Epilepsy and Rare Diseases:

From Silos to Synergies

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IBE International Bureau for Epilepsy

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Introduction

On December 2nd, 2025, IBE - with the Spanish Epilepsy Federation [FEDE] - organised a meeting at the European Parliament, Brussels. The meeting - hosted by MEP Elena Nevado del Campo, of the EPP Group - was entitled Epilepsy and Rare Diseases: From Silos to Synergies. Also in attendance were MEPs Sokol, Veryga and Dostal.

Speakers highlighted the broad clinical and socio-economic impact of epilepsy in Europe; drawing upon the results of IBE's landmark Global Epilepsy Needs Study (which highlighted a need for urgent action on rare and complex epilepsies). Panellists, then, examined how EU institutions and stakeholders can accelerate regional implementation of two key global frameworks to address the burden of epilepsy: The WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders [IGAP] (2022–2031), and the WHO Resolution on Rare Diseases (2025–2034).

Spain's EpiAlliance was presented as a best-practice case study on national implementation of IGAP; serving as a transferable model for other Member States. This event united policymakers, clinicians, researchers, patient organisations, and people with lived experience to strengthen synergies between epilepsy and rare diseases, reduce disparities, and improve access to care.

Reflecting on the meeting, Elvira Vacas Montero, Chair of European Regional Executive Committee said:

“The true value of a meeting like this is to remind us that epilepsy is not only a clinical or political issue, but a deeply human reality that touches the lives of millions of people and their families. And when we sit together —as we did in Brussels— the real possibility of driving meaningful change truly emerges.”

In 2026, IBE will launch its European public affairs strategy including the organisation of a European Epilepsy Summit and the coordination of a European Epilepsy Barometer.

Opening Words:

MEP Elena Nevado del Campo

The event was opened by MEP Elena Nevado del Campo, who highlighted the urgent need to strengthen Europe's response to epilepsy and rare diseases. She highlighted the scale of the challenge, noting that at least six million people in the WHO European Region live with epilepsy and more than 300 million people worldwide are affected by one of over 7,000 identified rare diseases, many of which have neurological manifestations. This close link between neurology, epilepsy and rare diseases, she noted, is not yet adequately reflected in public policy.

MEP Nevado acknowledged that while progress has been made, these areas have too often been addressed separately, leading to delayed diagnoses and major barriers to accessing specialist care and innovative therapies; with inequalities between access to care across the EU.

She referred to data from the European Parliament's public consultation on rare diseases, which revealed that nearly half of respondents have no available treatment, fewer than 5% of rare diseases have an EU-approved therapy, and many patients face discrimination and diagnostic delays due to limited access to specialised centres.

She also highlighted recent international milestones, including the WHO Intersectoral Action Plan on Epilepsy and Other Neurological Disorders (2022–2031) and the Global Resolution on Rare Diseases (2025–2034), stressing that these frameworks are complementary and should be implemented in a coordinated way in Europe to improve early diagnosis, integrated care, research and social support.

MEP Nevado reiterated strong support for the development of a European Rare Disease Plan and confirmed her commitment, as rapporteur for the forthcoming own-initiative report on rare diseases, to contributing to this goal.

She concluded by recognising the value of collaborative initiatives – referencing Spain's EpiAlliance – thanking participating organisations and experts, and expressing hope that the event's discussions would help build a more inclusive and coherent European approach to epilepsy and rare diseases.

Introductory Presentation 1:

Prof. Nicola Specchio, Chair, European Region, International League Against Epilepsy [ILAE]

In his presentation, Prof. Nicola Specchio highlighted that while epilepsy itself is not a rare disease, many epileptic syndromes are rare and complex, requiring highly specialised expertise. He described epilepsy as a brain network disorder with a significant societal impact. Across Europe, around six million people live with epilepsy, many of whom experience higher rates of stigma, unemployment, disability and preventable premature mortality, affecting not only health outcomes but also education, employment and social participation

Prof. Specchio emphasised that better outcomes depend on early and accurate diagnosis, timely referral to specialised centres and the establishment of integrated care pathways. He noted, however, that major challenges persist across Europe, including unequal access to specialised care, persistent treatment gaps, preventable deaths and insufficient investment in research.

Addressing these issues, he stressed, must be understood as a shared European responsibility rather than the sole burden of individual Member States.

He outlined a clear European vision built around four core priorities: improving diagnosis, ensuring equitable access to treatment, reducing stigma and discrimination, and strengthening research and innovation. According to Prof. Specchio, coordinated action in these areas is essential to reduce inequalities and improve quality of life for people living with epilepsy. He said Epilepsy Alliance Europe could be a vehicle for these efforts.

He also stated that Europe is well placed to implement the WHO's 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) as the region benefits from world-leading research, clinical expertise – including the European Reference Network, Epi Care – policy leadership, and strong patient voices.

