International Bureau for Epilepsy

IBE EUROPE

CHAPTER CONVENTION, ROME

12TH-13TH SEPTEMBER 2024

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IBE EUROPE Chapter Convention, Rome

2024

SUMMARY

IBE held its first European Chapter Convention, on September 12th and 13th 2024, at the Hotel Ripa Roma in Rome.

A representative from each of our European chapters was invited to join the two-day workshop

The workshop aimed to build a sense of camaraderie among the European chapters, whilst focussing on identifying and addressing the priority needs of the epilepsy community in Europe. The agenda covered:

- Projects and Programmes
- Policy and Advocacy
- Research and Innovation

Chapters shared best practices; enabling peer exchange and shared learning. Participants engaged in presentations, panel discussions, capacity-building activities, and networking events; returning to their home countries with practical skills, new ideas, and connections.

For IBE, the two day workshop was a chance to better understand each chapter's needs and explore ways to support people with epilepsy across Europe through a collaborative approach; informing future work in the region.

DAY 1

12TH SEPTEMBER
FOCUS ON THE GLOBAL EPILEPSY NEEDS STUDY

Scan QR code to register for GENS updates

The day began with a welcome address from IBE's President, Dr Francesca Sofia and IBE Vice-President for Europe, Elvira Vacas Montero.

IBE's Head of Engagement, Claire Nolan opened the convention's first session by presenting the developing Global Epilepsy Needs Study. Discussions focused on how the results of GENS, once released, could benefit chapters. Participants highlighted how comprehensive, region-specific data from the survey could be used to strengthen advocacy efforts, inform local strategies and enhance policy making.

It was also mentioned how the data has the potential to improve doctor-patient interactions by providing tailored insights into real patient needs, beyond seizures.

Furthermore, the data could also aid in strengthening relationships with key stakeholders - including policymakers; providing evidence to support policy and decision making, research and innovation, and healthcare service planning and delivery.

One challenge that arose was the need for validation of data to ensure accurate representation of needs across non-survey countries.

World Café

The World Café session focused on exploring the unmet everyday needs of people with epilepsy through five key domains identified in the Global Epilepsy Needs Study: Work and Income, Learning and Education, Sexual and Reproductive Health, Mental Health and Wellbeing, and Knowledge, Information, and Advice.
Participants identified key challenges, proposed initiatives, and highlighted where IBE could play a role in driving change.

Work and Income

Participants emphasised the widespread impact of stigma, underemployment, and overprotection on people's ability to work. Gaps in legal awareness and inconsistent application of disability legislation leave many without the protections or accommodations they need. Barriers include driving restrictions, limited vocational opportunities, and insufficient financial support for both PWE and caregivers.

- **Challenges**: Employer stigma, lack of awareness of legal rights, limited accommodations, underemployment, overprotection, and transport restrictions.
- **Initiatives**: Training for employers, healthcare professionals, and PWE; vocational skills programmes; promotion of remote work; free public transport; and sharing stories of successful employment.
- **Role for IBE:** Advocate for EU-level protections, share best practice through the Knowledge Hub, partner with trade unions and disability organisations, and promote "epilepsy-friendly" workplaces.

Learning and Education

Education was highlighted as a foundation for long-term inclusion, but many PWE face bullying, stigma, and a lack of seizure awareness in schools. Parents also carry a heavy burden navigating these challenges.

- **Challenges**: Bullying, exclusion, limited awareness among teachers, and stress on families.
- **Initiatives**: Free seizure-awareness training for teachers, embedding accommodations into school legislation, and promoting inclusive environments.
- **Role for IBE**: Support advocacy for education policies, raise awareness in universities, and develop a specialised education section on the Knowledge Hub.

Sexual and Reproductive Health

Participants identified a wide spectrum of unmet needs in this domain, ranging from contraception and medication risks to intimate conversations and safeguarding. The group also highlighted gaps for parents, transgender individuals, and people with intellectual disabilities.

- **Challenges**: Limited information on drug interactions and hormones, stigma around intimate issues, safeguarding needs, and gaps in guidance for diverse populations.
- **Initiatives**: Expert-led webinars on pregnancy, breastfeeding, and menopause; lactation registers; patient support groups; research collaborations; and use of AI solutions.
- **Role for IBE:** Develop translatable resources and doctor–patient guides, support patient advocacy groups, lobby for broader pharma research, and disseminate GENS findings in this area.

