. The data presented below includes answers ranging from rarely to always.

### Worthless



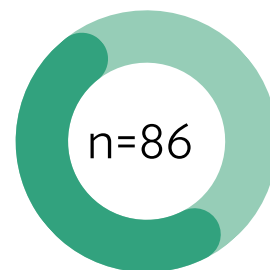
49% say they feel worthless because of GBS

### Helpless



59% say they feel helpless because of GBS

### Hopeless



55% say they feel hopeless because of GBS

# After the Hospital

\*In this section of the registry, patients are able to answer each question from a range of never, rarely, sometimes, often, to always. The data presented below includes answers ranging from rarely to always.

## Mobility



74% have difficulty completing chores



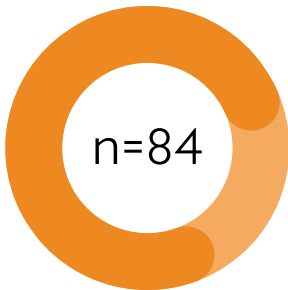
74% have difficulty going up and down stairs



60% have difficulty walking for at least 15 minutes



38% have difficulty driving or operating vehicles



82% say their condition limits their ability to do physical labor after 2 hours



82% have trouble enjoying and participating in leisure activities with family and friends

## Conclusion

Guillain-Barré Syndrome is a medical emergency that can have long-lasting, disabling impacts on patients who experience this rare condition. Even when properly identified and treated according to medical best practices, some patients live with ongoing physical, emotional, and social effects from their experience with GBS, including challenges with mobility, chronic pain, and mental health. These residual effects can significantly alter a patient's quality of life, underscoring the need for continued support and innovation in care. More research into this condition is essential to helping patients recover faster and more completely. The GBS|CIDP Foundation International hopes to bring awareness to the unmet needs of GBS and inspire research that improves outcomes and restores hope for patients and their families.

# From the Registry Team



Chelsey Fix, Director of  
Research and Advocacy



Champ Martinez,  
Research Intern

A Special Thank You to:

**ANNEXON**  
biosciences

**GBS Patients**

**National Organization for  
Rare Disorders (NORD)  
The Registry Committee**