

Japanese Declaration on Epilepsy

September 30, 2013

The Japan Epilepsy Society
Japan Epilepsy Association

Epilepsy is a well known disease from ancient times. Yet, even today, people with epilepsy still have many problems in their lives. Over the years, Japan Epilepsy Association and Japan Epilepsy Society have been working together to help people with epilepsy overcome these problems. Joint meetings have been held since 2010 to encourage close liaison. At the 8th joint meeting held on September 1, 2013, the following Declaration on Epilepsy was adopted.

We declare October of each year to be a special month to focus on epilepsy in Japan.

We proclaim the following:

To solve global issues of epilepsy, all people related to health care, organizations and policy making should

- Place epilepsy as a top priority in medical policy.
- Establish a medical system for epilepsy and ensure that people with epilepsy have access to modern and appropriate medical and health care.
- Promote social integration and eliminate discrimination against epilepsy in all spheres of life, especially concerning work, school and mobility.
- Encourage educational activities for the public to understand epilepsy and thereby reduce stigma and prejudice.
- Provide professionals and volunteers in the fields of health care, education, and employment with appropriate training on epilepsy.
- Introduce appropriate legislation to protect the rights of all people with epilepsy.
- Support and promote basic, clinical, psychological and social research on epilepsy in all areas including medicine, education, health and welfare, and employment.

Additional statements for proper understanding of epilepsy:

- Epilepsy is one of the most common brain disorders, estimated to affect one million people in Japan, with 50 thousand being diagnosed annually.
- Epilepsy occurs in all ages irrespective of gender, and is especially common among infants and the elderly.

- Epilepsy is a chronic disease that requires long-term treatment and care.
- The outlook of epilepsy varies, some persons become seizure-free while others may become resistant to treatment, with or without accompanying diseases.
- Although 70 to 80% of people with epilepsy may become seizure-free with appropriate treatment, many people do not receive such treatment due to inadequate health care system.
- Epilepsy can have serious physical, psychological, social and economic consequences for the afflicted and their families, but adequate measures against such consequences are largely lacking:
 - Physical consequences include risk of injury, fracture, and death.
 - Psychological consequences result from fear of seizure, lack of understanding and stigma of epilepsy.
 - Social consequences include discrimination and restrictions in mobility, education, employment, and legal system.
 - Economic consequences include financial burden on those afflicted, burden on medical economy, and economic loss due to difficulties with employment.
- Optimal medical system, health care education and public educational activities may reduce the cost of epilepsy treatment.
- Research funding for prevention, diagnosis, treatment and psychosocial care of epilepsy is insufficient.

White Paper on Epilepsy

- Action Plan for Care and Research

The Japan Epilepsy Society
Japan Epilepsy Association

October, 2016

Recommendations

Medical services for epilepsy

1. Epidemiology

a. Incidence/prevalence

- Epidemiology provides basic information on epilepsy, which is useful for basic research, clinical study and clinical practice.
- Epidemiological data of epilepsy provide essential information useful for planning and implementation of medical and welfare policies.
- The following facts should be disseminated as widely as possible: the prevalence of epilepsy is 5-7 per 1,000 population; the annual incidence of epilepsy is 45 per 100,000 population with the highest in young childhood and old age.
- An epidemiological study on prevalence and incidence of epilepsy in adulthood should be conducted in Japan.

b. Accidents/mortality

- Epilepsy-related death rates by etiology should be investigated.
- Research to elucidate the cause and pathogenesis of sudden unexpected death in epilepsy (SUDEP) should be promoted.
- Risk and predicative factors for SUDEP should be identified to guide prevention.
- When and how should a person with epilepsy and family be informed of the risk of SUDEP have to be discussed.

