Health and Global Policy Institute Mental Health Project

Belgium Pavilion Special Seminar, Expo 2025 Osaka, Kansai

"Rising to New Challenges in Health Sciences for Future Society: Novel Developments in the Field of Epilepsy in Japan and Globally"

September 18, 2025

Event Report

HGPI Health and Global Policy Institute

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Chapter 1: Background and Overview

Background and Purpose

Epilepsy is one of the most common neurological disorders, yet challenges remain in achieving accurate diagnosis and equitable access to treatment across regions. Globally, social stigma and a lack of accurate information continue to hinder treatment, resulting in a serious public health issue known as the “treatment gap.” Furthermore, people living with epilepsy are not only confronted with health-related challenges but also broader socio-economic difficulties, such as psychological issues, restrictions in daily life, and limited employment opportunities.

Against this backdrop, Health and Global Policy Institute (HGPI) organized a special seminar titled “Rising to New Challenges in Health Sciences for Future Society: Novel Developments in the Field of Epilepsy in Japan and Globally” at the Belgium Pavilion, Expo 2025 Osaka, Kansai.

This seminar placed particular emphasis on “placing the voices of people with lived experience at the center” and facilitated a multifaceted dialogue on the future of neurological disease treatment and support, drawing on insights from experts and policymakers. Through this event, HGPI aimed to deepen public understanding of epilepsy and other neurological disorders and to contribute to the creation of better environments for treatment and support.

Event Overview

■ Date & Time: Thursday, September 18, 2025; 13:00-15:00 JST
■ Format: In-person event with online streaming
■ Venue: Belgium Pavilion, Expo 2025 Osaka, Kansa
■ Language: Japanese / English (English available for online streaming)
■ Host: Health and Global Policy Institute (HGPI)
■ Sponsors: UCB Japan Co. Ltd., LivaNova Japan K. K.
■ Cooperation: Belgian Commission General for International Exhibitions

Program (Titles omitted, no particular order)

13:00-13:05 Explanatory introduction and Greetings from Hosts

13:05-13:35 Keynote Lecture

"Considering the Past and Future of Epilepsy Treatment from a Global Perspective"

Kensuke Kawai (Professor & Director, Department of Neurosurgery,
Jichi Medical University/ President, The Japan Epilepsy Society)

13:40-14:40 Panel Discussion

"Issues and Solutions for Epilepsy Treatment from the Perspectives of People Living with Epilepsy"

Panelists

Ogasawara Otoya (People living with epilepsy)
Kensuke Kawai (Professor & Director, Department of Neurosurgery,
Jichi Medical University/ President, The Japan Epilepsy Society)
Mika Sasabuchi (Executive Director for Health and Welfare, Nagano Prefecture)
Yohei Ohashi (Head of Medical Affairs Japan / UCB Japan Co. Ltd.)

Moderator

Shu Suzuki (Senior Associate, Health and Global Policy Institute)

14:40-15:00 Q&A

Chapter 2: Keynote Lecture

“Considering the Past and Future of Epilepsy Treatment from a Global Perspective”

Kensuke Kawai (Professor & Director, Department of Neurosurgery,
Jichi Medical University/ President, The Japan Epilepsy Society)

Definition, Classification, and Epidemiology of Epilepsy

■ What is Epilepsy

Epilepsy is a chronic brain disorder characterized by recurrent seizures caused by sudden, excessive electrical discharges in groups of brain nerve cells[i]. According to the World Health Organization (WHO), epilepsy is one of the most common neurological disorders, affecting approximately 50 million people worldwide.[ii]

People living with epilepsy not only experience recurrent seizures but are also more susceptible to neurobiological, cognitive, psychological, and social consequences, as well as an increased risk of premature mortality. The condition can develop in individuals of any age, sex, or ethnicity, meaning that anyone can be affected by epilepsy.

■ Classification of Epilepsy

Epileptic seizures are primarily classified into focal seizures and generalized seizures. Focal seizures occur when a specific region of the cerebrum becomes overactive, and the symptoms vary depending on the affected region, such as convulsions, visual disturbances, or palpitations. Some focal seizures are mild and may go unnoticed. In contrast, generalized seizures involve the entire cerebrum from the onset and are often accompanied by loss of consciousness and generalized convulsions. When a seizure does not fall into either category, and the site of onset cannot be identified, it is classified as an unknown onset seizure.

