

***Esteemed Council ES presidency***

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My name is Nancy Di Salvo and I am reaching out to you on behalf of my fellow Guillain-Barré Syndrome (GBS), CIDP and Multifocal Motor Neuropathy (MMN) patients, in representation of the GBS|CIDP Organisation Europe, I would like to express my concern on the imminent dialogue negotiation regarding the SoHo Regulation. Our health and future lays in the outcome of this negotiation and the future implementation of the SoHO Regulation. It is difficult to live with a rare disease, the uncertainty of the future, the fear of not being able to walk or even worse, breathe. Patients rely on PDMPs that can improve and stabilize their quality of life. We realize that we are fortunate to have such possibilities thanks to immunoglobulins (IGs), yet the uncertainty of the availability of an approved and effective therapy destabilizes the patient on a daily basis.

Today, the EU imports a large percentage of the required plasma. This high dependency on imports from the US should encourage the EU to increase plasma collection in Europe and the moment is propitious to focus on the opportunities to support patients who rely on plasma-derived medicinal products, without denying the need to support plasma donors.

I am a 53-year-old woman with a Rare Disease, specifically CIDP (Chronic Inflammatory Demyelinating Polyneuropathy). I was diagnosed when I was 36 years old, when life was finally evolving into what I had dreamt of as a child but only to halt and converge into a different direction with a chronic, disabling and immunoglobulin dependent condition.

Chronic inflammatory demyelinating polyneuropathy (CIDP) is an autoimmune disorder in which the body's immune system attacks the myelin that insulates and protects your body's nerves. A neurological disorder that involves progressive weakness and reduced senses in the arms and legs. CIDP is a condition that can lead to permanent disability if not properly treated. The longer the disease goes untreated, the increased nerve damage can permanently limit sensory and motor functions. Without treatment, 1 in 3 people with CIDP will need a wheelchair.

Early treatment is important to limit disease progression and includes medicines or other treatments to suppress the immune system, such as immunosuppressive drugs, steroids, intravenous immunoglobulin, and plasma exchange (plasmapheresis) to remove immune system proteins from the blood. Immunoglobulin and corticosteroids remain first line treatments for CIDP. The most effective therapy is that with immunoglobulins (intravenous or subcutaneous); corticosteroids can be effective as well only to cause various side effects that can lead to other serious health conditions.

Through the years, I have been constantly facing and overcoming healthcare barriers: from difficulties in diagnosis to access to proper and continuous treatment due to national healthcare budget constraints and later a pandemic that created major disruptions. A key barrier is shortage of plasma, a very important starting material for the manufacturing of medicines, such as immunoglobulins. We therefore hope that the SoHO Regulation contributes to more plasma collection in Europe.

Thank you for taking our concern into consideration and remain at your disposal for any additional information on GBS, CIPD, MMN.

With esteem and gratitude,

*Nancy Di Salvo*

Director of International Affairs  
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GBS-CIDP Organisation EU

*The GBS | CIDP Foundation International is a global nonprofit organization supporting individuals and their families affected by Guillain-Barre' syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), Multifocal Motor Neuropathy (MMN) and related conditions through a commitment to support, education, research and advocacy.*

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