NEWSLETTER OF THE INTERNATIONAL BUREAU FOR EPILEPSY - ISSUE 1 2015

INTERNATIONAL Epilepsy News

Reporting epilepsy news for 52 years 1963-2015

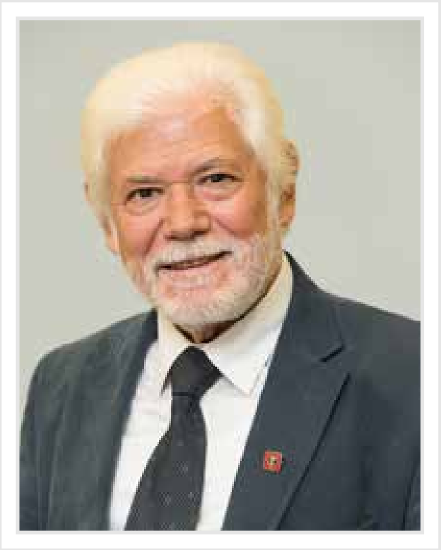
WHO approves resolution on epilepsy

CONGRESS AWARD WINNERS ANNOUNCED

The sky was the limit on International Epilepsy Day!

PRESIDENT'S LETTER

A busy start to 2015



Dear Friends

It is my privilege to welcome you to this issue of the International Epilepsy News occupied by very important events that have occurred in recent months.

Two major preparations took place a. for the approval of WHO Resolution on Epilepsy that was successfully approved February 2nd 2015 and b. the Launch and celebration of the 1st International Epilepsy Day February 9th 2015 in Strasburg a very important IBE/ILAE event worldwide. We are at present in the process of urging member states to support the Resolution to be passed from the next WHO General Assembly in May and develop plans for Government on how to improve epilepsy care, particularly in low- and middle-income countries. We also urge all IBE/ILAE members to co-ordinate their Epilepsy Day events around February 9th and use any colour, or combination of colours, they wish. For both events you will find more information and photos in this issue of the IEN.

Due to the indisposition of Hanneke de Boer, due to illness, Sherman Goh (Singapore) has graciously agreed to temporarily take over so that the work can continue uninterrupted. We hope that Hanneke will soon be well enough to resume her role as chair.

The IBE/ILAE Joint Task Force in Europe, through IBE and ILAE, has registered a legal entity in Europe. This is an important move that allows the task force to be involved in EU funded projects and, already, invitations have been accepted to participate in submissions to the EU under the latest call of the Horizon 2020 funding program.

A Global Research Initiative on Epilepsy was formed with a view to joint European, North American and Asian programs and the IBE/ILAE Global Outreach Task Forces has created Global Outreach Research and Global Advocacy Task Forces.

A new Strategic Plan for IBE has been developed and this will be presented during the next General Assembly.

In April the ILAE President and myself were among the invited speakers for the Congress on Challenges and Strategies to improve Epilepsy care, that took place in Moscow April 6th and 7th and in Astana April 9th and 10th respectively. During these meeting we had the opportunity to meet with the Russian and Kazakhstan Ministers of Health with the very constructive help of Alla Guekht. Both MOH promised support to our plans particularly to support the WHO resolution on Epilepsy to pass during the WHO General Assembly in May.

Looking forward, we are beginning to prepare for the 31st International Epilepsy Congress, which will take place in Istanbul in early September. During the congress we will have the mid-term General Assembly meeting with an important item on the agenda – approval of a revision of the Constitution and Byelaws – on which you will hear more in the coming weeks. Another important issue to be presented will be the Strategic Plan for the next three years, which has been developed by a special Task Force created for this purpose.

With best wishes to all,

Athanasios Covanis
President

IBE
International Epilepsy News
Issue 1 - 2015

INTERNATIONAL RELATIONS AND PARTNERSHIPS

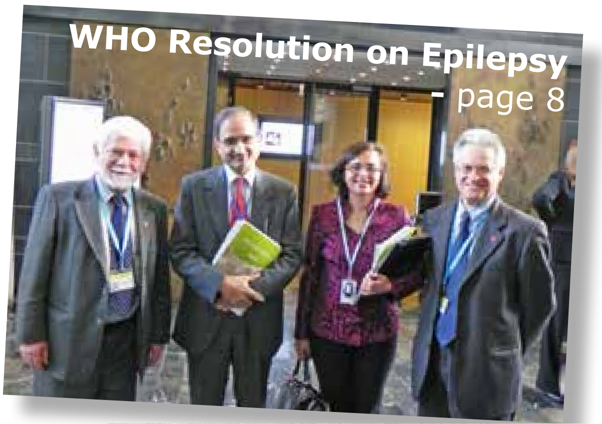
WHO
IBE is in official relations with the World Health Organisation (WHO).

ECOSOC
IBE enjoys Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC).

CoNGO
IBE is a member of The Conference of NGOs in Consultative Relationship with the United Nations CoNGO.

EFNA
IBE is a member of the European Federation of Neurological Associations (EFNA).

In this issue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Dear Readers

It's been a great few months and, although there have been long hours spent in preparation by IBE and ILAE at leadership level and by IBE and ILAE member associations right around the world, we are now enjoying some fantastic success.

First up was approval by the WHO Executive Board of a resolution on epilepsy on Monday 2nd February. This was a landmark day and you can read all about the resolution, the procedures involved in its approval, as well as what happens next, in this issue.

Exactly one week later, on Monday 9th February, we celebrated the first International Epilepsy Day. There is always trepidation when a new initiative is introduced but there was no need to fear - the event was embraced by IBE and ILAE members, by people with an interest in epilepsy, and by all those willing to support the cause. Social media was buzzing and by Tuesday 10th February we found that the hashtag #epilepsyday had appeared on more than 22 million devices and was 'trending' in Ireland! Our cover shows one brave man in Spain who took our #epilepsyday photo idea to the outer limits. Anyone for a Moon Walk next year?

This issue also announces the worthy recipients selected to receive the biennial congress awards in Istanbul in September.

And these are just some of the news contained between the covers of this issue. Enjoy!

Until next time -

Ann Little
Editor

Coming in the next issue


NEWS FROM ROUND THE WORLD


UPDATE ON WHO RESOLUTION


THE RUN UP TO ISLANBUL

THE HISTORY OF THE ILAE

INTERNATIONAL
LEAGUE
AGAINST
EPILEPSY

Part Seven: 1985-1993: Consolidation

In part 6 (Issue 1, 2014) Ted Reynolds described the creation but early demise of the flawed but well-intentioned Epilepsy International. Now the story continues....

Following the divorce from IBE, ILAE entered into a more settled period of administrative reorganisation and development. At the 1985 Hamburg Epilepsy International Symposium, which for the first time attracted more than 1,000 delegates, the new Executive included Fritz Dreifuss (USA) as President and Harry Meinardi (The Netherlands) as Secretary-General.