In addition to the classification of seizures, clinicians also classify epilepsy as a disease (syndromic or etiological classification). This classification is important for diagnosing epilepsy, selecting appropriate medications, determining the method of surgery, and assessing the overall prognosis.

Based on the type of seizure and findings from clinical examinations and diagnostic tests, epilepsy is categorized into four groups: focal epilepsy (partial epilepsy), generalized epilepsy, combined generalized and focal epilepsy, and unknown epilepsy. The classification is made comprehensively, taking into account seizure characteristics, age of onset, and underlying causes, such as genetic, structural, metabolic, immune, or infectious factors.

When necessary, an epilepsy syndrome[1] is diagnosed. Identifying a specific syndrome helps to predict the prognosis, the most effective treatment options, and the likelihood of recurrence.

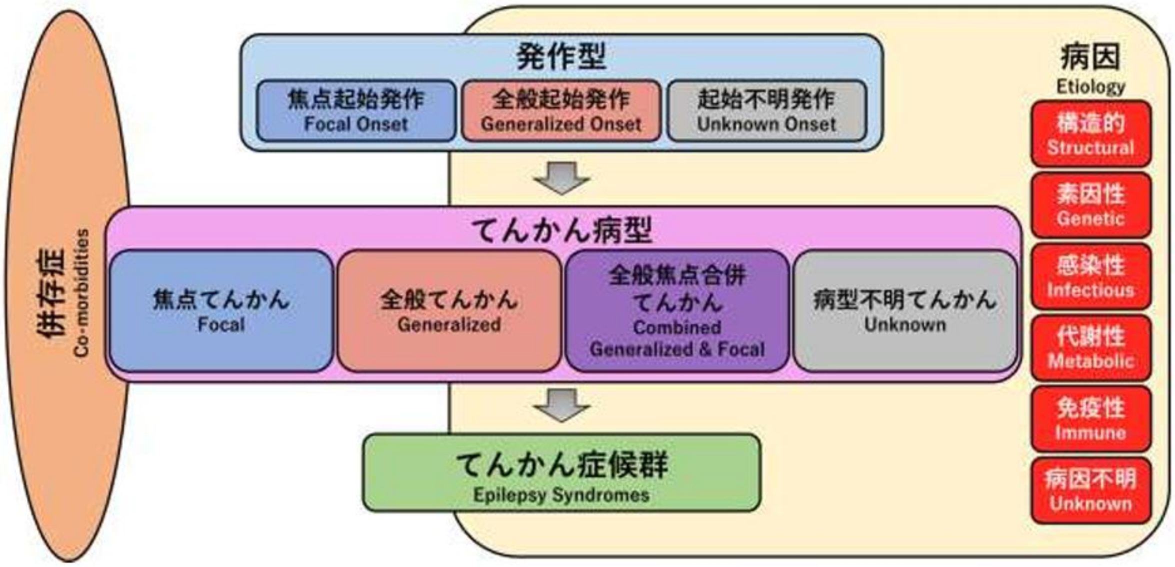

Figure 1. Framework of Epilepsy Classification[iii]
（Epilepsia. 2017 Mar 8;58(4):512–521. doi: 10.1111/epi.13709）

■ Epidemiology

In Japan, the prevalence of epilepsy is estimated to be between 0.5% and 1%, meaning that approximately one in every 100 people is affected[iv], making it a relatively common disorder. In childhood, congenital factors are the main causes, while in older adults, acquired factors such as stroke, brain tumors, and Alzheimer’s disease are often involved in its onset.

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[1] An epilepsy syndrome refers to a condition in which patients who share common features, such as seizure symptoms, EEG findings, neuroimaging results, and developmental characteristics, are grouped together into a single diagnostic category.

Examination, Diagnosis, and Treatment of Epilepsy

■ Process of Clinical Examination and Diagnosis

The clinical management of epilepsy begins with the recognition of episodes of seizures. In medical institutions, a detailed medical interview and physical examination are conducted, followed by essential tests such as an electroencephalogram (EEG) and magnetic resonance imaging (MRI). In most cases, a diagnosis is made by integrating the results of these examinations with clinical findings, and treatment is initiated at that stage.

Treatment is typically initiated with the administration of anti-seizure medication. At this stage, in addition to appropriate pharmacological therapy, providing an explanation of the condition and offering lifestyle guidance, including medication management, sleep, driving, and pregnancy, are key features of epilepsy care and treatment, and represent essential elements of effective management.