2. Etiology

- Currently, classification of the causes of epilepsy into genetic, structural/metabolic or unknown is recommended.
- Genetic study should be promoted to clarify the pathogenesis of genetic epilepsy.
- Neuroimaging study should contribute to the detection of structural abnormalities, hence increasing the number of surgical candidates.
- A comprehensive diagnostic system for metabolic disorders should be established, which may help formulate specific treatments.
- The causes of epilepsy should be extensively studied to reduce cases of unknown etiology.

3. Diagnosis

a. Classification

- The International League Against Epilepsy (ILAE) revised the proposed classifications for seizures and epilepsy several times in recent years, but the final classifications are yet to be approved. Medical professionals should be familiar with the recent classifications.
- A classification should allow users to understand the concept easily and be useful in the clinic as well as in research. Information such as age of onset, seizure symptoms, ictal/interictal electroencephalographic findings, cause of disease, and outcome should be included in the classification.
- If the current classifications and terms for seizures and epilepsy seem inadequate, the Japan Epilepsy Society should prepare a new classification proposal according to the objectives outlined above and submit it to the ILAE.

b. Physiology

- Electroencephalogram (EEG) is an essential tool to evaluate epileptogenesis. A high level of technical competence in clinicians and technicians should be maintained through systematic education.
- Long-term EEG/video monitoring is recommended for accurate diagnosis and preoperative evaluation for epilepsy surgery.
- In order to conduct the above-mentioned investigations safely, a team-based epilepsy-monitoring unit should be established.
- Collaboration between medicine and engineering is strongly recommended to promote the development of techniques such as new biomarkers for epilepsy, new examination instruments, and small continuous EEG equipment.
- Clinical indicators for new physiological methods (such as stereotactic depth EEG study, wide frequency band EEG analysis, cortico-cortical evoked potential) should be established and their efficacy should be evaluated in a large-scale joint project.

c. Imaging studies

- MRI should be a standard tool to detect lesions relevant for epilepsy.
- ¹⁸F-FDG PET is recommended to visualize the epileptic focus in the interictal state, as an area of decreased metabolism.
- SPECT is recommended to visualize the epileptic focus in the ictal state, as an area of increased blood flow.
- Image analysis methods such as subtraction ictal SPECT co-registered to MRI (SISCOM) are recommended, which contribute to automatic detection of epileptic foci.
- The role of neuroimaging in the diagnosis of epilepsy should be publicized widely to health care professionals and the general public.

d. Genetic testing

- In patients with congenital anomalies, conventional chromosomal tests followed by microarray test should be considered.
- In patients with progressive myoclonus epilepsy, genetic testing is recommended.
- In patients with Dravet syndrome, genetic testing is recommended.
- In patients with early onset epileptic encephalopathy, genetic testing is recommended.
- Genetic testing should be accompanied by correct interpretation of the results and appropriate genetic counseling.

e. Immunology and other diagnostic methods

- Treatment strategy based on molecular mechanisms of epilepsy should be established, to replace strategy based on seizure type and epilepsy type.
- To understand the molecular mechanisms of epilepsy, CSF examinations including immunological and biochemical markers, genetic testing, and examination of blood brain barrier markers (MMP-9, TIMP-1) should be considered, and these examinations should be covered by health insurance.
- Antiepileptic drugs should be developed based on molecular mechanisms of epilepsy.

f. Neuropsychology

- Persons with epilepsy should be evaluated for cognitive function (higher brain function) using appropriate neuropsychological tests.

- Common neuropsychological test battery should be used for the evaluation of cognitive function in persons with epilepsy.
- Appropriate neuropsychological tests should be developed using new technologies and disseminated after validation.
- Medical service for neuropsychological examinations should be an item for health insurance remuneration.

4. Treatment

a. Prevention

Childhood

- Long-term prescription of antiepileptic drugs solely for the purpose of epilepsy prevention should be avoided.
- Epilepsy may develop subsequent to conditions such as encephalitis, status epilepticus and head trauma. Therefore, brain protection or interventions to prevent sequela after these conditions should be established.
- Vaccination should be recommended to reduce febrile illness and to prevent febrile status epilepticus and acute encephalitis/encephalopathy, and children with a history of convulsion may also be included.
- Basic and clinical research to develop anti-epileptogenic interventions or agents should be promoted.