An early decision was to make the elections to the Executive more democratic. Under the 1953 Constitution the outgoing Executive proposed a new slate of Officers to the General Assembly. By 1973 this had evolved to the appointment of a Nominating Committee by the Executive Committee, who therefore still retained considerable influence on the outcome.

Now the Nominating Committee were charged to seek nominations from the Chapters and then to invite the Chapters to vote in a two stage process, first for the President and secondly for the Secretary-General, Treasurer, First and Second Vice-Presidents. In the second stage the successful top four candidates were allocated to their respective posts in consultation with the newly elected President.

This more democratic process was implemented for the 1989-1993 Executive and has been the foundation for all subsequent elections, with minor modifications.

A new byelaw was introduced, stating that the President, Secretary-General and Treasurer would act as a Management Committee in between meetings of the Executive Committee and subject to ratification by the Executive Committee.

Fritz Dreifuss expanded the work of ILAE Commissions. Three new Commissions were initiated i.e. Education, Neurosurgery and Genetics, Pregnancy and the Child.

The Commission on Classification and Terminology (see Part 5, 1965-1973, issue 1, 2013) continued the difficult and controversial task, still ongoing, of developing a classification of Epilepsies and Epileptic Syndromes. The Commission on Antiepileptic Drugs developed an international Glossary of Antiepileptic Drugs. The Long Range Planning Commission was revived in part to improve interaction between clinicians and basic scientists.

Another decision was to decouple ILAE and IBE Congresses from those of the quadrennial World Federation of Neurology (WFN) Congresses. Joint ILAE and Neurological Congresses had been a tradition since ILAE had been revived at the Second International Neurological Congress in London in 1935 (see Part 2, 1935-1946, Issue 1, 2011). The proposed divorce of the ILAE and WFN Congresses was for practical, not ideological, reasons as both Congresses were now attracting too many delegates to manage together.

Concern that epilepsy would be downgraded within WFN events was addressed by epilepsy becoming the focus of a Research Group of WFN. In fact ILAE and IBE had been holding International Symposia and Congresses on a yearly basis since 1967 (Paris), but since 1983 (Washington), had reverted to biennial Congresses. After Hamburg in 1985 the next one was in Jerusalem in 1987 where four industry sponsored Symposia reflected the growing interest and research into new drugs for epilepsy.

At the 1985 Hamburg Congress Ecuador, Guatemala, Indonesia and Yugoslavia were admitted to the League. It was noted that a few national chapters comprising both professional and lay members were, or wanted to be, affiliated both to ILAE and IBE. Admission criteria were clarified to ensure that each country had both a professional and a lay chapter in conformity with the Constitutions of ILAE and IBE. At the 1989 New Delhi Congress Algeria, Australia, Morocco, Panama, Venezuela and Zaire (Republic of Congo) were admitted, and the longstanding membership of Cuba, Peru and Sweden were ratified according to the ILAE Constitution and byelaws. By 1989 ILAE had 39 Chapters.

The 1989 ILAE/IBE Congress in New Delhi was the first in a developing country, despite the fact that India had no national Chapter. The 1989-1993 Executive now had Harry Meinardi as President, a unique honour as he had previously served as President of IBE (1977-1981). Roger Porter (USA) was Secretary-General. Harry and his Executive continued the process of ILAE consolidation begun by Fritz Dreifuss and his Executive. Four new Commissions were added i.e. Epidemiology and Prognosis, Neurobiology, Paediatric Epileptology and Tropical Diseases.

Between 1978 and 1985 the proceedings of the tenth to the sixteenth Epilepsy International Symposia had been published in detail in separate volumes (Advances in Epileptology, Raven Press, New York). With the steady growth in Congress participation this became impractical and the new Executive now arranged for all abstracts to be published in Epilepsia, beginning with the 1991 International Epilepsy Congress in Rio de Janeiro. Despite political and security anxieties this Congress again attracted 1,300 delegates and the concept of Regional meetings and organisations were discussed.

During the second half of the 1980's the League's complex finances, with resources scattered around the world, came under much better governance, transparency and accountability, largely initiated by Fritz Dreifuss with the help of Treasurer, Francisco Rubio Donnadieu (Mexico) and later Treasurer, Masakazu Seino (Japan). Chapters were more reliable at paying their dues. All accounts were integrated and later audited. Resources began to accumulate i.e. from 40,000 dollars in 1985 to 140,000 dollars in 1990, largely from Epilepsia and Congresses. Modest sums were now made available to support the Secretary-General's office and the work of Commissions who were also encouraged to raise funds of their own.

Reference:

Shorvon S, Weiss G, Avanzini G, Engel Jr. J, Meinardi H, Moshe S, Reynolds E, Wolf P. International League against Epilepsy 1909-2009: A Centenary History. Chichester, Wiley-Blackwell 2009.

Fritz Dreifuss
USA
ILAE President
1985-1989

Harry Meinardi
Netherlands
ILAE President
1989 – 1993

SUDEP Global Conversation:
New Online Edition

Epilepsy Australia, SUDEP Action and SUDEP Aware have collaborated, once more, to create an online knowledge resource on sudden deaths in epilepsy (SUDEP).

The third edition of the SUDEP Global Conversation is now available at **www.sudepglobalconversation.com** and builds on two books published in 2005 and 2011.

SUDEP the Global Conversation aims to combat the myth that seizures do not kill and to make knowledge available to tackle epilepsy deaths.

Denise Chapman, Epilepsy Australia said: 'The overall message is that while people continue to have seizures, especially convulsive and night-time seizures, the risk of SUDEP, although rare, cannot be ignored. Improving seizure control is the best way to reduce risk. There are simple measures that can be taken that people may want to know and try.'

For over 100 years, the belief that seizures were not fatal stood in the way of research and action to prevent epilepsy deaths. The myth was finally broken in 1996 when families, determined to find out the truth, met with pioneering researchers and clinicians from all over the world.

The new resource follows the journeys of bereaved families, of researchers, clinicians and organisations, to bring the facts to light so that the SUDEP can be tackled.

International Epilepsy Day

#epilepsyday - SELFIE ALBUM!

Thank you to the hundreds of people who took 'Selfies' to celebrate the day. You helped make it a great success. Here is a small sample of the wonderful images we received from all corners of the world.