■ Diagnostic Criteria

The WHO defines epilepsy as “chronic disorder of the brain characterized by recurrent seizures” due to excessive electrical discharges in cerebral neurons[v]. Seeing as this definition included the element of “recurrence,” it was traditionally understood that epilepsy should not be diagnosed, nor treatment initiated, until a patient had experienced at least two seizures.

However, about ten years ago, the International League Against Epilepsy (ILAE) proposed a more practical definition [vi] . According to this updated definition, epilepsy can be diagnosed even after a single seizure if any of the following criteria are met.

Table 1. Diagnostic Criteria for Epilepsy Based on the ILAE Definition

Cases in Which Epilepsy Can Be Diagnosed	Description
1. Recurrent seizures	Two or more unprovoked seizures occurring more than 24 hours apart.
2. High risk of recurrence	A single unprovoked seizure when the probability of further seizures within the next 10 years is estimated to be at least 60%, based on abnormal EEG or neuroimaging findings.
3. Diagnosis of an epilepsy syndrome	When a specific epilepsy syndrome, such as childhood absence epilepsy, is identified.

With this revision, it became formally accepted that epilepsy can be diagnosed and pharmacological treatment initiated even after a single seizure, if EEG or imaging results, or clinical characteristics, suggest the presence of an epilepsy syndrome.

■ Challenges in Diagnosis

The main reason why the diagnosis of epilepsy is often difficult lies in the uncertainty accompanying understanding seizure symptoms and interpreting test results. Specifically, the factors that make diagnosis challenging can be broadly divided into four categories.

Table 2. Major Factors That Make the Diagnosis of Epilepsy Difficult

Factors	Overview
1. Seizure symptoms are mainly based on second-hand information	Seizures are rarely observed directly in clinical settings and are often assessed based on reports from the patient or family members. As a result, it is difficult to objectively reproduce symptoms, and factors such as memory inaccuracies or subjective interpretations may affect the diagnosis.
2. EEG is performed during rest, not during seizures	Although EEG is an important diagnostic test, it is usually recorded when no seizure is occurring. Therefore, it is often impossible to capture seizure activity directly, and normal EEG findings do not necessarily indicate the absence of epilepsy.
3. EEG abnormalities exist on a spectrum rather than a simple normal–abnormal dichotomy	EEG findings often cannot be clearly categorized as normal or abnormal, sometimes showing borderline or non-specific changes. Their interpretation requires specialist expertise, and there is also a risk of overdiagnosis or underdiagnosis.
4. MRI findings do not always correlate with seizure activity	Even if structural abnormalities are found on MRI, they are not always the cause of seizures, and conversely, epilepsy can exist even when no visible lesion or abnormality is present.

Because of the diagnostic limitations described above, misdiagnosis can occur in both directions; non-epileptic seizures may be mistaken for epilepsy, or epilepsy may be mistaken for non-epileptic seizures.

■ Impact of Misdiagnosis and Measures for Prevention

Misdiagnosis can have serious consequences for patients’ daily lives and social activities. In the past, there have been cases in which syncope (a temporary loss of consciousness caused by hypotension or heart disease) was misdiagnosed as epilepsy, resulting in the unnecessary administration of anti-seizure medications with teratogenic effects and even restrictions on pregnancy or driving.

In addition, late-onset epilepsy, which often responds well to anti-seizure medications, has sometimes been misdiagnosed as dementia, leading to delayed treatment.

Such misdiagnoses can significantly affect patients' quality of life and social participation. Therefore, when epilepsy is suspected, it is recommended that patients consult an epilepsy specialist as soon as possible and at an early stage. Furthermore, long-term video EEG monitoring, which records both brainwave changes and clinical symptoms during seizures, is an effective method to improve diagnostic accuracy.

■ Treatment

The Japan Epilepsy Society[2]'s treatment guidelines are revised approximately every ten years, and standard epilepsy care in Japan is provided in accordance with these guidelines.

• General Treatment of Epilepsy

The cornerstone of epilepsy treatment is pharmacotherapy with anti-seizure medications. These drugs operate by suppressing abnormal excitation and synchronization of neurons, thereby reducing the likelihood of seizures and preventing recurrence. However, there is currently no medication that can cure epilepsy itself. A complete cure is only possible in cases where a clearly defined seizure focus can be surgically removed.

