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NEUROPATHY ACTION FOUNDATION ANNOUNCES RESULTS FROM CHRONIC INFLAMMATORY DEMYELINATING POLYNEUROPATHY (CIDP) SURVEY

Quality of life survey for Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) patients gives insight into diagnosis and treatment

Santa Ana, CA, August 11, 2021 - The Neuropathy Action Foundation (NAF) announced the results from a Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Quality of Life (QOL) Patient Survey. The survey focused on three primary areas: timely and accurate diagnosis, efficacy of treatment, and the impact of the disease on patient's quality of life.

"Early and accurate diagnosis can mean the difference between CIDP patients being successfully managed or becoming permanently disabled," said NAF President Dominick Spatafora. "Timely treatment can make a big difference in patients' lives." The NAF believes these survey results will increase awareness and action among providers, the public and public policy officials.

The majority of the 297 participants completing the survey were males (62%) from the United States (88%) with respondents from five other countries contributing to the results. While 70% of respondents reported that they were diagnosed between the ages of 41 and 65 years old, more than 54% of those completing the survey reported that it took more than one year to be accurately diagnosed. The majority of the misdiagnoses were made by Neurologists (60%) and Family Care Providers (21%).

"It is very clear that we need to do a better job at accurately diagnosing these patients. The sooner we can identify CIDP, the sooner we can start individuals on the proper therapy, alleviate their symptoms and improve their lives," said Jonathan Katz, Chief of Neuromuscular Services at California Pacific Medical Center.

When asked about treatment options, 76% reported receiving intravenous immunoglobulin (IVIg) and 11% reported receiving subcutaneous immunoglobulin (SCIg). A reduction in symptoms was reported within three months of their first Ig treatment by 68% of respondents. Only 7% reported that Ig did not help them manage their symptoms. If recommended by their Neurologist, 67% would consider SCIg treatment. Interruptions in treatment due to COVID-19 were experienced by 39% of the respondents.

Nearly 30% of all participants stated that CIDP often or always interferes with their employment and 51% said it impacts their quality of life. Loss of balance (51%) and weakness in legs (49%) were the most common symptoms before starting treatment.

CIDP has a direct impact the participant's emotional wellbeing. Fatigue was reported by 43% of the respondents. Some 46% reported feeling depressed and 28% of those completing the survey said they had time when they felt hopeless. Feeling embarrassed by their physical limitations was a concern for 49% of respondents.

“The survey results illustrate the complexity of CIDP and the impact it can have on people’s lives,” said Spatafora. “The good news is that the data also shows that treatment helps many individuals.”

About Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

CIDP is a rare disorder that can affect any age group and the onset of the disorder may begin during any decade of life. CIDP affects males twice as often as females and the average age of onset is 50. The prevalence of CIDP is estimated to be 5-7 cases per 100,000 persons. CIDP causes weakness and sensory abnormalities that usually develop over several months. Although there is no cure there are treatments available to control CIDP. Treatments that have been shown to be effective are glucocorticoids (steroids), intravenous immunoglobulin (IVIg) and plasma exchange (PLEx).

About the Neuropathy Action Foundation (NAF)

The Neuropathy Action Foundation (NAF), a 501(c)(3) nonprofit, is dedicated to ensuring neuropathy patients obtain the necessary resources to access individualized treatment to improve their quality of life. The NAF increases awareness among providers, the general public, and public policy officials that neuropathy can potentially be a serious, widespread and disabling condition, which may be treatable when appropriate medical care is provided.

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