Mental Health and Wellbeing

Mental health emerged as one of the most pressing cross-cutting issues. Participants described a vicious cycle where seizures, stigma, and lack of access to services reinforce poor mental health. Waiting times for care are long, services are scarce, and epilepsy-specific needs are often overlooked.

- **Challenges**: Under-recognition of mental health needs, stigma, poor integration of services, long waiting lists, lack of specialists, and financial barriers.
- **Initiatives**: Embedding social workers in epilepsy units, multidisciplinary care teams, adapted interventions for young people, and peer-support groups. Lessons could be drawn from cancer, MS, and Alzheimer’s pathways.
- **Role for IBE:** Campaign for better services, share best practice across countries, facilitate collaborations with other organisations, support chapters in advocacy, and raise visibility of successful mental health initiatives.

Knowledge, Information, and Advice

Reliable and accessible information was seen as essential but often missing. Participants noted that patients frequently leave diagnosis appointments without clear guidance, leading to misinformation and reliance on the internet. Language barriers, lack of digital records, and funding gaps also complicate access.

- **Challenges**: Inconsistent or absent information at diagnosis, low health literacy, poor digital infrastructure, stigma, and over-reliance on pharma-funded resources.
- **Initiatives**: Use of animations and videos, school-based awareness initiatives, plain-language guidelines, European projects like Epipicto, and accessible national resources such as those in the Netherlands and Spain.
- **Role for IBE**: Promote best practice in resource development, support workshops for health professionals on effective communication, and advocate for “one-stop shop” models of patient information.

KEYNOTE WHO PRESENTATION AND PANEL DISCUSSION

Dr. Neerja Choudhary from the WHO’s brain health unit presented an overview of the global burden of neurological disorders and highlighted the significant treatment gap affecting these conditions. She explained the WHO's Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) 2022-31, detailing its vision, strategic objectives, and proposed actions to address these challenges. A key focus was on building collaboration; with the WHO playing a convening role through NGO meetings, regional workshops, and engagement with people with lived experience, as well as via the Global Clinical Exchange Platform.

During the panel discussion that followed, ideas emerged on how scientific, political, and social shifts can influence epilepsy advocacy. One major insight was how political changes, such as elections, can unexpectedly shift priorities, necessitating more frequent awareness-raising events. Collaboration with other partners from the neurological health sector, particularly on IGAP related initiatives, was recognised as important to boost the visibility of epilepsy, by aligning it with broader neurological issues. Additionally, European activities - such as those coordinated by the European Patients' Forum - can trickle down to impact national-level priorities, ensuring that local needs are addressed by regional policy making.

PANELLISTS

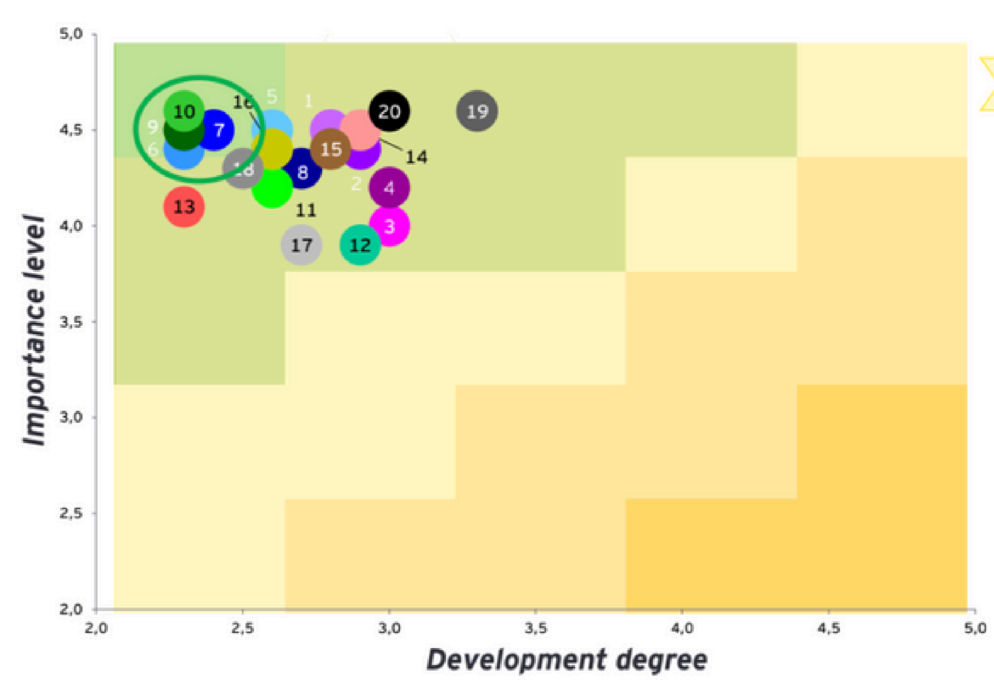
- Prof. Alla Guekht, President Elect, International League Against Epilepsy
- Frederic Destrebecq, Executive Director, European Brain Council
- Dr Orla Galvin, Executive Director, European Federation of Neurological Associations
- Claudia Louati, Head of Policy, European Patients’ Forum
- Barbara Nadine De Gol, Global Patient Advocacy Specialist, Angelini
- Andrea Tomasini, Member, IBE Community Council