The choice of anti-seizure medications is guided by the classification of epilepsy and seizure type, with first-line drugs[3] specified in the guidelines. Standard treatment is therefore provided based on these recommendations. When initiating anti-seizure medications therapy, it is important for patients to receive counselling on medication adherence, lifestyle management (including driving), and pregnancy. With the appropriate drug used at the correct dosage, seizure control can be achieved in approximately 70–80% of patients.

Newer anti-seizure medications offer seizure control that is comparable or slightly superior to that of traditional drugs, but with fewer side effects and drug interactions, making them safer and easier to use. Consequently, their use is increasingly common among specialists. However, in general medical settings, knowledge and experience regarding these newer drugs remain limited, highlighting the need for better dissemination of medical specialist information and training for healthcare professionals.

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[2] https://jes-jp.org/en/

[3] It refers to a medication that offers the best balance of efficacy and safety for a specific disease or seizure type and is recommended as the initial treatment option.
In epilepsy, first-line drugs are determined according to the classification of seizures (such as focal or generalized seizures) and the type of epilepsy syndrome, and are selected based on the guidelines of the Japan Epilepsy Society.

- **Treatment for Drug-Resistant Epilepsy**

When seizures cannot be adequately controlled with pharmacotherapy, the condition is referred to as drug-resistant epilepsy. In such cases, non-pharmacological treatments such as surgical intervention or neurostimulation therapy are considered. These approaches aim to reduce or eliminate seizures by directly removing or modulating the brain regions responsible for seizure generation.

Table 3. Representative Treatments for Drug-Resistant Epilepsy

Treatment Method	Overview	Objective
1. **Craniotomy (focal resection surgery)**	The abnormal area of the brain that causes seizures is surgically removed.	Cure
2. **Craniotomy (palliative surgery)**	When resection is difficult, procedures such as corpus callosotomy are performed to reduce the severity of seizures.	Reduction of seizures
3. **Electrical stimulation therapy (neuromodulation therapy)**	Devices such as Vagus Nerve Stimulation (VNS), Deep Brain Stimulation (DBS), Responsive Neurostimulation (RNS) are implanted to suppress seizures.	Reduction of seizures
4. **Dietary therapy (ketogenic diet, etc.)**	A high-fat, low-carbohydrate diet alters brain metabolism to help prevent seizures.	Reduction of seizures
5. **Investigational drug use**	Use of investigational drugs undergoing clinical evaluation for potential seizure reduction.	Reduction of seizures

In Japan, the introduction of new neurostimulation devices faces challenges from both regulatory and economic perspectives. In the past, the approval of Vagus Nerve Stimulation (VNS) therapy took considerable time, resulting in its clinical adoption more than ten years later than in Europe and the United States. Although the approval process has since been accelerated, significant barriers remain, including the high cost of devices, currency fluctuations, and adjustments to reimbursement prices under the national health insurance system.

These circumstances make it difficult for companies to ensure profitability in the Japanese market, creating a structural challenge that hinders the introduction of cutting-edge medical devices. Moreover, Japan’s overall economic stagnation has also become one of the factors impeding the widespread adoption of innovative medical technologies.

Epilepsy and Society

■ Main Public Support Systems for Epilepsy

In Japan, epilepsy is administratively classified as a mental disorder[4]. For adults, support systems such as the Medical System for Services and Supports for Persons with Disabilities and disability pensions are available. In contrast, for children, medical and welfare program tailored to developmental stages, such as the Specified Chronic Pediatric Diseases system and the Rehabilitation Handbook, are applicable.

Table 4. Main Administrative Support Systems for Epilepsy

Category	Main Public Support Systems
Adults with Epilepsy	1. Medical System for Services and Supports for Persons with Disabilities (Mental Outpatient Care) 2. System of Certification for Persons with Disabilities 3. Disability Pension (for mental disorders)
Children with Epilepsy and Related Disorders	1. Research Project on Treatment of Chronic Pediatric Specific Diseases 2. Rehabilitation Handbook 3. Special Child Rearing Allowance / Child Disability Welfare Allowance

■ Social Issues Surrounding Epilepsy

Epilepsy remains strongly associated with stigma rooted in prejudice and discrimination. As a result, despite the availability of effective treatments, some patients are still unable to access appropriate care, leading to a treatment gap that contributes to regional disparities both within Japan and globally.

In addition, under Japanese law, individuals with epilepsy are allowed to obtain a driver’s license only after remaining seizure-free for two years. However, some experts have pointed out that this requirement may be overly strict compared with regulations in other developed countries.

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[4] It is classified as a neurological disorder by the WHO.

