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Newsletter

Dysimmune Inflammatory Neuropathies Community Insight

April 2025 N° 2

Editorial

Advocating for DIN Patients: EPODIN's ongoing engagement in policy and science

EPODIN continues to strengthen its role as a key voice for patients with dysimmune inflammatory neuropathies (DIN) across Europe. In recent months, the association has actively participated in several policy and scientific forums, ensuring that the needs and rights of DIN patients are represented at the highest levels.

In March, EPODIN responded to the European Union's proposed Critical Medicines Act. The association welcomed this initiative to reinforce medicine supply chains and emphasized the importance of transparency and equitable distribution—particularly vital for protecting vulnerable patient populations during shortages.

EPODIN also contributed to strategic discussions at the European Directorate for the Quality of Medicines & HealthCare (EDQM), highlighting the essential role of plasma-derived medicinal products in the treatment of DIN.

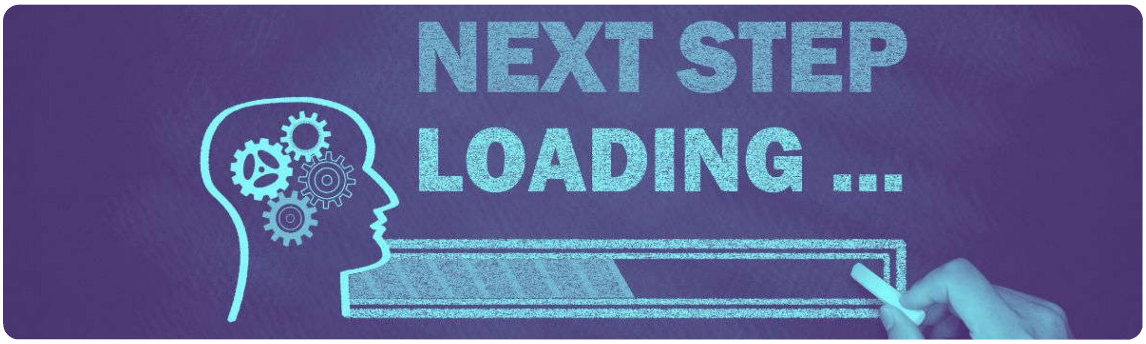
The association stressed the need for robust regulatory frameworks to ensure sustained access to safe, high-quality therapies.

As part of its scientific engagement, EPODIN actively participated in the EURO-NMD webinar series on Inflammatory Neuropathies. These sessions served as a valuable platform to share expertise, raise awareness of patient perspectives, and promote best practices across the rare neuromuscular disease community.

In addition, EPODIN was present at the ISSAID Congress in Paris (International Society of Systemic Auto-Inflammatory Diseases), an important gathering focused on systemic auto-inflammatory and autoimmune disorders. Given the immune-mediated nature of DIN, this congress provided a relevant context for highlighting the diagnostic challenges and care inequalities faced by patients, while fostering connections with the wider community of immune-related diseases.

Through these initiatives, EPODIN reaffirms its commitment to advocacy, education, and collaboration—working toward a future where all DIN patients across Europe receive timely, effective, and dignified care

Projects on the Move



Update on EPODIN White Paper on unmet medical needs as to DINs

After a thoroughly completed scientific literature review, as never done before, the White Paper (WP) is currently in the phase of drafting of the content; key medical opinion leaders in the WP projects' Scientific Committee are about to revise and complement the draft.

Further to the first ever most complete DIN's conditions literature review, the White Paper will have for instance an outstandingly strong patient perspective on patient needs, and comprise, amongst others, the latest knowledge on immunomodulation approaches. The White Paper content is expected to be ready around summer 2025.

NEUROQUALI: patient-driven European research on life with CIDP

NEUROQUALI is a new European study designed to better understand the daily impact of Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) on patients' lives. This study was developed and conducted by EPODIN, which engaged a clinical research organization (CRO).

This six-month, fully remote, patient-driven study invites adults living with CIDP to self-register online and share their experience through monthly questionnaires.