Adulthood

- The information that stroke prevention may reduce elderly-onset epilepsy should be disseminated widely.
- EEG should be performed more actively to detect epilepsy in patients suspected of dementia.
- Tests for autoantibodies related to autoimmune-mediated encephalitis should be made more available for early diagnosis and treatment.
- Safety measures to avoid head trauma and effective brain protection or interventions after head trauma should be established.
- Various risk factors for epilepsy should be investigated focusing on the possibility of prevention.

b. Medical treatment

Childhood

- Clinical trials of antiepileptic drugs for new indications or expanded indications (including monotherapy) should target both pediatric and adult populations simultaneously.

- New orphan drugs for specific epilepsy syndromes should be developed.
- Treatment guidelines for newer antiepileptic drugs by seizure and epilepsy type should be established, and economic aspect should also be considered.
- Clinical research should focus not only on the time of initiation and selection of antiepileptic drugs, but also on the timing of cessation of antiepileptic drugs.

Adulthood

- Guidelines should be revised regularly in response to updated medical knowledge as well as development of new antiepileptic drugs and new order-made treatments.
- Large-scale clinical research is necessary to accumulate evidence about the selection of antiepileptic drugs, rational polytherapy and cessation of treatment.
- Safety of generic drugs, resolution of drug lags, facilitation of clinical trials, and speedy review of expanded indications should always be discussed.
- Information in the package insert should be revised according to evidence obtained from clinical use, as promptly as possible.
- To promote non-pharmacotherapies such as surgical therapy, along with educational activity, a medical collaboration network to facilitate access to tertiary medical centers should be established.

Status epilepticus

- Transmucosal administration of benzodiazepine in the early stage of convulsive status epilepticus should be introduced in Japan.
- Multicenter joint research to investigate the effectiveness of treatments other than barbiturates for intractable status epilepticus should be promoted
- Epilepsy and higher brain dysfunction after status epilepticus should be prospectively studied.
- Facilities and staffing for monitoring status epilepticus should be established.

c. Surgical treatment

Surgical resection

- Seizures are controlled at a high rate after surgeries for medial temporal lobe epilepsy, focal epilepsies due to structural lesions, and epilepsies caused by extensive lesions in one cerebral hemisphere. Therefore, surgical resection should be considered actively for cases not responding to drug treatment.
- Early surgical treatment is recommended for patients with indications for surgery.
- Surgical treatment should be performed within the framework of comprehensive epilepsy care.

- Awareness campaign and education regarding the efficacy of surgical treatment should be promoted.

Palliative surgical treatment

- Palliative surgical therapies such as vagus nerve stimulation, corpus callosotomy and multiple subpial transection should be considered when epilepsy is refractory to drugs and not indicated for resection surgery.
- Research should be done to clarify the mechanism of action of vagus nerve stimulation and to predict its effectiveness by analyzing long-term follow-up data in Japan.
- Medical devices for electrical brain stimulation therapies such as deep brain stimulation and responsive neurostimulation should be developed, and early introduction of such therapies should be promoted.

d. Other treatments

- The effectiveness of treatments other than drugs and surgical resection, such as immunomodulatory therapy, diet therapy and biofeedback therapy should be evaluated.
- To establish these therapies as alternative treatment for epilepsy, their efficacy and safety should be confirmed by high-quality clinical research.
- Elucidation of the mechanisms of action of the above therapies may lead to the development of more effective, safer and more tolerable treatments.
- Treatments that have higher level of evidence should be incorporated into treatment guidelines, which currently include mainly antiepileptic drugs and surgical intervention.