Epilepsy Organizations

The main organizations involved in epilepsy care in Japan can be categorized into four groups: academic societies, patient and advocacy organizations, councils of specialized centers, and government-affiliated bodies implementing epilepsy-related programs. These organizations work collaboratively while maintaining distinct roles and responsibilities.

Table 5. Organizations Related to Epilepsy in Japan

Organization	Role	Details of Activities
Japan Epilepsy Society (JES)	**Ensuring Quality of Care**	Promotes academic advancement and publishes clinical guidelines and terminology glossaries. Ensures the quality of advanced epilepsy care through the certification of epilepsy specialists, training facilities, and comprehensive epilepsy centers. A member of the ILAE. As of September 2025, the Society has 3,168 members.
Japan Epilepsy Association	**Public Awareness**	A patient and family association that promotes public understanding of epilepsy, engages in social support activities, and advocates for enhanced policy measures. Serves as the Japan branch of the International Bureau for Epilepsy (IBE). Approximately 5,000 members (25% people living with epilepsy, 55% family members)[vii].
Ministry of Health, Labor and Welfare (MHLW)	**Access to Care**	Promotes the development of regional collaborative care systems for epilepsy through the "Epilepsy Regional Healthcare Collaboration System Improvement Project" aiming to improve the quality of care provided by non-specialist physicians (broadening the base of care provision).
Japan Epilepsy Center Association (JEPICA)	**Education for Co-medical Professionals**	Provides training opportunities for healthcare professionals other than physicians (e.g., nurses, psychologists).

National and Global Policies

■ Global Policy

Internationally, in 1997, the WHO, the ILAE, and the IBE jointly launched the "Out of the Shadows" campaign[viii], aiming to eliminate discrimination and prejudice against people living with epilepsy.

Subsequently, in 2015, the World Health Assembly (WHA) adopted a resolution calling for the reduction of disparities in access to epilepsy treatment — the so-called "treatment gap" — further strengthening global efforts in this field[ix].

In 2022, the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) [x]was adopted.

IGAP sets international targets to be achieved by 2031, including:

- All Member States to increase service coverage for epilepsy by 50% compared to 2021 levels;
- 80% of Member States to develop or update legislation protecting the human rights of people living with epilepsy; and
- Achievement of the "90-80-70 Cascade Target for Epilepsy," which aims to expand diagnosis, treatment, and follow-up coverage globally.

Table 6. 90-80-70 Cascade Target (IGAP 2022–2031)

Indicators	Target	Description
90%	90% of people living with epilepsy are aware that epilepsy is a treatable condition.	Promote correct understanding by raising awareness and reinforcing medical education.
80%	80% of people living with epilepsy have access to affordable, safe, and appropriate antiseizure medication.	Improve access to and knowledge of medical care and reduce financial barriers.
70%	70% of those receiving treatment achieve adequate seizure control.	Enhance the quality of treatment and ensure continuity of care.

■ Japan's Policy

In Japan, the Ministry of Health, Labour and Welfare (MHLW) launched Epilepsy Regional Healthcare Collaboration System Improvement Project[xi]in 2015 as a model initiative. This project aims to establish regional medical collaboration networks and promote awareness activities, with designated Epilepsy Support Core Hospitals in each prefecture serving as central hubs. At present, there are approximately 30 such core hospitals nationwide (As of July 2025)[xii], and the initiative and its outcomes have been recognized internationally.

Future Prospects

At the International Epilepsy Congress 2025, held in Lisbon, Patient and Public Involvement (PPI) was highlighted as a central theme.
During the Presidential Symposium titled “Patient-centered healthcare: from challenge to change,” the Presidents of the ILAE and the IBE co-chaired the session, which featured many patient speakers. The symposium showcased a new model of medical practice and research based on collaboration between patients and professionals.
Looking ahead, in line with the WHO’s Intersectoral Global Action Plan (IGAP, 2022–2031) and the ILAE’s strategic direction, key priorities will include:

1. Strengthening policy leadership
2. Promoting patient participation in education and research
3. Expanding international collaboration

Furthermore, it is becoming increasingly important to redefine outcomes that truly matter to patients, not only seizure control, but also aspects, such as minimizing side effects from medication, employment opportunities, and driving eligibility.

In Japan as well, the future of epilepsy care must be built on the principles of patient participation and social inclusion. By involving people with lived experience at every stage, from healthcare delivery to education, research, and policymaking, the realization of genuine patient-centered epilepsy care will be the result.