Introductory Presentation 2:

Elvira Vacas Montero, Chair, European Region, IBE

Elvira Vacas Montero introduced the International Bureau for Epilepsy [IBE]– on of the event co-organisers – with a focus on its Global Epilepsy Needs Study [GENS]; highlighting the results from Europe.

She presented GENS as a scientifically rigorous study with a robust research methodology, designed and delivered by a diverse Expert Advisory Committee comprising people with epilepsy, caregivers, patient organisation representatives, healthcare professionals, and researchers. GENS examined the unmet everyday needs of people with epilepsy worldwide across 10 life domains, including education, work and income, driving and transport, knowledge and information, and safety and security.

Four European countries took part: Bosnia, Croatia, Denmark and Spain.

A very clear pattern emerged with similar needs repeated in every country: easier access to healthcare, better mental health support, protection of human rights, and increased social understanding.

She said Europe has both the capacity and the responsibility to address these barriers through implementation of the WHO's 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP), endorsed by all EU Member States. She noted that the IGAP follow-up report published in October shows progress has been slower than expected, stressing that this should be seen not as criticism but as a strategic guide. As the WHO report makes clear, progress remains limited and uneven, and urgent, coordinated action is required.

She added that this assessment is closely linked to the recent WHO Resolution on Rare Diseases and the forthcoming Global Action Plan on Rare Diseases, which will strengthen the global framework for rare and complex epilepsies. She then introduced the next panel discussion on how Europe can respond to this international mandate with greater coherence, ambition, and impact.

Integrating Epilepsy into European Policy Priorities:

Stefan Schreck, Adviser for Stakeholder Relations, DG SANTE, European Commission

Stefan Schreck began by commending the organisers on aiming to identify synergies between epilepsy and other EU priorities, particularly given the EU's limited capacity.

He said the EU had clearly prioritised rare diseases and said this was essential given the number of people living with a rare disease in Europe is the equivalent of the population of Poland. He mentioned the European Reference Networks, and in particular EpiCare, as an example of an infrastructure that can address rare epilepsies, and reiterated the EU's vision for the sustainability of these networks.

He said EpiCare was a success story, with 12,700 new patients and 6,600 listed on its registry which is now being used by 70% of the centres. The use of orpha-codes has gone from 27 to 67%, which is increasing interoperability. This, he said, showed the value of a true European response focussed on data, innovation and cross-border solidarity.

He finished by stressing the need for Europe to focus on diagnosis, care and dignity. When expertise is shared, hope become tangible, he concluded.

Scaling National Best Practice, Panel Discussion

EpiAlliance, Spain

Frederic Destrebecq, Executive Director, European Brain Council moderated a panel discussion with the following participants:

- Elvira Vacas, President of FEDE and Co-Director of EpiAlliance
- Mar Carreño, President SEEP and Co-Director of EpiAlliance
- Patricia Arias, Head of Social Transformation, FEDER

The following key points were raised:

- EpiAlliance is a best practice, national model that can be scaled to accelerate progress across the EU.
- Spain has 17 autonomous communities but there is a need for coordinated administration and implementation. This can serve as a model for the EU and its member states.
- It is important to ensure global, regional, national and local efforts are aligned; inter and intra-regional collaboration is key. We need to leverage global resolutions to drive local efforts.
- EpiAlliance shows how epilepsy can be an entry point for efforts on other neurological disorders. It paves the way in areas such as defragmenting data, developing care pathways and supporting creation of specialist centres.
- Efforts on epilepsy and/or rare disease cannot be isolated and need to be integrated with wider public health initiatives.
- Collaboration is essential to increase our pool of knowledge and advance innovation.
- The co-leadership between the scientific society (SEEP) and the patient federation (FEDE) was highlighted as a structural element of the EpiAlliance model, enabling the alignment of clinical priorities and real-world needs, accelerating implementation, and strengthening the institutional legitimacy of proposed actions.
- In line with the IGAP, it was underlined that EpiAlliance demonstrates how epilepsy can act as a tracer condition to address shared challenges across other neurological disorders, offering a multi-stakeholder governance model and a coordinated action framework that is transferable to other areas of brain health, both nationally and at European level.

Representatives from the pharmaceutical industry agreed on the importance of multi-stakeholder collaboration to address unmet needs in epilepsy, particularly in rare and complex epilepsies, and to translate scientific evidence into coordinated and sustainable action that improves people's lives.

Víctor Usó highlighted UCB's long-standing commitment to epilepsy, focused on addressing unmet needs, including rare epilepsies, through a people-centred, evidence-based approach. He noted that significant gaps persist, including diagnostic delays and territorial inequalities, which require coordinated action to be effectively addressed.

Isabel Botella emphasised Jazz's commitment to improving the lives of people living with severe conditions with unmet needs, highlighting rare epilepsies as an area characterised by complex care pathways and a substantial emotional, social and economic impact on families. She noted that inequalities persist in access to diagnosis, specialised teams and advanced therapeutic options, underscoring the need for a more equitable and dignity-centred approach.