5. Comprehensive epilepsy care and rehabilitation

- Problems in daily and social lives of persons with epilepsy should be thoroughly identified.
- Continuous comprehensive medical care for persons with epilepsy provided by an interdisciplinary team should be encouraged.
- Psychosocial severity rating of epileptic seizures (risk category) should be developed.
- Risk management criteria based on severity rating in the domain of education and employment should be developed.

6. Gender issue

- Special attention should be paid to women with epilepsy:

- Women of childbearing age affected by epilepsy are recommended to avoid drugs with high risk of teratogenicity and polypharmacy as well as to initiate folic acid before pregnancy.
- An abrupt change of antiepileptic drugs should be avoided during pregnancy.
- In principal, lactation may be permitted while taking medication.
- All medical personnel should share knowledge about gender and epilepsy, and provide appropriate information to persons with epilepsy.
- A consultation system for gender and epilepsy should be established.

7. Age-specific considerations

a. Neonatal period

- Neonatal seizures should be diagnosed based on ictal EEG findings.
- Education for the evaluation of neonatal EEGs and amplitude-integrated EEGs (aEEG) should be promoted.
- Education for the evaluation of neonatal neuroimaging studies should be promoted.
- A system for close collaboration between pediatric neurologists and neonatologists should be established.
- Appropriate antiepileptic drugs for neonates should be developed.

b. Childhood and adolescence

- Management of childhood epilepsy should consider the characteristics of children, including age dependency of different epileptic syndromes, adverse effects of seizures or abnormal EEG discharges on mental development, specific comorbidities, and adverse effects of drugs on cognitive function.
- Examinations such as EEG and neuroimaging in children require specific skills and safety considerations.
- Efforts should be made to help children with epilepsy actively understand their illness.
- Children with epilepsy should be given equal opportunities as healthy children to receive child care and education.
- An appropriate life care system should be established taking into consideration the transition from childhood to adulthood.

c. The elderly

- Both physicians and the general public should be aware of the following: the prevalence of epilepsy is high in the elderly; epilepsy in the elderly may be misdiagnosed as dementia; and epilepsy in the elderly generally responds well to appropriate antiepileptic drugs.

- A medical collaborative network should be established to connect physicians in general practice with institutions equipped with EEG.
- Epidemiological study on epilepsy in the elderly as well as on the relationship between dementia and epilepsy should be conducted in Japan.

8. Comorbidities

a. Developmental disorders

- Evaluation of development is indispensable for children with epilepsy, and appropriate support should be given if developmental disorder exists.
- To predict the developmental outcome, elucidation of the underlying condition of epilepsy using neuroimaging and tests for metabolic and genetic abnormalities is recommended, if necessary.
- Epileptic encephalopathy of infancy should be treated appropriately and as early as possible.

b. Physical comorbidities

- The public should be informed that most physical comorbidities are due to the underlying disease of epilepsy and not due to epileptic seizures.
- The public should be informed that the risk of injury by epileptic seizure is not higher at school or workplace than at home.
- Medical professionals should recognize that epilepsy surgery may reduce the physical and mental comorbidities in infants with focal epilepsy caused by organic brain lesions.
- Appropriate antiepileptic drugs should be used to reduce the physical comorbidities of epilepsy.

c. Cognitive comorbidities

- Large-scale study on cognitive issues in persons with epilepsy should be conducted.
- The relationship between cognitive dysfunction and remarkable EEG abnormality should be evaluated to consider the possibility of treatment.
- A multicenter collaborative study on the effect of epilepsy surgery on cognitive function evaluated using a common neuropsychological test battery should be undertaken, comparing surgical procedures, timing of interventions and changes of cognitive functions.
- Adverse effects of antiepileptic drugs on cognitive function should always be considered when treating patients with epilepsy.

d. Psychiatric comorbidities

- The pathology of psychiatric symptoms, one of the most common comorbidities in epilepsy, should be elucidated.
- Comprehensive treatment, not limited to the treatment of seizures, is required in patients with epilepsy.
- Psychiatrists should treat psychiatric symptoms of persons with epilepsy.
- Incentive is required for psychiatrists to be involved in epilepsy care.
- Quality of epilepsy care will be improved if psychiatrists participate in epilepsy care while non-psychiatric physicians engage in their specialty areas of epilepsy.