Chapter 3: Panel Discussion

“Challenges and Solutions in Epilepsy Treatment from the Patient’s Perspective”

Perspective 1: Raising Awareness to Eliminate Stigma and Improve Access to Appropriate Treatment

■ Initiatives to Promote Accurate Information and Understanding

Epilepsy is a neurological disorder that affects approximately one in every hundred people in Japan (prevalence rate of 0.5–1%) and can occur across all age groups. While seizures often serve as the first sign of diagnosis, many forms of epilepsy are difficult to detect. Misinformation and biased narratives can foster discrimination and stigma. It is therefore essential to promote accurate understanding and awareness among the general public, regardless of whether they are directly affected.

Local governments, with their well-established regional communication networks, are well positioned to disseminate targeted information through various channels. For instance, websites and social media platforms are effective for younger and child-rearing generations, while prefectural or municipal newsletters may be more suitable for older populations. Beyond one-way dissemination, participatory initiatives such as public and community events, such as Purple Day, lectures by specialists and people with lived experience, and educational outreach programs for schools and workplaces can deepen understanding and empathy within communities.

■ Dissemination of Information to Healthcare Professionals to Enhance Access to Accurate Diagnosis

Information for healthcare professionals is mainly delivered through networks built by academic societies and pharmaceutical companies, which enables relatively effective communication with epilepsy specialists. However, general practitioners, such as doctors working in local clinics, often have limited access to the latest findings and information on new antiepileptic drugs. Consequently, some continue to prescribe conventional first-generation medications even after the introduction of second-generation medication resulting in disparities in diagnosis and treatment, and ultimately affecting patients’ access to appropriate care.

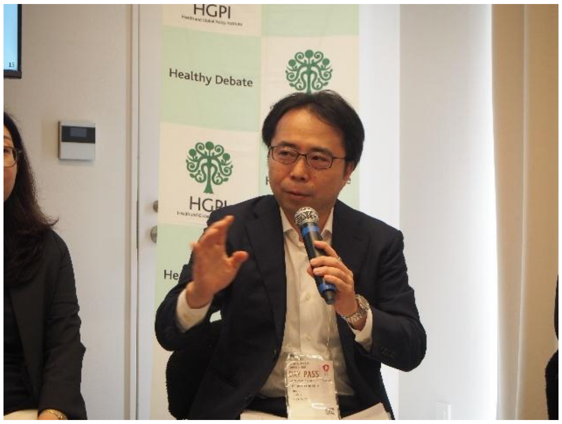
■ Future Directions

Although the combined efforts of various stakeholders have led to progress in epilepsy awareness and information dissemination, it remains challenging to reach populations with little interest or knowledge of the condition. Going forward, it will be crucial for patients, local governments, healthcare professionals, and private companies to collaborate and explore more effective communication strategies.

From an educational standpoint, early awareness from childhood is vital. Some municipalities have already begun implementing teacher training programs through collaboration between boards of education and regional epilepsy hub hospitals[xiii][xiv]. For broader public outreach, leveraging the influence of the media should also be considered.

Improving access to accurate diagnosis is another urgent challenge, especially in rural areas. In rural areas, the limited number of facilities capable of treating adult epilepsy has led to cases being managed in pediatric departments. As Japan's population continues to age, it will also be important to strengthen systems for the accurate epilepsy diagnosis in older adults, who are often misdiagnosed with dementia, and to develop appropriate strategies to raise public awareness.

Finally, the classification of epilepsy warrants review. Internationally, epilepsy is categorized as a neurological disorder, whereas in Japan, it has long been treated under the administrative framework of psychiatry. This discrepancy may influence both societal perceptions (stigma) and policy discussions. Analyzing the implications of this difference and reconsidering epilepsy's institutional position will be an important task for the future.



Perspective 2: Improving Access to Treatment

■ The Crucial Role of Epilepsy Support Hub Hospitals and the Challenges of Sustaining Them

The “Project for the Development of Regional Epilepsy Care Networks” was launched in fiscal year 2015, and as of July 2025[xv], 30 epilepsy support hub hospitals (hereinafter, “hub hospitals”) have been established nationwide. These hospitals serve not only as central institutions for regional epilepsy care but also as key platforms for promoting collaboration among professionals and stakeholders from multiple sectors.

