



## **ROMANIAN NEUROLOGICAL IMMUNE PATIENTS ACCESS TO IGIV THERAPY**

# NATIONAL STANDARD

The Romanian Ministry of Health sets the optimal treatment for CIDP patients in the Medical Protocol from 2021:

- ✓ **1-2g /kg /dose;**
- ✓ **Duration of the dose administration: 2 - 5 days;**
- ✓ **Frequency of doses: 4 - 6 weeks;**

*(pag. 306-307 Protocol therapeutic, position 100, cod J001G: DCI IGIv)*

# DATA SOURCE

*Since 2008, Romania has a National Program of Treatment for Rare Diseases including neurological immune diseases patients treated with iv Immunoglobulins.*

**From June to August 2021, ARBNP - the Romanian Peripheral Neurological patients' association - implemented a study:**

***All 19 Romanian hospital treating neuro immune (CIDP /GBS) patients were contacted and asked to provide statistical data with regards to their patients treated between 2019 to 2021. 14 answered, of which 2 stated they do not administer IGiV despite being registered in the National Program.***

Following data refers to **patients coming from 12 of 17 hospitals.**

*For reference, the National Institute for Statistics puts the Romanian resident population at 19.186.000 persons as of January, 2021.*

# CHRONICAL PATIENTS (CIDP)

- ✓ Total number of registered patients in the 12 of 17 hospitals: **203**, leading to an estimated total of **288 patients**;
- ✓ Patients' **distribution** per hospital is uneven, starting with **68, 28, 22, 21** and **18 patients** and down to a single patient in one.
- ✓ **Average age** of the patient is approximatively **57 years**, mainly due to difficult access to diagnose;
- ✓ **A very large number of patients received a suboptimal number of doses** due to the lack of IGIv, according to doctors;
- ✓ **Situation is deteriorating: 2,22%** of the patients received 4 or more doses in 2021, down from **8,45% in 2020** and **10,38% in 2019**;
- ✓ **The pandemics affected access to diagnose as well: 3** chronical patients were diagnosed in the first half of 2021, down from 17 in 2020;

# ACUTE PATIENTS

- ✓ **8 hospitals** mentioned acute patients treated with IGIv;
- ✓ **total number** of acute patients: **327**;
- ✓ **Average age** of acute patients: **54,5 years**;
- ✓ **83 patients were treated in 2020**, a decrease on almost **33%** from **129 patients in 2019**,
- ✓ **43 patients** were treated in the first part of **2021**;