9. Economic aspects

- Improved epilepsy care should contribute to prevent developmental disorder and learning disability in children as well as facilitate employment and self-support in adults with epilepsy, eventually resolving the major psychosocial issues of epilepsy.
- Improved epilepsy care contributes to prevent seizure-related accidents, secure human resource for employment, and reduce excessive drug costs, eventually resolving the major socio-economic issues of epilepsy.
- Health care remuneration for epilepsy is insufficient at present, which hampers appropriate specialized epilepsy care and efficient medical collaboration for epilepsy in the community.
- A community-based medical collaboration network for epilepsy should be constructed with financial resources based on health insurance remuneration.

10. Social aspects

a. Education

- Information about epilepsy should be widely disseminated to the public, such as: epilepsy is a common disease that may occur in everyone; epileptic seizure usually stops within several minutes; preparation for accidents allows persons with epilepsy to participate in marathon or swimming.
- Special arrangement is needed to allow children with epilepsy to participate in activities at school, such as presence of supporters as needed or improvement of the safety environment.
- When a child has frequent seizures, parents, doctors and teachers should work together to reduce risk of injury or accident following guidelines.
- Persons involved in school education of children with epilepsy should get detailed and accurate information on the disease in order to understand the individual children and decide how to support them in consultation with the attending physicians.

b Employment

- Utilizing past experiences to assist persons with disability to find job or to work is recommended also for epilepsy.
- Information concerning employment rates of persons with mental disorders and experiences of recently opened employment support organizations should be shared with persons with epilepsy.
- Employment support system for persons with epilepsy by disease condition should be investigated.
- A model project should be promoted to assist persons with frequent epileptic seizures to find job.

c. Insurance and other issues

- An insurance system that allows persons with epilepsy to lead a secure and stable life should be guaranteed.
- A system should be established to eliminate the difference in insurance fee and compensation for persons with a past medical history.
- Evidence-based criteria are required to construct insurance system and define persons to be insured.
- The individual medical condition, not the type of epilepsy, should be the basis of insurance decision.
- The restrictions of insurance commodities for buying properties or overseas travels imposed on persons with epilepsy should be eased.

d. Stigma

- Stigma against epilepsy in everyday social life in Japan and the causes of stigma should be investigated.
- The needs of education, welfare, treatment and prevention for persons with epilepsy should be identified.
- A project to reduce stigma against epilepsy should be promoted in Japan in collaboration with WHO, IBE and ILAE.
- A widespread campaign that epilepsy is a treatable disease of the brain which can affect any person should be conducted targeting the public and various professionals using also the mass media.
- Reasonable accommodation for persons with epilepsy should be directed toward provision of appropriate opportunities for education, employment, medical care and welfare based on individual conditions, and not provision of uniform treatment.

11. Risk management

- Risk management is an important aspect not only for the head of an organization, but also for all its members.
- People with epilepsy should be educated to memorize the prescriptions on the drug note and where the note is kept.
- In case of disaster, pharmacist should be included as a member of the relief team to ensure appropriate distribution of drugs.
- In hospital pharmacies, valproic acid and levetiracetam should be appropriately stocked for emergency use during disaster.
- Education and information provision on epilepsy conducted as routine activities may help manage risks during disaster.

Laws and regulations

1. Medical and welfare system

- Persons with epilepsy and medical personnel should know the medical support and welfare service systems.
- The current medical support system with permanent financial resources (specific pediatric chronic diseases, intractable diseases) should be continued.
- Reformation of the health care system against the rise in medical cost in the aging society with declining birthrate should consider the increase of epilepsy in the elderly.
- A support system for school and employment specific to children and adults with epilepsy should be established.
- Designing and implementation of welfare services for epilepsy should consider rational measures.