However, maintaining these systems remains challenging. National government funding for the project covers only about half of the required costs, leaving each prefecture responsible for securing the remaining half. Consequently, some municipalities, constrained by limited budgets, have yet to establish hub hospitals. Moreover, hub hospitals must recruit and retain personnel and conduct programs within restricted budgets. Given the current levels of medical reimbursement and project subsidies, it is difficult to ensure comprehensive patient care, including medical, psychological, and social support, and to carry out ongoing activities that strengthen regional healthcare systems.

■ The Importance of Workforce Development and Clinical Guidelines

Regional and inter-specialty disparities in physician distribution remain a major issue in Japan’s healthcare system. In epilepsy care, progress often depends on the voluntary commitment of a small number of dedicated physicians. In rural regions, the shortage of epilepsy specialists makes it difficult for patients to obtain second opinions. Furthermore, a lack of understanding among physicians regarding the social challenges faced by patients has been cited as a factor behind the barriers to obtaining disability certification. Structural challenges, such as insufficient funding for research and training, and a shortage of professionals qualified to train others, also hinder the development of specialized human resources.

To address these disparities, the regular updating and dissemination of clinical guidelines by the Japan Epilepsy Society play a pivotal role. Such guidelines help reduce knowledge gaps among physicians and promote the standardization of care nationwide. Pharmaceutical companies, leveraging their networks, contribute by promoting awareness of new medications and facilitating the understanding of these guidelines.

In addition, inter-hospital collaboration for workforce development is gradually expanding. For example, well-equipped hub hospitals are beginning to train healthcare professionals dispatched from other prefectures through “horizontal cooperation” frameworks designed to strengthen capacity across regions.

■ Future Challenges

Owing to regional depopulation and the uneven distribution of physicians, the need for telemedicine, such as online consultations, has grown rapidly across Japan. In epilepsy care, telemedicine providing online consultations with a specialist has been introduced as a means of addressing regional disparities. At present, however, it is used mainly for second opinions, and reimbursement rates remain lower than those for in-person consultations.

With population decline and the need to ensure the sustainability of healthcare delivery systems, the consolidation of medical functions is expected to progress, increasing the importance of telemedicine. While face-to-face consultation remains essential in the initial stages of diagnosis, online consultations can be effectively used for follow-up care in stable patients and for the adjustment of VNS devices, offering improved convenience and continuity for both physicians and patients.

Perspective 3: Institutional and Policy Challenges

■ The Need to Strengthen the Drug Development Ecosystem

Japan is gradually losing its international competitiveness as a hub for pharmaceutical research and development. Moreover, as a result of prolonged healthcare cost containment policies, the suspension of domestic clinical development investment has led to the emergence of "drug loss" and "drug lag", which are situations where new medicines available for prescription overseas cannot be used domestically, or where their development and introduction into the national health insurance reimbursement system are delayed.

In the case of medicines targeting rare forms of epilepsy, small patient populations dispersed across the country make it difficult to recruit sufficient participants for clinical trials, leading to rising development costs. To address this situation, the establishment of unified national disease registries, or larger-scale registries encompassing patient data from Southeast Asian countries, should be considered to facilitate clinical research and accelerate drug development.

■ Designing Systems to Support Employment for People living with epilepsy

In order to promote the employment of people living with epilepsy, Japan's legal employment quota system obliges employers to hire a certain proportion of people with disabilities. Individuals with epilepsy who hold a Mental Disability Certificate are eligible under this system.

In addition to ensuring employment opportunities, it is crucial to design and implement systems that enable employers to understand and provide reasonable accommodation throughout the course of employment. Since April 2024, all companies in Japan have been legally required to provide reasonable accommodation for employees with disabilities, strengthening the legal foundation for workplace inclusion.

Nevertheless, challenges remain, particularly the fact that small and medium-sized enterprises are only under a "best-effort" obligation, and that sufficient mechanisms are not yet in place to help employers understand and implement appropriately.

Germany, for example, has developed guidelines that clearly specify the standards for reasonable employment based on the type and frequency of seizures[xvi]. These include detailed recommendations on conditions for operating forklifts, working with electrical equipment, and performing solitary tasks involving direct contact with people. In Japan, it will be important to draw on such international examples while considering domestic employment realities, and to explore improvements and applications of existing systems accordingly.

Patient and Public Involvement (PPI)

There is growing recognition of the importance of Patient and Public Involvement (PPI) in designing better healthcare delivery systems. The International League Against Epilepsy (ILAE) has also identified PPI as one of its key priorities in recent years.