Canada

Philippines

UK

European Parliament

USA

Ireland

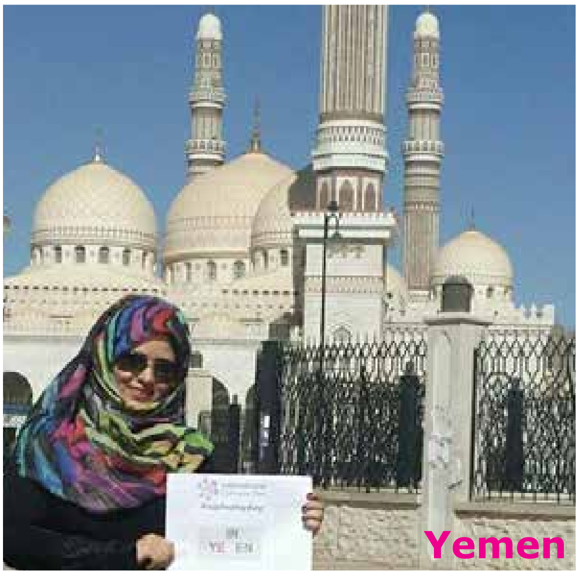
Australia

Malaysia


International Epilepsy Day
#EPILEPSYDAY
neuropediatra.org
#epilepsyday
USA


USA
Epilepsy Day in Clovis, CA with "Nepo"


PEOPLE MAKE GLASGOW
#epilepsyday in Glasgow
Scotland

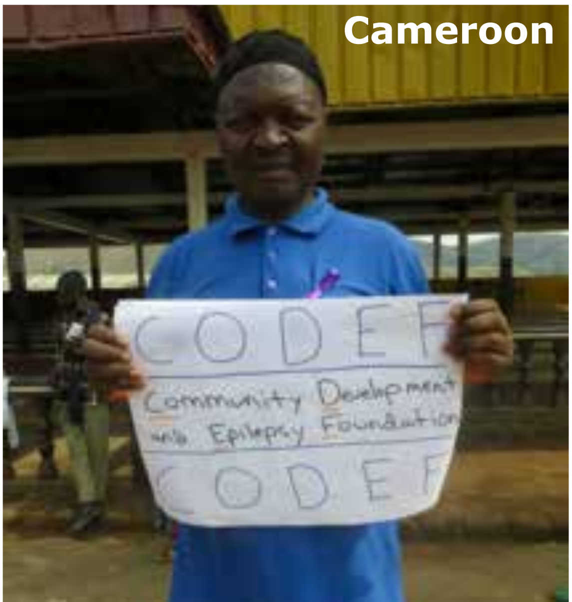

#epilepsyday
IN YEMEN
Yemen


#epilepsyday in MEXICO
Mexico


Ireland
International Epilepsy Day


#epilepsyday in Lyon
LA FRESQUE DES LYONNAIS
France


International Epilepsy Day
9th February
Free Health camp & Awareness Programme
Nepal Epilepsy Association
Namaste Hospital, Branch Office, Nepal
Nepal


Cameroon
CODEF
Community Development and Epilepsy Foundation
CODEF


Philippines
INCREASE IN RESEARCH FUNDING FOR EPILEPSY
ACCESS TO EPILEPSY TREATMENT AND CARE
EPILEPSY is more than SEIZURES!
CAMPAIGN TO EDUCATE AND END STIGMA
CALL FOR APPROPRIATE LEGISLATION FOR EPILEPSY

WHO approves Resolution on Epilepsy

Read the full text on page 8

Monday 2nd February 2015 was a landmark day for people with epilepsy, as the WHO Executive Board approved a resolution on epilepsy that recognises the need for a coordinated effort at country level to address all aspects of epilepsy.

The resolution calls on Member States of WHO/OMS to take action on a number of fronts in order to prioritise epilepsy care in a coordinated fashion around the world, placing equal weight on both the medical care and social aspects of the disease and recognising the importance of all stakeholders, including people with epilepsy and their carers.

The resolution also requests the WHO Secretariat to begin work on a framework program, which will include drafting of technical documents to assist Member States, particularly in low income countries, in implementing the actions stated in the resolution. What is particularly significant about the document is that it mentions, by name, both the International Bureau for Epilepsy and the International League Against Epilepsy. In terms of WHO resolutions, this is extremely rare.

Since it was confirmed that epilepsy was on the agenda for the WHO meeting in Geneva in January, IBE and ILAE associations, groups and individuals, have been working hard to ensure that the resolution would be passed when it came up for discussion.

These valiant efforts paid off, with a very high number of WHO Executive Board Members making statements on the day. Of the 34 Executive Board Members, 20 requested to speak to the resolution. A further eight Member States also made oral statements. Some of the statements made were extremely strong and supportive on the need for improved healthcare services and measures to reduce stigma and discrimination.

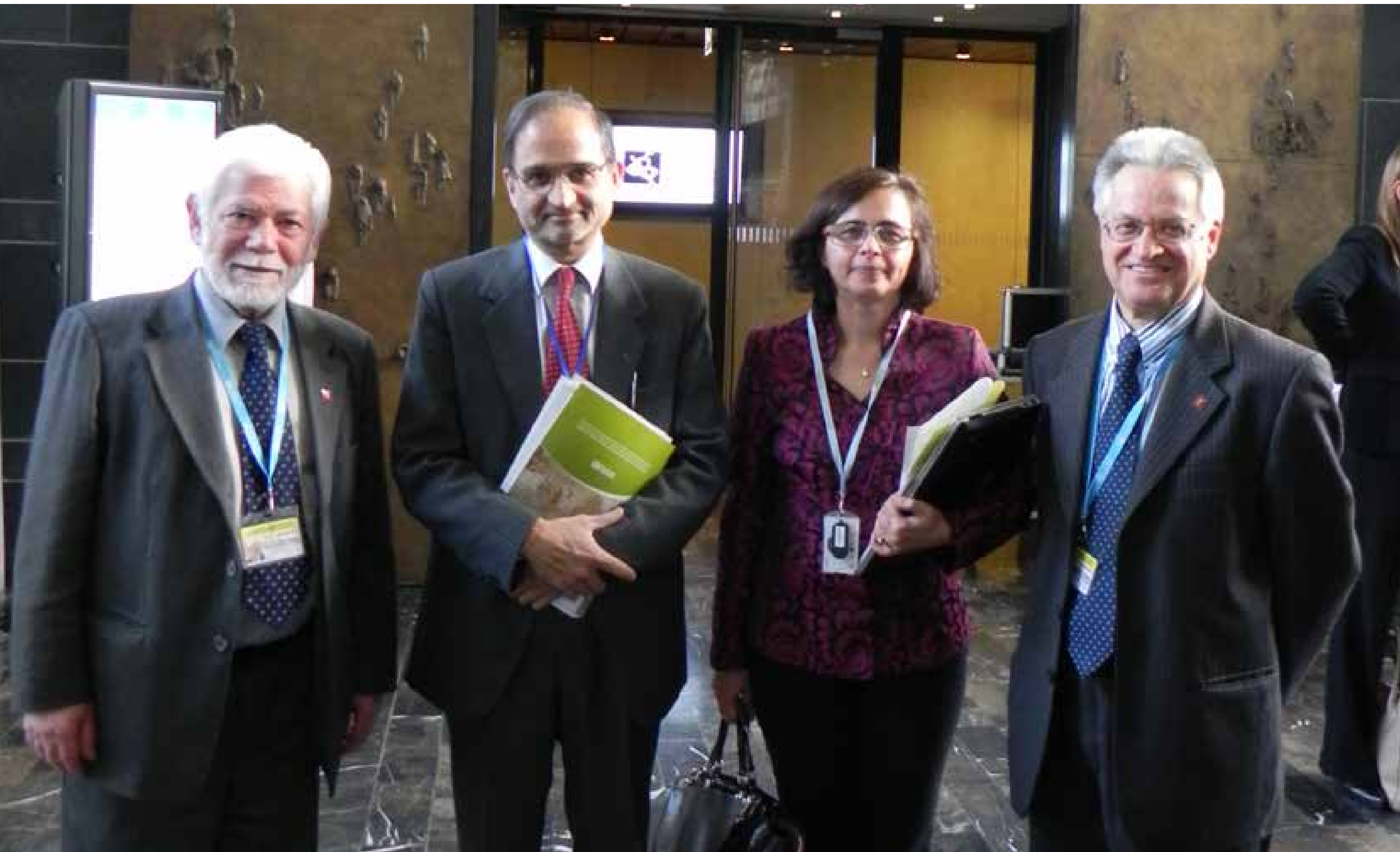
In all, epilepsy was discussed for 90 minutes, with every speaker in favour of the resolution and with no votes against when the issue was put to a vote.