2. Laws and regulations for qualification

- Persons involved in epilepsy care should know which qualifications/licenses a person with epilepsy cannot obtain if his/her condition does not meet certain criteria.
- Whether the restriction on certain qualifications/licenses in persons with epilepsy are necessary should be reviewed.
- The restriction on each qualification/license in persons with epilepsy should be clarified in practical terms such as disqualification under specific conditions and provision for recovery.

3. Driving license

- Various measures should be implemented to eliminate fatal accidents and serious injuries caused by persons with epilepsy driving vehicles.
- The practicality of current driving regulations should be verified.
- The criteria for granting driving license to persons with epilepsy should be amended, which should address the diversity of conditions and be based on scientific evidence.
- Physicians involved in epilepsy care should have standard knowledge about the conditions of epilepsy and driving regulations. They should explain and persuade persons with epilepsy and their families to follow the regulations, in order to eliminate traffic accidents caused by persons with epilepsy. This should be supported by a political action to improve quality of epilepsy care.
- Strengthening and expansion of the social security system is needed to eliminate traffic accidents caused by persons with epilepsy whose disease condition does not fulfill the eligibility criteria for driving.

Education and awareness of epilepsy

1. Medical professionals

a. Medical doctors and students

- Postgraduate education on epilepsy should be promoted in close collaboration with affiliated medical societies.
- A systematic education program on epilepsy that fulfills the requirements of the World Federation for Medical Education and the Japan Accreditation Council for Medical Education should be established.
- General education on epilepsy and specialized training on EEG are important for general physicians and epileptologists, respectively.
- Continuing education for interpreting EEG, one of the core skills for the diagnosis of epilepsy, is highly recommended. Efficient training using digital EEG system, Internet and the ANZAN program is recommended.
- A comprehensive educational system accessible by epilepsy institutes nationwide should be constructed.

b. Allied health professionals

- Provision of practical medical information about epilepsy to allied health professionals should be promoted.
- An educational system to train health professionals specialized in epilepsy, such as

epilepsy specialist nurse, should be constructed.

- An educational system to train health professionals as coordinators among various medical and non-medical professionals should be constructed.

c. Non-medical professionals

- Field surveys should be performed to assess current status of education on epilepsy for non-medical professionals.
- Field surveys should be performed to assess the needs of education on epilepsy for non-medical professionals.
- Various professional associations should include an educational program on epilepsy in their continuing educational courses.
- Epilepsy education should be provided to persons engaged in the care of the elderly, since epilepsy is frequently associated with old age.
- Educational training programs for non-medical professionals should incorporate both basic medical knowledge on epilepsy and practical seizure management.

2. General public

a. Media

- Education and awareness about epilepsy should be promoted in close collaboration with mass media.
- Serial media reports on epilepsy from different angles, which are based on accurate diagnosis and respect patients' privacy, are recommended.
- Media or press outreach activities, such as regular media seminar, should be promoted to provide updated information about epilepsy.
- Press conference to discuss issues related to epilepsy is important for mutual understanding between the epilepsy community and mass media.

b. Education at school

- At school, all students should learn seizure management as a part of first aid in the health and physical education class.
- School nurses should learn seizure management to take initiative to promote seizure management at school for teachers and affiliated staff through role-playing lectures.
- Websites for education on epilepsy tailored for teachers should be established.
- School doctors and nurses should hold regular meetings on epileptic seizure events to discuss seizure management at school.

c. General awareness

- Awareness programs for the public should allow people to learn epilepsy with fun.