In Japan, while there are some instances of patient organizations participating in national advisory councils, opportunities to discuss PPI as a central topic within academic societies remain limited. Moving forward, it will be essential to promote PPI more actively within the field of epilepsy through patient involvement in academic activities, the development of clinical guidelines, and other collaborative initiatives.

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[i] https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/0000070789_00008.html

[ii] https://japan-who.or.jp/factsheets/factsheets_type/epilepsy/

[iii] https://pubmed.ncbi.nlm.nih.gov/28276062/

[iv] https://epilepsy-center.ncnp.go.jp/pdf/230723_document2_01.pdf

[v] https://iris.who.int/server/api/core/bitstreams/6b0554df-ddbe-4716-a7d7-4a3ec6f0e85a/content

[vi] https://pubmed.ncbi.nlm.nih.gov/24730690/

[vii] https://www.jea-net.jp/jea/organization

[viii] https://www.ilae.org/about-ilae/public-policy-and-advocacy/global-campaign-against-epilepsy

[ix] https://pubmed.ncbi.nlm.nih.gov/26391429/

[x] https://www.who.int/publications/i/item/9789240076624

[xi] https://epilepsy-center.ncnp.go.jp/about.html

[xii] https://epilepsy-center.ncnp.go.jp/pdf/250727_document2_04.pdf

[xiii] https://epilepsy-center.ncnp.go.jp/pdf/report_r4_04.pdf

[xiv] https://www.saitama.med.or.jp/kanri/output.php?file=news.43.1.pdf&org=chirashi.pdf

[xv] https://epilepsy-center.ncnp.go.jp/pdf/250727_document2_04.pdf

[xvi] https://publikationen.dguv.de/widgets/pdf/download/article/345

Health and Global Policy Institute: Guidelines on Grants and Contributions

As an independent, non-profit, non-partisan private think tank, HGPI complies with the following guidelines relating to the receipt of grants and contributions.

1. Approval of Mission

The mission of HGPI is to achieve citizen-centered health policy by bringing stakeholders together as an independent think-tank. The activities of the Institute are supported by organizations and individuals who are in agreement with this mission.

2. Political Neutrality

HGPI is a private, non-profit corporation independent of the government. Moreover, we receive no support from any political party or other organization whose primary purpose is political activity of any nature.

3. Independence of Project Planning and Implementation

HGPI makes independent decisions on the course and content of its projects after gathering the opinions of a broad diversity of interested parties. The opinions of benefactors are solicited, but the Institute exercises independent judgment in determining whether any such opinions are reflected in its activities.

4. Diverse Sources of Funding

In order to secure its independence and neutrality, HGPI will seek to procure the funding necessary for its operation from a broad diversity of foundations, corporations, individuals, and other such sources. Moreover, as a general rule, funding for specific divisions and activities of the Institute will also be sought from multiple sources.

5. Exclusion of Promotional Activity

HGPI will not partake in any activity of which the primary objective is to promote or raise the image or awareness of the products, services or other such like of its benefactors.

6. Written Agreement

Submission of this document will be taken to represent the benefactor’s written agreement with HGPI’s compliance with the above guidelines.

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Acknowledgement

This report has been prepared based on the discussions held at the special seminar "Rising to New Challenges in Health Sciences for Future Society: Novel Developments in the Field of Epilepsy in Japan and Globally", organized as part of HGPI's Mental Health Project at the Belgium Pavilion of the Expo 2025 Osaka, Kansai. We would like to express our deepest gratitude to all speakers and to everyone who contributed to the organization of this seminar.

Regarding the independent nature of these recommendations

These policy recommendations are based on discussions at meetings HGPI held for this project and has been compiled in HGPI's capacity as an independent health policy think-tank. It does not, in any capacity, represent the opinions of any participating expert, speaker, related party, or organization to which those parties are affiliated.

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Health and Global Policy Institute (HGPI) is a non-profit, independent, non-partisan health policy think tank established in 2004. In its capacity as a neutral think-tank, HGPI involves stakeholders from wide-ranging fields of expertise to provide policy options to the public to successfully create citizen-focused healthcare policies. Looking to the future, HGPI produces novel ideas and values from a standpoint that offers a wide perspective. It aims to realize a healthy and fair society while holding fast to its independence to avoid being bound to the specific interests of political parties and other organizations. HGPI intends for its policy options to be effective not only in Japan, but also in the wider world, and in this vein the institute will continue to be very active in creating policies for resolving global health challenges. HGPI's activities have received global recognition.

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