The next step will be the WHO General Assembly in May at which time that, we are confident, the resolution will be passed. This will the lead to the development of a set of recommendations for governments on how to achieve their aims, working with WHO and with particular support to low- and middle-income countries. The aim is to see a positive change that can be reported back at the time of the WHO General Assembly in 2018.

But, of course, there is no room for complacency. Between now and the meeting in May there is a lot of preparation work to be undertaken and the support of IBE and ILAE member associations will, once again, be sought.

There is no doubt that the joint efforts of IBE and ILAE on this issue send out a very strong message on the need to address all aspect of epilepsy, both medical and social and the importance of all stockholders, in particular people with epilepsy, in this process.

Pictured attending the WHO Executive Board Meeting in Geneva, 2nd February 2015 are, from left, Athanasios Covanis, IBE President; Shekhar Saxena and Tarun Dua, WHO; and Emilio Perucca, ILAE President



REQUESTS TO SPEAK

Country names badges of WHO Executive Board Members and Member States are turned sideways in the WHO Executive Committee Boardroom, to send a signal to the Chair that the Member wishes to speak.

The photo above shows a number of cards turned up in readiness as the agenda item on epilepsy prepares to begin.

People's Republic of China, Russian Federation and Maldives originally sponsored the resolution. During discussion, a further four countries asked to be co-sponsors: Argentina, Islamic Republic of Iran, Japan and Panama, adding further strength to the resolution.

WHO Member States who presented Written Statements

listed by the order in which they spoke

1. PR China
2. Malaysia
3. Uruguay
4. Nepal
5. Russian Federation
6. Rep of Korea
7. Japan
8. Lithuania
9. DR Congo
10. Lebanon
11. Egypt
12. Islamic Rep of Iran
13. USA
14. Panama
15. Saudi Arabia
16. Albania
17. Suriname
18. Argentina
19. Australia
20. Maldives
21. Brazil
22. Canada
23. Romania
24. Italy
25. Czech Republic
26. Greece
27. India
28. Thailand

IBE President Athanasios Covanis (top) and ILAE President Emilio Perucca (above) had the privilege of presenting their cases to the Executive Board. Dr Covanis spoke to the social aspects of the disease, while Prof Perucca delivered on the scientific aspect.

Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications

The Executive Board

Having considered the report on the global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications,[1]

RECOMMENDS to the Sixty-eighth World Health Assembly, the adoption of the following resolution:

The Sixty-eighth World Health Assembly,

Considering resolution WHA66.8, in which the Health Assembly adopted the comprehensive mental health action plan 2013–2020, and resolution WHA67.22 on access to essential medicines;

> **neurological disorders are an important cause of morbidity and contribute to the global noncommunicable disease burden, necessitating provision of equitable access to effective programmes and health-care interventions**

Acknowledging United Nations General Assembly resolution 68/269 and resolution WHA57.10 on road safety and health, resolution WHA66.12 on neglected tropical diseases, resolution WHA67.10 on the newborn health action plan, resolution WHA67.15 on strengthening the role of the health system in addressing violence, in particular against women and girls, and against children, and the discussions on the control of neurocysticercosis and its association with epilepsy at the Fifty-sixth World Health Assembly;[2]

Noting the Political Declaration of the High-level Meeting of the United Nations General Assembly on the Prevention and Control of Non-communicable Diseases,[3] at which Heads of State and Government recognized that mental and neurological disorders are an important cause of morbidity and contribute to the global noncommunicable disease burden, necessitating provision of equitable access to effective programmes and health-care interventions;

Considering the Millennium Development Goals, the outcome document of the United Nations Conference on Sustainable Development entitled "The future we want",[4] and the report of the Open Working Group on Sustainable Development Goals, established pursuant to United Nations General Assembly resolution 66/288, which proposes a Goal 3 (Ensure healthy lives and promote well-being for all at all ages) and target 3.4 (by 2030 reduce by one-third premature mortality from non-communicable diseases (NCDs) through prevention and treatment, and promote mental health and well-being);

Recognizing that epilepsy is one of the most common serious chronic neurological diseases, affecting 50 million people of all ages globally, and that people with epilepsy are often subjected to stigmatization and discrimination because of ignorance, misconceptions and negative attitudes surrounding the disease, and that they face serious difficulties in, for example, education, employment, marriage and reproduction;

Noting with concern that the magnitude of epilepsy affects people of all ages, gender, race and income levels, and further that poor populations and those living in vulnerable situations, in particular in low- and middle-income countries, bear a disproportionate burden, posing a threat to public health and economic and social development;

Cognizant that large differences exist in the level of epilepsy management in different countries, with, for example, the median number of neurologists in low-income countries standing at only 0.03/100 000 population, that the essential antiepileptic medicines are often unavailable, that the treatment gap is estimated to be over 75% in low-income countries and to be substantially wider in rural areas than in urban areas;

Noting that the majority of people with epilepsy can be free from seizures if appropriately treated with cost-effective, affordable antiepileptic medicines;

Recognizing in addition that certain causes of epilepsy can be prevented and that such preventive action can be promoted in the health sector and in sectors outside health;