- Awareness programs for the public should be implemented not only by supporters but ideally also by persons with epilepsy who actively engage in social activities.
- A reliable portal website that provides accurate information on epilepsy should be constructed.
- Education in the community should focus on hands-on workshop in which trainees participate actively in epilepsy learning.
- Education about disease and disability should start from school age.

d. Patient and family education

- Opportunities should be provided for patients and their families to receive appropriate education on epilepsy.
- A systematic and many-sided educational program for patients and their families should be developed and evaluated.
- Medical staff specialized in education on epilepsy should be trained.
- Peer support activities by persons with epilepsy should be assisted.
- Medical service for education of patients and families on epilepsy should be an item for health insurance remuneration.

System for epilepsy service and care, system for cooperation

1. Community-based medical collaboration network for epilepsy

- A community-based medical collaboration network should be constructed to provide information on appropriate medical resources that can be accessed by both persons with epilepsy and general physicians in each community, who seek specialized medical and surgical care for intractable epilepsy.
- A community-based medical collaboration network should be built to manage social aspects of epilepsy care such as issues on driving, schooling and employment of persons with epilepsy.
- Each local government should incorporate an epilepsy care program in its regional medical management plan and facilitate education of public health nurses and general physicians who may provide care to persons with epilepsy.
- Each local government should plan community-based epilepsy management program by specifying primary, secondary and tertiary levels of epilepsy care, with financial incentives by remuneration of medical fees.
- Standards for secondary and tertiary levels of epilepsy cares should include education of physicians and medical personnel in the local community.

- Specialized personnel should be assigned to coordinate and facilitate linkage and collaboration among various providers of epilepsy care in the local community.

2. Transition of epilepsy care

- The number of doctors (neurologist, neurosurgeon, psychiatrist) who are able to treat adult epilepsy should be increased to promote the transition from pediatric to adult care for patients with non-intractable epilepsy.
- Epilepsy specialists should be trained to accept the transition of patients with intractable epilepsy.
- Epileptological knowledge should be shared among members of child neurology society, epilepsy society, neurology society, psychiatry society and neurosurgical society through joint seminars and symposia.
- A medical collaboration network for epilepsy should have no barrier for age and medical discipline.
- Epilepsy awareness should be promoted with cooperative efforts from patient groups, medical societies, pharmaceutical or medical equipment companies and mass media.

3. Epilepsy care system and cooperation

- The methods and contents of information exchange among persons related to epilepsy in the fields of medicine, education, welfare and labor should be studied with consideration for human rights.
- Persons with epilepsy in the transition phase should be educated to self-manage their disease and to live independently.
- To assure collaboration between related personnel, a coordinator should be appointed, who can be a social worker, a teacher, an administrator, an employment supporter, or a job assistant in the factory, depending on the situation of the person with epilepsy.
- Concrete figures of reasonable accommodation in employment for workers with epilepsy, which meet the anti-discrimination law, should be presented.

Organizations, actions, knowledge sharing, and network

1. Medical organizations

- The Japan Epilepsy Society should strive to promote highly integrated quality medical care and epilepsy education by developing strong relationship with other organizations involved in providing epilepsy care.

2. Non-medical organizations

- Persons with epilepsy should be supported not only by providing medical care, but also by providing welfare and assistance regarding education and employment.
- A government consensus should be established so that persons with epilepsy can participate in social activities according to their own choices.
- Social organizations should be established to help develop strong relationship, communication, and collaboration among persons living with epilepsy and their families.
- Specialists who may care for people with epilepsy at different life stages need to be provided with appropriate information regarding epilepsy.
- Resources that provide information on epilepsy at the community level (epilepsy resource map) should be established.

3. Knowledge sharing and social network in relation to epilepsy

- A social network should be established for persons with epilepsy, their families and the general community to share information on epilepsy.
- General information regarding epilepsy provided on Internet websites should be confirmed and approved by specialists of various fields.
- Internet website providing general information on epilepsy should be established and organized by specific committee consisting of epilepsy specialists as well as those with expertise in marketing and IT.
- An appropriate system, including operating funds, is needed for continuous operational management of Internet websites providing general information on epilepsy.