Daniel Pérez stressed Angelini Pharma's commitment to brain health and epilepsy, highlighting the importance of addressing these areas through an ecosystem approach. He underlined that while evidence and human urgency are essential, progress is only sustainable when supported by robust governance, coordination and collaboration. In this context, he highlighted EpiAlliance as a national framework that enables the structured and coherent implementation of the principles of the IGAP.

All agreed that we need to work together to advance innovation that improves the quality of life of people living with epilepsy in Europe. It was clear that multi-stakeholder alliances around a clear strategic goal is essential to drive change.

All expressed their commitment to partnership, and the importance of looking beyond diagnosis and treatment to address the everyday social and emotional impact of epilepsy.

Partnering for Progress in Europe, Panel Discussion

Donna Walsh, Chief Executive Officer at the International Bureau for Epilepsy moderated a panel discussion with the following participants:

- Masa Malenica, Chair, Education and Training Working Group, European Reference Network - EpiCare
- Frederic Destrebecq, Executive Director, European Brain Council
- Arabela Acalinei, Vice President, European Federation of Neurological Associations
- Isabella Brambilla, President, E+A (Complex and Rare Epilepsies Alliance)
- Christina Kyriakopoulou, Scientific Policy Officer, DG Research and Innovation European Commission

The following key points were highlighted:

- The needs of people with epilepsy, as identified in the Global Epilepsy Needs Study, are largely aligned with those of people living with other neurological conditions, underscoring the importance of joint advocacy for neurology.
- Epilepsy, particularly rare and complex forms, extends beyond seizures. Its wider social impact must be recognised, including the need for improved social inclusion for people with epilepsy and their families, especially primary caregivers, who are most often mothers.
- The SANT Committee plans to begin work on a neurological strategy in 2026, making it essential that epilepsy is strongly represented.
- Epilepsy research has benefited significantly from EU funding, and opportunities remain to position epilepsy within upcoming research calls, including non–disease-specific calls, given the condition's heterogeneity.
- A new brain health research partnership will launch in January 2026, creating further funding opportunities. Continued engagement by the epilepsy community in EU consultations will be critical to shaping research priorities.
- Clinical expertise continues to grow, and the European Reference Network EpiCare must be sustained and expanded.
- Natalia Wierzbicka, Global Policy and Public Affairs Lead for Neurology at UCB, emphasized the need for the epilepsy community to generate evidence at the European level, advocate for faster access to treatment, and engage policymakers to ensure innovation and broader patient access. She highlighted that epilepsy remains a high-burden area of unmet need that should be integrated into brain health plans and strategies.

Interventions from Members of the European Parliament

MEPs Sokol, Veryga and Dostal

MEPs Sokol, Veryga and Dostal addressed the meeting. All expressed their willingness to support IBE to position epilepsy, and the needs of people living with epilepsy, in efforts they are leading via the SANT committee and beyond.

All agreed that brain health should be a priority for the EU, and it was essential to ensure that epilepsy was featured in any initiatives in this area such as the EU brain health partnership, neurological health strategy, etc. – with acknowledgement made to the mental health impact of epilepsy on those affected.

European priorities such as the pharmaceutical strategy, health data space and cross border healthcare directive were raised as opportunities for the epilepsy community to inform and influence.

However, it was made clear that protecting the standalone public heath budget under the next multi-annual financial framework would be difficult but necessary, with IBE encouraged to join other civil society groups in advocating for the monies to continue to be ringfenced.

Closing Words

MEP Elena Nevado del Campo

In closing the event, MEP Elena Nevado del Campo closed the session by thanking all participants, including representatives from European institutions, scientific organisations, patient associations and industry, for their expertise, contributions and continued dedication. She underlined that the discussions clearly demonstrated that epilepsy and rare diseases cannot be addressed in isolation, as they are complex challenges requiring a joint, coherent and coordinated European response.

She highlighted the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) and the Global Resolution on Rare Diseases as a unique opportunity to drive progress, stressing that these frameworks must be implemented as complementary and interconnected tools. According to MEP Nevado del Campo, Europe has both the responsibility and the capacity to lead this change, particularly when knowledge, resources and political will are aligned.

Referring to initiatives such as EpiAlliance, she emphasised that multi-stakeholder collaboration is not only desirable but demonstrably effective in delivering tangible improvements for people living with epilepsy and rare diseases. She reaffirmed her team's commitment to ensuring that the outcomes of the day's discussions translate into concrete policy actions that improve patients' lives across all Member States.

The speech concluded with renewed thanks to FEDE, IBE Europe and all contributors, and with a call to continue building a more inclusive, cohesive and fair Europe that places the needs of the most vulnerable at the centre of decision-making.


I. Brambilla
A. Acălinei


Understanding Epilepsy: what it is and how it impacts lives
EU adoption of the IGAP: an opportunity for action
Epilepsy-specific objective within IGAP
Strategic objective 5:
Strengthen the public health approach to epilepsy
Global targets:
World Health Organization
The Global Epilepsy Needs Study
GENS


D. Walsh