Aware that in 1997, WHO and two international nongovernmental organizations, the International League Against Epilepsy and the International Bureau for Epilepsy, launched the Global Campaign against Epilepsy – "Out of the Shadows", and that in 2008 WHO launched its mental health gap action programme, which provided a sound basis for WHO to further lead and coordinate global development work on epilepsy;

Aware also that practice in China and some other low-income countries has proved that country-level coordinated action may be very effective in controlling the disease and improving the quality of life of millions of people with epilepsy at little cost;

Recognizing the remarkable progress made recently in the technology of epilepsy management, from basic research to diagnosis and treatment;

Considering that international governmental organizations, nongovernmental organizations, academic societies and other bodies have recently enhanced their investment in epilepsy management and have undertaken a significant amount of work in collaboration with national governments, such as the International League Against Epilepsy and the International Bureau for Epilepsy, which have official relations with WHO and have been collaborating with WHO in epilepsy management for several decades;

Recognizing the role of WHO to demonstrate further leadership and coordination and take effective action for epilepsy management, in view of the large public health impact,

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[1] *Document EB136/13.*

[2] *See document WHA56/2003/REC/3.*

[3] *United National General Assembly resolution 66/2.*

[4] *United National General Assembly resolution 66/288.*

World Health Organization

1. URGES Member States:[1]

1. to strengthen effective leadership and governance, for policies on general health, mental health and noncommunicable diseases that include consideration of the specific needs of people with epilepsy, and make the financial, human and other resources available that have been identified, as necessary, to implement evidence-based plans and actions;
2. to introduce and implement, where necessary and in accordance with international human rights norms and standards, national health care plans of action for epilepsy management, aiming to overcome inequalities and inequities in health, social and other related services, paying special attention to people with epilepsy living in conditions of vulnerability, such as those living in poor and remote areas, including by strengthening public health care services, and training local human resources with proper techniques;
3. to integrate epilepsy management, including health and social care, particularly community-based services, within the context of universal health coverage, including community-based rehabilitation, into primary health care, where appropriate, in order to help to reduce the epilepsy treatment gap, by training non-specialist health care providers to provide them with basic knowledge for the management of epilepsy so that epilepsy can be diagnosed, treated and followed up as much as possible, in primary health care settings, as well as by empowering people with epilepsy and their carers for greater use of specified self and home care programmes, by ensuring a strong and functional referral system and by strengthening health information and surveillance systems to routinely collect, report, analyse and evaluate trends on epilepsy management;
4. to support the establishment and implementation of strategies for the management of epilepsy, particularly to improve accessibility to and promote affordability of safe, effective and quality-assured antiepileptic medicines and include essential antiepileptic medicines into national lists of essential medicines;
5. to ensure public awareness of and education about epilepsy, in particular in primary and secondary schools, in order to help to reduce the misconceptions, stigmatization and discrimination regarding people with epilepsy and their families that are widespread in many countries and regions;
6. to promote actions to prevent causes of epilepsy, using evidence-based interventions, within the health sector and in other sectors outside health;
7. to improve investment in epilepsy research and increase research capacity;
8. to engage with civil society and other partners in the actions referred to in subparagraphs 1(1) to 1(7) above;

2. INVITES international, regional, national and local partners from within the health sector and beyond to engage in, and support, the implementation of the actions set out in subparagraphs 1(1) to 1(7) above;

3. REQUESTS the Director-General:

1. to review and evaluate actions relevant to epilepsy that WHO has been leading, coordinating and supporting in order to identify, summarize and integrate the relevant best practices with a view to making this information widely available, especially in low- and middle-income countries;
2. to develop, in consultation with relevant stakeholders, on the basis of work requested in paragraph (1), a set of technical recommendations guiding Member States, in the development and implementation of epilepsy programmes and services, and to provide technical support to Member States in actions for epilepsy management, especially in low- and middle-income countries;
3. to report back to the Seventy-first World Health Assembly on progress in the implementation of this resolution.

Fourteenth meeting, 2 February 2015
EB136/SR/14

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[1] *And, where applicable, regional economic integration organizations.*

Report from Western China

By Dr Dong Zhou and Dr Jiani Chen

West China Hospital, Sichuan Province, China

The western part of China covers 12 provinces and autonomous regions and has a population of approximately 380 million people. A study carried out in 2003 estimated that there were about 9 million people with epilepsy in China, of whom about 2.7 million were living in western China.

The West China Hospital is the biggest hospital in the region. It's a tertiary referral center, located in Chengdu, the capital city of Sichuan Province, and serves 22,000 people with epilepsy each year.

However, the care provided by this hospital covers only a small fraction of people with epilepsy. There are vast poor rural areas in western China and a great many patients living there are left neglected and untreated.

A study showed that the treatment gap in rural areas of Sichuan was as high as 66%. Epilepsy care should rely not only on large hospitals and epilepsy clinics in urban centres but also on village health-care stations and primary care doctors in rural areas. To achieve this goal, a Network of Seizure Control was formed in Sichuan rural areas as a joint force of the government, CDC and West China Hospital, Professors Ling Liu and Dong Zhou and their colleagues. Since 2005, 16 epilepsy control bases have been established around Chengdu (see map). Those bases provided political, financial and technological support to the village health-care stations. The Network has three branches:

- public health administration department, which provides financial support;
- disease control and prevention centers, which execute and monitor the process;
- medical institutions, which provide technical support.

All these departments and institutions come together to train local primary doctors to carry out the task of patient screening, free treatment with Phenobabital, and long-term follow-up.

The project has covered 350 villages and towns with a population of 7 million, and 7,000 patients were recruited for free treatment. After treatment with Phenobabital, seizures frequency of most patients reduced by 50% and nearly half of the patients became seizure free. Besides free anti-epileptic drugs, an education program was also conducted by epileptologists from the West China Hospital to increase adherence of the treatment. Seizure frequency would be decreased by a further 18% after follow up.

***Main photo:** School children carry firewood to school in a remote mountainous region of Sichuan province*
***Above left:** An public education station in the Xichong County, Sichuan Province*
***Above right:** The team of epileptologists at West China Hospital in Chengdu*

In western China, efforts were made not only to have epilepsy care extended to cover rural areas, but also to have epilepsy care to expand to provide more comprehensive care for patients. Seizures are only the tip of the iceberg.

Epilepsy creates a series of problems for patients, including emotional problem, impact on quality of life, marital issues, pregnancy problems, driving issues, economic burden, stigma, job difficulties and so on. Each of these issues can cast a dark shadow over the life of the patient.

