# The Journey to Diagnosis for Patients with CIDP: Results from a Real-World International Survey

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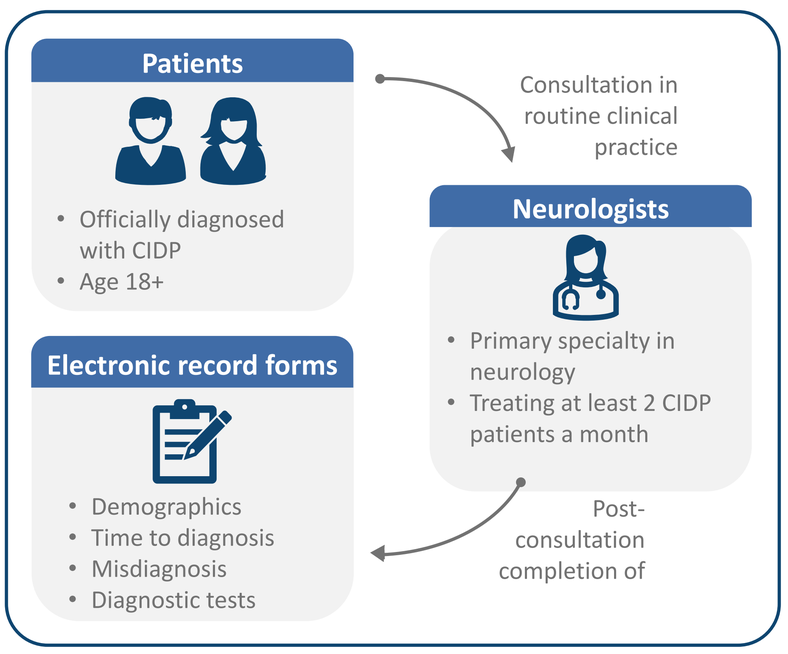
## BACKGROUND | METHODS

- Chronic Inflammatory Demyelinating Polyradiculoneuropathy (CIDP) is a rare, progressive, immune-mediated neurological disorder characterized by distal and/or proximal muscle weakness and sensory deficits.
- CIDP's heterogeneous presentation, lack of reliable biomarkers[1], misinterpretation of diagnostic test results[2,3], and the existence of similarly presenting diseases[4] complicate the diagnostic process.
- This is a secondary analysis of CIDP patients' diagnostic journey, using real-world data.
- Data were drawn from Adelphi's CIDP Disease Specific Programme™ (DSP) (September 2022 - April 2023), a real-world, cross-sectional survey involving neurologists and their patients in the UK, France, Germany, Italy, and Spain (n=542).
- The association between misdiagnosis and patient characteristics was tested using Chi-squared tests. The difference in median time to diagnosis between groups was tested for significance using Mood's median test.
- A multiple linear regression was performed on log-transformed time to diagnosis (months), with predictors: disease severity at onset, CIDP type, and misdiagnosis (yes/no).




## RESULTS

### 1. Demographics

- The mean (SD) patient age was 54.0 (12.4) years. Most patients were male (62%). Immunoglobulin and corticosteroids were the most often prescribed treatments **(Table 1).**

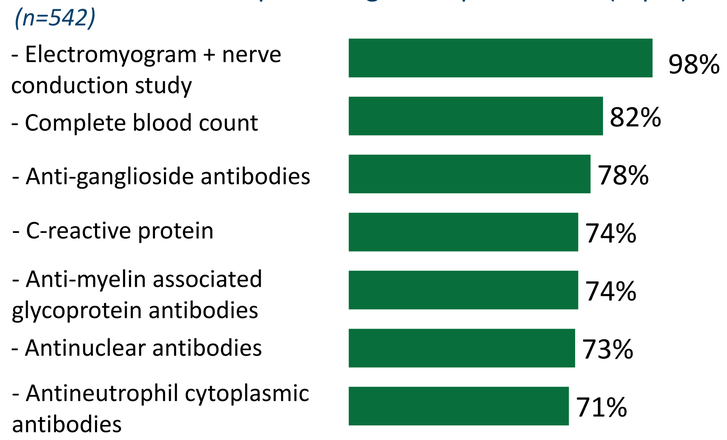
**TABLE 1** Patient characteristics *(n=542)*

| | |
|---|---|
| **Age (years),** mean (SD) | 54.0 (12.4) |
| **Sex, male,** N (%) | 337 (62%) |
| **Prescribed treatment,** N (%) | 463 (85%) |
| **Immunoglobulins (no corticosteroid)** | 182 (39%) |
| **Corticosteroids (no immunoglobulin)** | 142 (31%) |
| **Both immunoglobulins & corticosteroids** | 67 (14%) |
| **Other** | 72 (16%) |
| **Variant CIDP, N (%)** | 175 (32%) |