PRIORITY-SETTING SESSION

LED BY EY

The rest of the afternoon was led by the consulting team at Ernst and Young [EY]. Their workshop, ‘Epilepsy in Focus: Addressing the Challenges and Enhancing Care Across Europe,’ was an invaluable exercise that used a ‘design thinking approach’.

Participants were asked, initially, to select the top 10 challenges that must be addressed in Europe to improve the lives of people with epilepsy and their caregivers. Afterwards, table discussions took place to plot out actions that could be pursued to support IBE and its European chapters to address these challenges. You can see both the challenges and the proposed lines of action overleaf. An interactive polling exercise was then conducted to map these priorities - as per importance level and ‘development degree’ (see screenshort below).



The outputs of the EY-led workshop will serve as a foundation for IBE-Europe’s new policy advocacy strategy. Working closely with EY, IBE will ensure that the insights from chapters and the communities they represent are embedded in this work, helping to drive forward solutions that reflect real-world needs and priorities.

PRIORITY-SETTING SESSION
CHALLENGES AND LINES OF ACTION

Access to specialised epilepsy care

1. Provide epilepsy education and training to HCPs at primary care level
2. Partner with ILAE to support specialised eduction of general neurologists in epilepsy

Epilepsy stigma

1. Engage in evidence based advocacy and awareness raising
2. Share new scientific data with patients in easy-to-understand ways

Mental health in PWE

1. Ensure alignment of mental and neurological health services (advocate for holistic, integrated care)
2. Produce accessible content for PWE on mental health and epilepsy

Multidisciplinary holistic care

1. Advocate/education to make mental health a core part of epilepsy care
2. Develop a tool to assess and improve knowledge of both PWE and their HCPs

Access to (innovative) treatment

1. Advocate for faster approval and cross-border access to innovative treatments
2. Develop and implement an action plan to address and prevent ASM shortages

Timely access to proper diagnosis

1. Work with ILAE to develop guidelines/best practice care pathways
2. Work with ILAE to establish unified diagnostic protocols across Europe

Digital health

1. Partner with ILAE to develop a centralised platform to list approved wearables and related technologies
2. Create a digital platform to facilitate information sharing/data collection

Provide schools with knowledge on managing children with epilepsy

1. Advocate for, and implement, educational programmes tailored for children with disabilities
2. Train teachers/educators to understand epilepsy

Health literacy

1. Translate and adapt an online informational resource for PWE into multiple languages
2. Work with healthcare professionals to create a platform for sharing information with PWE

Employment opportunities

1. Support chapters in sharing resources related to epilepsy at work
2. Forge partnerships at the European level to address epilepsy at work as part of wider initiatives on disability

DAY 2

13TH SEPTEMBER

On the second day of the convention, the sessions were focused on addressing the unmet needs of people with epilepsy through research and innovation. Professor Matthew Walker kicked off the discussion, highlighting the potential of new technologies, especially data collection methods like wearable devices. He emphasised that while these tools could transform epilepsy care, it's essential for medical professionals to interpret the data effectively.

IDEAS EXCHANGE FORUM

In the Ideas Exchange Forum, the conversations that took place centred on how people with epilepsy can actively participate in research and shape its direction. Examples from different organisations all highlighted the importance of patient involvement in research efforts, driving the agenda from the ground up. The four presentations showcased significant progress in epilepsy research and care, emphasising innovation and patient involvement. For example, Biohaven's new drug candidate, BHV 7000, offers a promising solution for seizure control with fewer side effects, with clinical trials currently underway.