To consider seizure-related problems in western China in more detail, a series of studies were conducted by Prof Dong Zhou and his team at the neurology department of West China Hospital. Between 2011 and 2012, a survey was conducted on the marital problem of epilepsy patients. One hundred and thirty-six (136) patients who were married and 145 controls joined the survey and nearly half of the patients reported an impact on marital relationship due to epilepsy. The marital quality of people with epilepsy was compared with that of healthy controls by marital adjustment scale. People with active epilepsy got significant lower marital adjustment than that of healthy controls. The survey also showed that the low marital quality of the patients can cause depression, less social support and long duration of disease. The study showed that patients with active epilepsy may encounter more problems in marital relationships than healthy controls. Managing mood disorder and social support intervention and good seizure control might be helpful for the quality of marital life of patients.

Female patients who are pregnant also need special care. Folic acid supplements are a cheap and useful way to lower the chance of fetus mal-formation. A survey on folic acid usage was conducted on 153 pregnant women with epilepsy during 2013-2014. The rate of folic acid supplementation among pregnant patients was 64%, while the rate was 91.3% in Canada, 73.9% in the United States, and 80% in the average pregnant woman in China. Use of folic acid supplementation is far from sufficient and patient knowledge of folic acid was poor.

Prof Zhou and his colleagues now ask every female patient of child-bearing age about their family plans to improve folic acid usage. They have also published two books to increase the knowledge of female patients. These books are Women and Epilepsy and Perinatal Neurological Disease published by people's medical publishing house in 2012 and 2014.

Nowadays, with an increasingly wide usage of motor vehicles in China, the need for people with epilepsy to drive has also become a problem. The driving status of 657 adult patients was surveyed between 2012 and 2013. Although Chinese law does not allow people with epilepsy to drive, the survey found 19.5% of the adult patients were still driving, of whom 62.5% had experience at least one seizure in the past year. The result indicated the conflict between the need of people with epilepsy to drive and public safety. They now routinely screen epilepsy patients who drive to and from the clinic, and request the patients who drive to provide more information to doctors and legislators.

It is a long and hash journey for epilepsy patients 'to come out of shadows'. Although many efforts have already been made for epilepsy care in western China, there is still much work to be done. The rural Network is an ongoing project; new areas in Sichuan Province will be chosen as seizure control bases every three to six years.

Hopefully, one day this project will cover every town in Sichuan. And further research on pregnancy, driving issues and the quality of life will be conducted to achieve more comprehensive epilepsy care. Thousands of doctors, researchers, volunteers and patients are now working together to improve epilepsy care and to help people with epilepsy in western China to enjoy a brighter future.

Request to oppose the European Citizen's Initiative "Stop Vivisection"

The ILAE and IBE Executive Committees, the AES-ILAE Translational Research Task Force, and the Neurobiology Commission of the ILAE have sent a letter of response to the members of the European Parliament to oppose the March 3rd, 2015, European Citizens Initiative Stop Vivisection. This initiative, which requests the phasing out of animal experimentation in biomedical research in Europe, is expected to be discussed and voted on in the parliament in the next couple of months.

The position of the ILAE-IBE is that this initiative is deleterious for the future of biomedical research. IBE Members in the European Region are being urged, therefore, to contact their national Members of the European Parliament asking them to oppose this Citizens Initiative. The full letter listing signatories and references can be found in Featured News on the IBE website epilepsy.org.

April 10th, 2015

Honorable President and Members of the European Parliament,

We strongly urge the European Parliament and Commission to oppose the "Stop Vivisection" Citizens' Initiative submitted in March 2015 that requests to abrogate the directive 2010/63/EU of the European Parliament and of the council of 22 September 2010 and ban animal research. We support the existing directive 2010/63/EU that provides for ethical and justified use of animals for biomedical research while allowing the progress in scientific advances that have significantly benefited both human and veterinarian care. Adopting the initiative's proposal to stop animal research would have deleterious effects on the progress of medical research at a critical time when the research and medical communities are actively collaborating to find cures for devastating diseases that affect human beings of all ages. As a result, a ban on animal experimentation would:

1. drastically halt our efforts to find better and safer treatments for both humans and animals under veterinarian care,
2. put the unborn foetus, neonate, infant, child, and adult patients at unnecessary risk of harm by exposing them to chemicals that have not undergone safety and toxicology testing in animals,
3. deprive investigators of model systems that can be used rigorously to obtain information on the effects of specific genes, signaling pathways, and candidate treatments within a live complex organism, and prepare the field for human experimentation.

We would like to specifically address the points raised in the "European's Citizens' Initiative – Stop Vivisection" (http://www.stopvivisection.eu) which do not accurately represent the reality.

Point 1: "there are solid scientific principles that invalidate the "animal model" for predicting human response; indeed, statistical analysis provides empirical evidence in support of this decision."

Animal studies have successfully predicted human responses in studies evaluating epilepsy drugs for their anticonvulsant effects. Specifically, the vast majority of antiepileptic drugs (~ 30) that are currently in clinical practice have been tested and validated in animal studies prior to entering clinical use. In the United States, the Anticonvulsant Screening Program (ASP) of the National Institutes of Health / National Institute of Animal models have allowed the Neurological Disorders and Stroke (NIH/NINDS), to successfully identify 9 drugs that are currently considered standards of care for people with seizures. Of equal importance, many of these drugs identified through animal studies are also standards of care for animals that are under veterinarian care for epilepsy. The continuing efforts to provide more effective antiepileptic drugs are of equal benefit to animals, that otherwise may face euthanasia due to frequent seizures.

We acknowledge that there is a vigorous and ongoing discussion on how to perform animal studies humanely, improve the predictive power of animal studies using the fewest number of subjects, and deliver better therapies. The International League Against Epilepsy (ILAE) has indeed formulated specific Task Forces (AES/ILAE Translational Research Task Force of the Neurobiology Commission of the ILAE) assigned to re-evaluate research strategies and optimize the way animal studies are done so that they can deliver better therapies. These discussions and efforts will further advance our current drive to develop curative therapies, including for diseases that have no satisfactory treatments, and treatments that can improve the quality of life of those afflicted with seizures.

Point 2: **"Animal experimentation can therefore be considered as posing a danger to human health and the environment"**

Safety and toxicological studies in animals are required by regulatory bodies to ensure that candidate treatments under development do not have adverse effects that could harm patients or offspring of pregnant women who might have to be treated with them. There are no satisfactory alternatives. Although due to species differences, animal studies cannot predict all human potential adverse effects, animal testing has been able to predict 2/3 of toxic side effects seen in humans 5. Animal safety / toxicology studies effectively filter out compounds that could cause serious side effects, including carcinogenesis, teratogenesis, cardiac toxicity, lethality, and cognitive impairment. Failure to meet these high regulatory safety and toxicology testing is indeed the number one reason that compounds do not enter clinical trials.