### 2. Diagnostic procedures & misdiagnosis

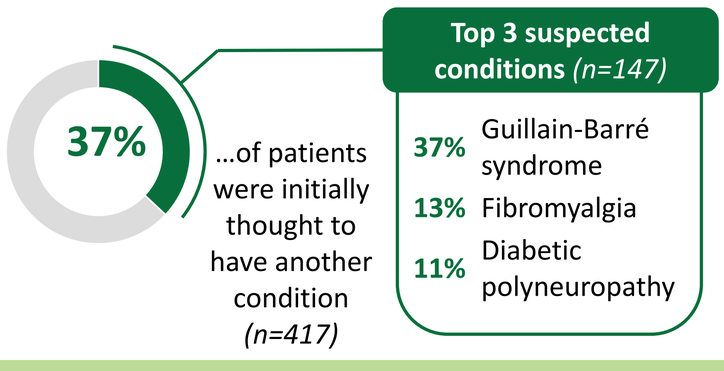
- The mean (SD) number of diagnostic procedures per patient was 19.6 (9.4). An electromyogram and nerve conduction study were used most often to aid diagnosis **(Figure 1)**.

**FIGURE 1** Most frequent diagnostic procedures (top 7) *(n=542)*




- Over a third of patients initially received a different diagnosis with Guillain-Barré syndrome (37%) being the most common **(Figure 2)**.

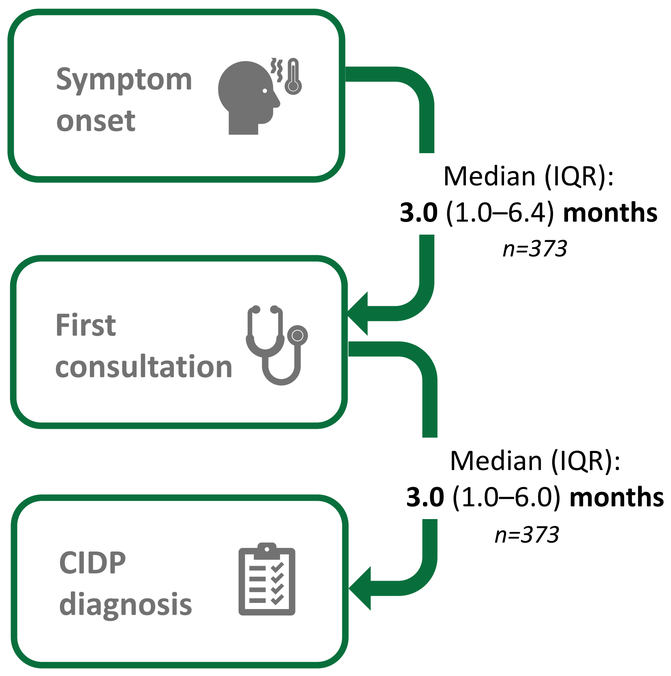
**FIGURE 2** % of patients misdiagnosed + misdiagnoses




### 3. Time to diagnosis

- The median (Q1-Q3) time between patients' symptom onset and getting diagnosed with CIDP by a healthcare professional was 7.0 (3.8-13.0) months **(Figure 3).**

**FIGURE 3** Time to diagnosis




### 4. Probability of being misdiagnosed

- No significant associations were found between being misdiagnosed and the variables sex, severity at symptom onset, age at symptom onset, BMI and CIDP type **(Table 2)**.

**TABLE 2** Associations between patient characteristics and misdiagnosis

| | | No misdiagnosis (n, %) | Misdiagnosis (n, %) | P-value of Chi-squared test |
|---|---|---|---|---|
| **Sex** | Female | 102 (66%) | 52 (34%) | 0.3993 |
| | Male | 162 (62%) | 101 (38%) | |
| **Disease severity at symptom onset** | Mild | 106 (65%) | 58 (35%) | 0.9239 |
| | Moderate | 114 (62%) | 71 (38%) | |
| | Severe | 36 (65%) | 19 (35%) | |
| **Age at symptom onset** | <30 | 25 (74%) | 9 (26%) | 0.4082 |
| | 30-<45 | 52 (60%) | 34 (40%) | |
| | 45-<60 | 103 (59%) | 73 (41%) | |
| | ≥60 | 34 (58%) | 25 (42%) | |
| **BMI** | <25 | 137 (62%) | 85 (38%) | 0.4710 |
| | 25-<30 | 116 (66%) | 59 (34%) | |
| | ≥30 | 11 (55%) | 9 (45%) | |
| **CIDP subtype** | CIDP variant | 74 (59%) | 52 (41%) | 0.2436 |
| | Typical CIDP | 190 (65%) | 101 (35%) | |