The study will assess **quality of life**, **fatigue**, **mental health**, **access to care**, and **social impact**, using validated tools and patient-reported outcomes.

By aiming to collect data directly from up to **500 participants**, NEUROQUALI seeks to highlight unmet needs and support improvements in care pathways for this rare and disabling condition.

Available in **9 languages** and soon launching across Europe. NEUROQUALI gives patients the chance to make their voices heard—because every experience matters.

Each national association that is a member of EPODIN will have access to data from its own country.

European Public Affairs Advocacy Spotlight

Plasma supply continuity in Europe: EPODIN highlights patient priorities

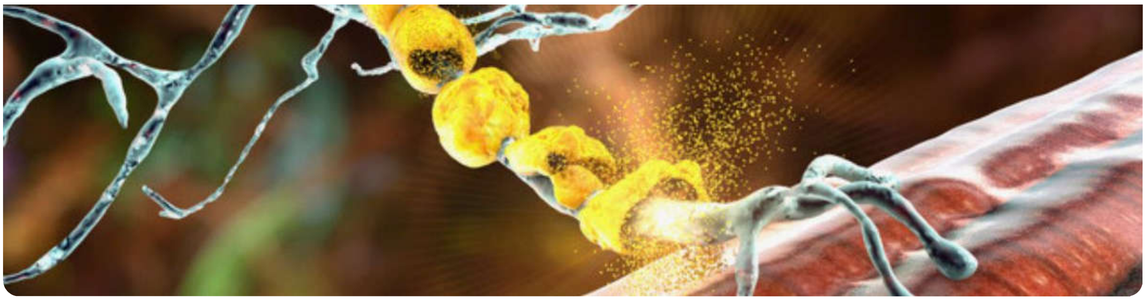
The **European Department for the Quality of Medicines** (EDQM) within the **Council of Europe** organized a Stakeholder Conference “Plasma Supply Continuity” from 26-27 March 2025 in Strasbourg (France).

The Conference aimed to look at the latest developments and needs for action to increase and improve plasma and PDMP supply in Europe as well as to debate and scrutinize the strategies on how concretely to increase the safe collection and adequate supply of plasma and plasma-derived medicinal products (PDMP), when it comes to EU member states having to implement the EU SoHO Regulation on national level.

The event covered the entire plasma-to-PDMP-to-patient chain, and was attended by professionals working in blood and plasma collection, PDMP industry, patient associations (EPODIN being amongst the 2 invited), donor associations, EMA, EU Commission, European country plasma collection representatives such as from Spain, UK, Austria, Denmark, France, Italy, Baltic countries etc,

EPODIN was invited to participate in this “Place To Be” Conference, to deliver in front of a packed +300 audience a well received audacious Impact Statement requesting concrete **Action NOW** to get plasma collection increases.

In a nutshell, EPODIN’s **Jean-Philippe Plancon** called the policymakers that European plasma collection has to significantly and rapidly be increased, given on the one side the constantly growing IG needs for DIN patients (+4,5% every year by 2030), with patients having no time to wait for ages to get treatment, and on the other side, the currently very high geopolitical risks related to Europe’s being still dependent on around 5 million liters plasma imported from the US.



EPODIN represents patients at European Parliament debate on autoimmune health challenges

EPODIN was invited to participate as speaker in the European Parliament event “**Autoimmune Diseases in Focus: Tackling Unmet Needs as a European Public Health Priority**”, as part of the Health Longevity Series, co-organized by European Business Summits (EBS) and industry sponsor.

The event took place on April 9 at the European Parliament in Brussels, Belgium and was hosted by MEP Andriukaitis from Lithuania, a former EU Health Commissioner.

The event targeted to bring together stakeholders including patient organisations, EU and national policymakers and biotech industry association, to advance solutions for concerns related to autoimmune diseases. It was about exploring the growing public health, economic, and societal impact of these conditions and highlight key EU policy actions, research gaps, and innovation strategies to improve patient care.

A central focus of the event was on cutting-edge biotech solutions, including novel therapeutics, precision medicine, and advancements in immuno-therapy, and their potential to transform treatment outcomes. EPODIN was the only patient organization selected to participate in the panel discussion.