Point 3: **"Animal experimentation can therefore be considered as constituting a hindrance to the development of new methods in biomedical research, based on the most recent scientific advances and an obstacle to taping into much more reliable, relevant, cheaper and more efficient research methods, provided by new technologies expressly conceived for humans."**

In compliance with the directive 2010/63/EU of the European Parliament and of the council of 22 September 2010, animal experimentation is done under the principle that it serves a purpose that cannot be addressed through the use of other models, such as computer models, in vitro studies, or studies in non sentient organisms. Computer models are valuable tools that predict effects on well-characterized cells but they cannot substitute for or predict the effects of a drug on networks of cells with the enormous complexity found in the human brain. Therefore, animal studies are currently irreplaceable. They do not hinder the use or development of other research tools and strategies, but rather complement their use so that the target mechanisms can be effectively studied within a more complex in vivo test system.

Point 4: **"Urge the European Commission to abrogate directive 2010/63/EU "on the protection of animals used for scientific purposes" and put forward a new proposal aimed at phasing out the practice of animal experimentation, making compulsory the use - in biomedical and toxicological research - of data directly relevant for the human species."**

We strongly urge the European Commission to vote against the recommendation to abrogate directive 2010/63/EU and phase out animal experimentation, because this would hinder efforts to develop therapies for potentially treatable diseases that significantly impact the quality of life of both human and animals. In epilepsy, a disease that affects 1% of the world population, animal experimentation is essential when we do not have any reasonable or better alternative for biomedical and toxicological research (in accordance with directive 2010/63/EU). Justification for the purpose and necessity of animal experimentation is already routinely required in every animal protocol that researchers submit for approval prior to conducting these experiments. In many situations, human specimens or human experimentation cannot serve as an option. Specific examples in the field of Epilepsy include (but are not limited to) the following:

1. *Understanding the pathophysiology and developing therapies for pediatric and developmental disorders:* There are strict regulations for the testing of new candidate therapies in the pediatric human population, due to both safety concerns and issues about consenting very young individuals to be tested with drugs that could have life-long impact. The response of several pediatric epilepsy syndromes to drugs cannot be predicted by the response of older individuals to a new drug. A typical example is infantile spasms 6 a catastrophic and still poorly treated form of infantile epilepsy. In addition, several developmental disorders appear to involve injury to the developing brain during gestation, and may be due to drugs given to the pregnant mother. Using pregnant women to solve these issues and exposing the unborn fetuses to unknown risks of tested drugs would therefore be unethical. In these and many other similar settings, animal experimentation is necessary.
2. *Understanding the pathophysiology and developing therapies for rare conditions:* Many conditions (e.g., genetic disorders) are too rare to allow for rigorous clinical studies. The availability of animal models of such diseases has significantly advanced the field by providing experimental model systems to understand the pathogenesis and develop new treatments.
3. *Human specimens are not always feasible or ethical to obtain for research:* Although having living human tissue specimens for research would be ideal, this is usually not possible or ethical for brain diseases. Furthermore, these specimens are of limited or very specialized nature, obtained strictly for diagnostic or treatment purposes (e.g., post-operatively) and usually when the disease is quite advanced. Often appropriate controls are not possible to obtain, rendering animal experimentation necessary.

Thank you for your kind consideration of this important matter.

Collaboration in ECUADOR

In a joint collaborative effort to celebrate an Epilepsy Awareness Day, members of the Association of Parents of Children with Epilepsy/National Center for Epilepsy (the IBE member association) joined forces with the Ecuadorian League Against Epilepsy (LECE) at an event in Guayaquil. Speaking at the event, Dr Iasaac Yépez, President of LECE said "I never thought that this would be such a wonderful day of camaraderie and brotherhood, with all of us gathered in a big hug that says it all - Friendship!'

A riot of lavender filled the sky with a balloon release to mark the end of a great day for all.

Ingrid Scheffer and Sam Berkovic awarded Australian Prize for Science

Sam Berkovic and Ingrid Scheffer have changed the way the world thinks about epilepsy. Twenty years ago doctors tended to regard most forms of epilepsy as acquired rather than inherited.

The clinician-researchers from the University of Melbourne, Australia, have led the way in finding a genetic basis for many epilepsies, building on their discovery of the first ever link between a specific gene and a form of epilepsy. Finding that answer has been of profound importance for families. Their discoveries of the connections between epilepsy and genes have opened the way to better targeted research, diagnosis and treatment. Together with collaborators, they have shown that genes can lead to seizures in different ways in different forms of epilepsy.

An important cause, for instance, is interference with the movement of nutrients across nerve cell membranes. In one of these cases, treatment using a diet that avoids glucose is effective.

For their contribution to the study of epilepsy, its diagnosis, management and treatment, Laureate Professor Sam Berkovic and Professor Ingrid Scheffer were awarded the Australian Prime Minister's Prize for Science 2014.

31st International
Epilepsy Congress
05 – 09 September 2015
Istanbul 2015

CONGRESS AWARDS

The IBE/ILAE congress awards are presented biennially at the time of the International Epilepsy Congress, to honour individuals who have made significant contributions, over a long period of time and at international level, in the field of epilepsy. There are three categories: Ambassador for Epilepsy - presented to a maximum of 12 recipients; Social Accomplishment, presented to one individual; and the highest honour, Lifetime Achievement Award which, as its name implies, recognises a lifetime of achievement of an individual.

Lifetime Achievement Award

This is the highest award bestowed by IBE/ILAE and is given to an individual to recognise his or her exceptional and outstanding personal contribution over a long period of time to activities to advance the cause of epilepsy.

***Presented to:* Frederick (Fred) Andermann, Canada**

Fred Andermann's scientific activities, dedicated to advance epilepsy knowledge, and his dedication as a clinician to the care of people with epilepsy, span a period of almost 60 years. He has shown an extraordinary ability to identify epilepsy syndromes and to assemble and motivate multidisciplinary teams of researchers to conduct further clinical investigations.

The results of his studies in such areas as cortical dysplasias, progressive myoclonic epilepsies, epilepsy surgery and genetically determined disorders have been published in 6 books and over 400 peer-reviewed articles in top journals. His monographs on alternating hemiplegia, Rasmussen's Syndrome and migraine-epilepsy syndrome have contributed significantly to the understanding these disorders and have led to further research in these areas.

He has inspired and trained dozens of epileptologists from all over the world who became leaders in their own country. He has also been very actively engaged in ILAE activities, including his serving as ILAE Vice-President.

Social Accomplishment Award

Every two years, one person who has carried out outstanding activities aimed at improving the social circumstances of people with epilepsy, over a long period of time, is recognised.

***Presented to:* Shunglon Lai, Taiwan**

Soon after the start of his medical career, Shunglon observed the huge impact of stigma in epilepsy and was encouraged by his teacher, Dr Marshall Hsih, to help people with epilepsy deal with the social issues they encountered. He has raised funds and established employment projects, including a bakery and a second-hand shop. A cycle race in 2007 with 3,000 participants gained huge media publicity.