### 5. Time between symptom onset and time to diagnosis

- A significant association was found between time to diagnosis and the variables disease severity at onset, CIDP subtype and misdiagnosis **(Table 3).**
- A multiple linear regression analysis on the log-transform of the time to diagnosis showed that patients with moderate and severe disease severity at symptom onset received a diagnosis more quickly than patients with mild symptoms, with a reduction factor of 0.74 and 0.81, respectively. Having a CIDP variant increased the time to diagnosis by a factor of 1.22, compared to typical CIDP. Prior misdiagnosis significantly delayed diagnosis, increasing the time by a factor of 1.54.

**TABLE 3** Associations between patient characteristics, misdiagnosis and time to diagnosis

| | | N | Median (Q1 – Q3) time to diagnosis (months) | P-value of test for medians |
|---|---|---|---|---|
| **Sex** | Female | 158 | 6.0 (3.2 -14.0) | 0.276 |
| | Male | 273 | 7.0 (3.6 – 13.0) | |
| **Disease severity at symptom onset** | Mild | 155 | 9.1 (5.0 – 18.9) | **<0.0001** |
| | Moderate | 192 | 5.5 (2.9 – 11.0) | |
| | Severe | 58 | 4.0 (2.6 – 9.7) | |
| **Age at symptom onset** | <30 | 38 | 6.3 (4.2 – 20.5) | 0.564 |
| | 30-<45 | 113 | 6.9 (3.6 – 13.1) | |
| | 45-<60 | 213 | 6.7 (2.9 – 12.1) | |
| | ≥60 | 67 | 8.0 (5.0 – 15.0) | |
| **BMI** | <25 | 224 | 6.7 (3.7 – 13.9) | 0.309 |
| | 25-<30 | 184 | 7.0 (3.0 – 12.0) | |
| | ≥30 | 23 | 11.0 (5.0 – 19.0) | |
| **CIDP subtype** | Variant | 131 | 8.4 (4.1 – 19.5) | **0.004** |
| | Typical | 300 | 6.0 (3.1 – 11.6) | |
| **Misdiagnosed** | No | 208 | 5.0 (2.9 – 10.0) | **<0.0001** |
| | Yes | 140 | 9.1 (4.4 – 20.0) | |

## KEY TAKEAWAYS

- The median time to diagnosis for patients with CIDP in the survey was 7 months.
- A third were initially suspected to have another condition or misdiagnosed prior to confirmatory CIDP diagnosis
- Mild symptoms at onset, having a CIDP variant, and having been misdiagnosed were found to be associated with a longer time to diagnosis.

PRESENTED AT THE PROFESSIONAL SOCIETY FOR HEALTH ECONOMICS AND OUTCOMES RESEARCH (ISPOR); NOV 9 – NOV 12, 2025; GLASGOW, SCOTLAND, UK

**ABBREVIATIONS:** **CIDP**: Chronic Inflammatory Demyelinating Polyneuropathy, **N**: Sample size, **SD**: standard deviation, **BMI**: body mass index, **IQR**: Interquartile Range, **Q1**: first quartile (25% percentile), **Q3**: third quartile (75% percentile)

**ACKNOWLEDGMENTS:** This study used data from the Adelphi Real World CIDP DSP, an independently conducted survey. Argenx were one of multiple subscribers to the DSP, and funded the analysis described here. The material in this poster has not been previously presented or published. **CA** and **SP** are employees of and hold stock in argenx. **FB, LV** and **SD** are paid consultants for and receive grant support from argenx. **YT** and **JW** are employees of Adelphi Real World.

**REFERENCES: 1.** Allen JA, et al. *Expert Rev Neurother*. 2021. **2.** Allen JA, Lewis RA. *Neurology*. 2015. **3.** Allen JA, et al. *Muscle Nerve*. 2018. **4.** Neligan A, et al. *Pract Neurol*. 2014.

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