Research

1. Basic and translational research

- To prevent the development and intractability of epilepsy, basic research on the process of epileptogenesis after brain insults should be promoted.
- To establish prevention methods for epilepsy and to improve their effectiveness, identification of biomarkers related to risk factors of epilepsy should be promoted.
- Advance in pathological studies of brain tissues from patients with epilepsy should contribute to elucidate the molecular mechanisms and to develop novel antiepileptic drugs as well as new surgical treatments.

- Antiepileptic drugs based on novel mechanisms of action should be developed to reduce the number of patients with drug-resistant epilepsy.

2. Clinical Research

a. Childhood

- To conduct high-impact clinical research in children with epilepsy, it is essential to form a group of researchers from various disciplines and institutions, and to establish a system that allows researchers to continue research even if they change their position.
- To facilitate meta-analyses using all the data generated in Japan, the outcome evaluation indicators should be standardized by the initiative of the Japan Epilepsy Society.

b. Adulthood

- The epileptogenic mechanisms caused by acquired cerebral lesions such as cerebrovascular, neurodegenerative, traumatic, and infectious diseases should be elucidated.
- The pathomechanisms and effective treatments of elderly-onset epilepsy, which is increasing in Japan, should be studied.
- Methods including telemedicine for accurate EEG evaluation and correct diagnosis of epilepsy should be established.
- A large-scale database for epidemiological surveys, prognostic evaluation studies and drug adverse effect surveys should be created.
- To promote multicenter collaborative study, a regional communication network connecting local hub facility and local clinics should be developed.
- It is necessary to secure research budget and personnel who can engage in research.

c. Neurosurgical treatment

- The long-term clinical outcome of patients who have undergone epilepsy surgery in Japan should be studied.
- New examination methods for determining accurate epileptogenic foci and improving safe surgical approaches should be explored.
- Methods of integrated surgical treatment including palliative therapy should be improved.
- Discussions on the nationwide strategy to establish specific centers for epilepsy surgery are needed.

3. Research on comorbidity issues

- A framework for multicenter-based collaborative research on various comorbidity issues should be created to allow medical personnel to participate in the research.
- Activities of young psychiatrists who are the core of this research field should be supported, and neurologists and neurosurgeons who are interested in comorbidity issues should be encouraged to participate in the study.
- Research should focus on practical issues in the clinical setting and their countermeasures.
- Simple evaluation scales should be developed for use in various situations.
- Developmental disorders including intellectual disability and autism spectrum disorders may be associated with epilepsy, and they also may cause psychological and social issues.
- Issues that coexist in persons with epilepsy include psychiatric, developmental, physical, and cognitive problems. These issues may be associated with the pathomechanisms underlying epilepsy, epileptic seizure activities, or effects of antiepileptic drugs. Research is required to evaluate these issues properly and identify methods to address each issue.

4. Social medicine research

- Research is needed to verify whether changes in the legal system and medical and welfare services in Japan are consistent with the needs of persons with epilepsy and their families.
- It is necessary to evaluate the quality of life (QOL) of persons with epilepsy, and to perform research on education and awareness programs aiming to improve their QOL.
- Practical research based on scientific evidence on psychosocial approach is necessary to enhance self-determination ability of persons with epilepsy.

International relations

- As our knowledge of epilepsy is changing rapidly on a global scale in the 21st century, measures to respond to this trend should be developed (or formulated).
- Over the next 10 years, measures should be formulated to solve issues related to medical care and research in Japan in line with the global campaign for epilepsy initiated by the WHO in 2015.

- There is an urgent need to develop a system to support future large-scale multicenter clinical research as well as basic research in Japan, in alignment with global trends.
- The aforementioned large-scale multicenter research is essential for studying future trends and Japan's international contributions, especially in Asia and Oceania. Active promotion of these contributions is recommended.