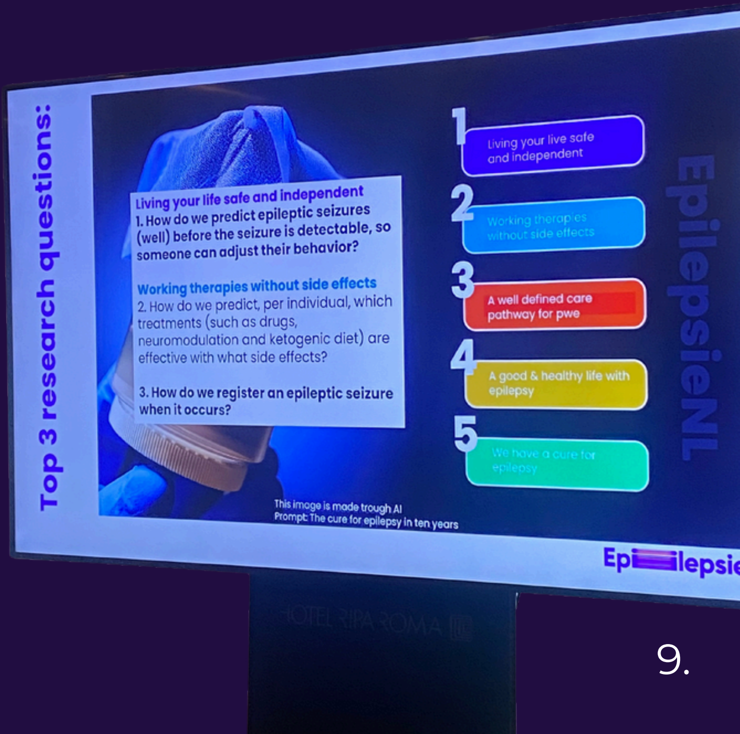
The Epilepsy Research Institute UK highlighted the disparity in epilepsy funding and their efforts to involve the community in shaping research through the SHAPE network. Epilepsy Ireland focused on supporting research that advances understanding and treatment, addressing practical challenges like funding and patient involvement. Finally, EpilepsieNL presented their Seizure Radar 1.0 for reliable seizure monitoring, along with efforts to prevent deaths from SUDEP and provide personalised care tools, marking a collaborative and patient-centred future for epilepsy care.

- The panel discussion will featured the following speakers:
- *Professor Matthew Walker*
- *Francesca Sofia, IBE president*
- *Dzenana Rustempasic, IBE Community Council member*
- *Frederic Destrebecq, European Brain Council executive*
- *Rosemarie Pardington, Chief Executive of the Epilepsy Research Institute*
- *Lisa Moore-Ramdin, Jazz pharmaceuticals*
- *Andrea L. Wilkinson, UCB.*

The conversation highlighted key obstacles in epilepsy research: limited funding, a lack of innovation in clinical trials, and difficulties in bringing treatments to patients, especially in lower-income areas.

Collaboration emerged as a crucial solution, with multi-stakeholder engagement; patients, industry, government, and healthcare professionals, being vital for progress. One of the challenges identified was the need for more comprehensive care pathways that integrate epilepsy care with other neurological conditions.

The discussions also touched on the rising costs of new treatments and the barriers to access across different regions in Europe. Industry representatives discussed ongoing efforts to work with regulators and build sustainable relationships with the patient community, emphasising the importance of clinical trial engagement and ensuring that new innovations can reach the people who need them.


Top 3 research questions:

Living your life safe and independent
1. How do we predict epileptic seizures (well) before the seizure is detectable, so someone can adjust their behavior?

Working therapies without side effects
2. How do we predict, per individual, which treatments (such as drugs, neuromodulation and ketogenic diet) are effective with what side effects?

3. How do we register an epileptic seizure when it occurs?

1 Living your live safe and independent
2 Working therapies without side effects
3 A well defined care pathway for pwe
4 A good & healthy life with epilepsy
5 We have a cure for epilepsy

This image is made trough AI
Prompt: The cure for epilepsy in ten years

FINAL REMARKS AND FEEDBACK

Throughout the two days, collaboration and the perspectives of those with lived experience were repeatedly emphasised as essential for change. The day closed with a collective reflection on the need to continue raising awareness and building networks to advance epilepsy care across Europe. Feedback from the convention was overwhelmingly positive, highlighting how people left with a sense of optimism, inspired by the shared ideas, future collaboration opportunities, and the palpable desire to make a difference for people living with epilepsy.

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