As IBE Vice President for the Western Pacific region (2005-2013) he helped establish strong ties with new Members and potential future members and visited China, Mongolia, Viet Nam, Laos and the Philippines to hold conferences or provide training, often at his own expense.

He has devoted his academic life to research in epilepsy and caring for people with epilepsy and was chief of the epilepsy section at the Department of Neurology of Kaohsiung Chang-Gung Memorial Hospital, Taiwan.

His dream is that people living with epilepsy will not suffer from the disease as they have in the past.

Ambassador for Epilepsy Award

The Ambassador for Epilepsy Award is the oldest IBE/ILAE award, having been introduced in 1968. To date, a total of 312 worthy recipients have received an Ambassador pin to reflect international peer recognition and which is given for the lifetime of the recipient. Twelve Ambassadors will be presented with their awards in Istanbul.

Ed Bertram, USA

ILAE Information Officer since 2007, Ed Bertram is editor of *Epigraph* and ILAE Webmaster and an ex-officio member of its Executive Committee.

In his medical career, he developed methods for long term EEG and video monitoring which he used to demonstrate the usefulness of real epilepsy models in new therapy discovery.

Ingmar Blümcke, Germany

Director, Neuropathology Dept, University Hospital Erlangen and professor at Friedrich-Alexander University School of Medicine, Dr Blümcke is an innovative researcher in clinical and molecular neuropathology of epilepsies. Chair of the ILAE commission on Diagnostic Methods and the Neuropathology Task Force, he is director of the European Epilepsy Brain Bank consortium.

Roberto Caraballo, Argentina

Dr Caraballo established a clinic for refractory epilepsy at Garrahan Hospital, Buenos Aires and is an inspiring teacher for young epileptologists from remote areas of Argentina and other countries in the region. He is member of the faculty of the Epilepsy Summer Schools Venice and Sao Paulo and has worked with PAHO. He is a member of the Commission on Pediatrics of the ILAE.

Denise Chapman, Australia

Denise Chapman has been involved in the epilepsy fraternity for more 21 years. She is the current Chair of the IBE Western Pacific Region and has gained many friends and colleagues through her dedication in this role. She has helped countless people living with epilepsy and has a special interest in SUDEP, on which she has published. She has been involved in organising several Epilepsy & Society programmes held during the Asian & Oceanian congress.

Aristrea Galanopoulou, USA

Dr Galanopoulou is Professor of Neurology and Assoc Professor of Neuroscience, Albert Einstein College of Medicine. Since 2003 she has served as a member of many Task Forces and committees, recently playing a leading role in establishing the Joint ILAE/ AES/ Translational Research Task Force, which aims to optimize preclinical epilepsy research and therapy discovery. She also has a strong record of trainees, many now have independent careers across the world.

Jean Gotman, Canada

Jean Gotman is ILAE Director of Interactive Media, with responsibility for its web site and e-Newsletters. He chairs the ILAE Communication Task Force; he is a member of the Publication Task Force, and of the Task Force on Clinical Neurophysiology of the Diagnostic Methods Commission.

He has been involved in organizing several congresses, including the last International Epilepsy Congress, Montreal 2013.

Presentation of Ambassador for Epilepsy Awards

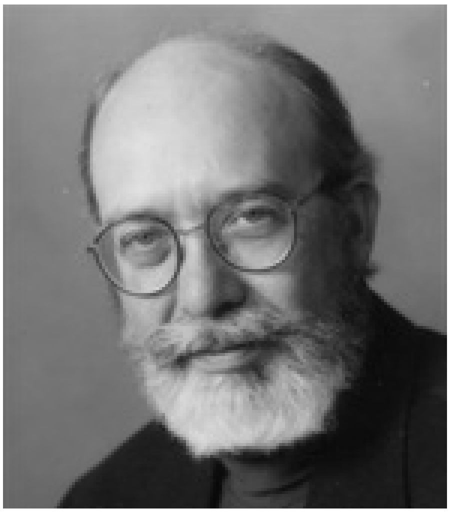
The Ambassador for Epilepsy Awards, together with the Social Accomplishment and Lifetime Achievement Awards will be presented to these most deserving recipients during the Opening Ceremony of the congress in Istanbul on Saturday 5th September 2015.

Mike Kerr, UK

Mike Kerr's research examine the delivery of acute and community-based epilepsy services. Council member of the British ILAE chapter, he is Chair; of Intellectual Disabilities Task Force; Treasurer, Commission in the Neuropsychiatric Aspects of Epilepsy; and Member of the Mood and Anxiety Disorders Task Force. His personal contribution is evidenced through the development of internationally accepted guidelines.

Philippe Ryvlin, Switzerland

Philippe Ryvlin participated in several ILAE, ENFS and AAN taskforces relating to epilepsy. He initiated three European consortia in the field of epilepsy (ENER, EEMA, and E-PILEPSY), and currently serves the Joint Task Force of ILAE/IBE.
One of the founders of the journal "*Epileptic Disorders*" he has served on editorial boards of several other journals. He has co-organised several international epilepsy congresses.



Dennis Spencer, USA

Dr Spencer's primary focus is surgery for medically intractable epilepsy, seizure disorders associated with brain tumors, and pituitary tumors. He designed the most common neocortex preserving anteromedial temporal resection for medial temporal lobe epilepsy. In the 1980's he set up an epilepsy surgery program in China and has been active ever since in developing epilepsy surgery in countries in Asia, Africa and Latin America..

Frank Vajda, Australia

Born in Budapest, Prof Vajda emigrated to Australia, where he became a neurologist and epileptologist with a special interested in neuropharmacology. He is a leading figure in the clinical pharmacology of epilepsy. He contributed hugely to the development of epileptology globally and students include Sam Berkovic, Mark Cook and Terence O'Brien. His contribution to the literature on the clinical pharmacology of AEDs spans over 5 decades.

Steve White, USA

Dr White has been Principle Investigator, NINDS-sponsored Anticonvulsant Screening Program at University of Utah Anticonvulsant Drug Development Program since 2001, which has evaluated over 31,000 investigational anti seizure drugs and contributed to discovery and development of many of the drugs available for the treatment of the patient with epilepsy today. He is involved in the education of the next generation of epilepsy researchers and clinician-scientists.

Elza Marcía Yacubian, Brazil

Dr Yacubian is a specialist in neurology, child neurology and neurophysiology in Brazil. In the 90`s, with colleagues she developed a program with the Ministry of Health establishing centers of excellence in the treatment of epilepsy. She is involved in the Latin American Summer School on Epilepsy (LASSE), and ALADE, which offers migrating courses in epilepsy, semiology, pharmacotherapy, EEG and epilepsy surgery in Venezuela, Guatemala, Cuba, Chile and Bolivia.

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www.epilepsyistanbul2015.org