DIN*
Day

*Dysimmune and
Inflammatory
Neuropathies Day

DIN Day 2025: a milestone event at the European Parliament on June the 11th

Dysimmune and Inflammatory Neuropathies Day 2025 will be celebrated on June the 11th with a special event for amplifying the voice and interests of DIN patients at the EU level. The event will bring together all relevant stakeholders to raise awareness of the current challenges for DIN patient access and to outline possible solutions.

The Round Table will take place at the **European Parliament in Brussels** and will serve as a forum to discuss key EU legislative developments — including the **EU Critical Medicines Act**, the **EU Pharma Package**, and the forthcoming **EU Biotech Act** — in the context of DIN patient access challenges. These discussions will be also fed by EPODIN's forthcoming **White Paper on Unmet Medical Needs of DIN Patients**, currently under development, which will also include a set of policy recommendations and a Call to Action.

We are pleased to announce that the event will be **hosted by two prominent Members of the European Parliament (MEPs)**. Alongside EPODIN representatives, the Round Table will gather leading medical experts (KOLs), representatives from the European Commission, the Vice Minister of Health of the Czech Republic, industry associations, other MEPs, and Health Attachés from EU Member States' permanent representations in Brussels.
EPODIN members are warmly invited to attend this important event and actively raise their voices in support of DIN patients.

Around Europe: Members Focus

Asociatia Romana pentru Boli Neurologice Periferice is launching a national awareness project focused on the challenges faced by CIDP (Chronic Inflammatory Demyelinating Polyneuropathy) patients. Since 2007, ARBNP has advocated for better diagnosis, treatment access, and healthcare policies. Despite these efforts, Romanian patients still lack access to information, recovery services, and essential treatments like immunoglobulin. Structural issues—such as poor coordination among the Ministry of Health, insurers, hospitals, and pharmacies—have resulted in severe treatment shortages. To address this, the association plans to launch interactive awareness tools and information kits targeting the general public, patients, doctors, specialists, and decision-makers. These will be unveiled at a national rare disease conference and distributed to university centers. The project aims to build a well-informed support network and drive systemic change for better care..

CIDP Italia APS is supporting an important Italian research project on rare neuromuscular diseases (NMDs). Led by PhD student Alessia Bevilacqua, the study adopts a biopsychosocial approach to better understand the care, social, and existential needs of people living with NMDs. The project also highlights the value of assistive technologies and the essential role of trained caregivers. This initiative perfectly aligns with EPODIN’s mission to improve quality of life and care pathways for patients with dysimmune neuropathies.

ERN-EURO NMD Webinars on DINs

Our members proudly contributed to the **EURO-NMD Webinar Series on Dysimmune and Inflammatory Neuropathies**, a seven-episode programme gathering leading clinicians, researchers, and patient representatives. The series addressed key topics such as diagnostic challenges, treatment advances, guidelines, emerging biomarkers, and patient quality of life.

EPODIN members played an active and valuable role in this initiative. Our representatives also contributed as moderators, patient advocates, and discussion leaders throughout the series, ensuring patient needs and priorities were visible at every step.

This collaboration reflects EPODIN’s ongoing commitment to supporting education, fostering dialogue between professionals and patients, and advancing care for people living with dysimmune neuropathies across Europe.

Replays of the full series are now available online on the EURO-NMD website.

Watch now

Agenda - May 2025

17 – 19 May Edinburgh

The Peripheral Nerve Society annual meeting. Let's join there at EPODIN's stand

20 – 21 May Warsaw

International Plasma Protein PPTA Annual Congress. Join us at the stakeholders meetings

About us

EPODIN aims to amplify the voice of European citizens living with **Dysimmune Inflammatory Neuropathies (DIN)**, striving to reduce the burden and inequities associated with their condition.
By connecting European institutions and patient organisations, we seek to empower patients, support research, and promote equitable treatment and care.

members

ecosystem

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BUILDING

hope

www.epodin.org

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