



# THE HISTORY OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY



ESTABLISHED 1909

## Part 1: 1909 The Early Years

In the last issue, Harry Meinardi described some of the origins of the IBE, which evolved from the ILAE in the early 1960's. In this article, Edward Reynolds reviews some of the origins of the much older ILAE.



The ILAE was founded during the 16th International Medical Congress in Budapest between August 29th and September 2nd 1909. Medical congresses had been held every 4 years since 1867 (Paris) and over 5,000 delegates came to Budapest during one of the last years of the Austrian-Hungarian Empire. Forty-six of them, mainly neurologists and psychiatrists, held two side meetings in the Hotel Bristol to found the ILAE, which was immediately approved by the Congress.

The two prime motivators were Louis JJ

Muskens from Amsterdam and Gyula J Donath from Budapest, both neurologists. They were assisted by August Marie, a psychiatrist from Villejuif, near Paris, and J van Deventer, a psychiatrist from Amsterdam. Marie chaired the two meetings and in his report to the Congress he described the purposes of ILAE as follows:

*'The League will devote itself to special projects on behalf of epileptics, and to finding a cure and means of prevention, as well as providing aid and social rehabilitation. Nor will the League neglect experimental research and*

*comparative physiopathology, or laboratory work, which is essential for elucidating a series of problems as complex as those raised by the origin, evolution and nature of seizure disorders, with their attendant range of somatic and psychic complications.'*

Interestingly, the journal *Epilepsia*, which was immediately adopted as the official journal of ILAE, had been founded earlier in 1909 with the first publication in March of that year. The two key players were again Donath, Editor-in-Chief, and Muskens, Secretary of the Editorial Board. They had



## Photographs:

### Previous page:

Budapest, where the ILAE was founded during the 16th International Medical Congress in 1909. The centenary of the event was celebrated when the 28th International Epilepsy Congress took place in the city in 2009.

### This page:

Louis Jacob Joseph Muskens (ca. 1909), far left, and Gyula Julius Donath (ca. 1909), left. Donath and Muskens were the two prime motivators of the foundation of the ILAE.

Below, from left, Harry and Marianne Meinardi with Ted and Angela Reynolds at the ILAE's celebratory dinner in Budapest.

persuaded a distinguished group of patrons to support their initiative, including:

- W Bechterew (Russia)
- O Binswanger (Germany)
- J Hughlings Jackson (UK)
- L Luciani (Italy)
- H Obersteiner (Austria)
- F Raymond (France).

The purpose of *Epilepsia* was “*the study of the pathology, therapy and social legal aspects of epilepsy and nervous disorders of the same class*”.

However it seems that a subsidiary objective was to promote the foundation of the ILAE and this was rapidly accomplished within 6 months of the first issue. The ILAE got off to a flying start with subsequent meetings in Berlin (1910), Zurich (1912) and London (1913); the latter in the context of the 17th and last International Medical Congress attended by over 7,000 delegates. At this time the ILAE now had over 100 individual members from 19 countries. The First World War brought this encouraging momentum to a complete halt. As will be discussed in a subsequent article, the ILAE was not revived until 1935 and even then was nearly extinguished again due to the



Second World War. It took until the 1960's for as many as 19 countries to be represented again in the ILAE. This is one small example of the disastrous impact of the First World War on human creative endeavour. Nevertheless the ILAE did eventually revive and flourish and now has over 100 Chapters world wide.

As far as I am aware, the ILAE and *Epilepsia*

are the oldest sub-specialty organisation and journal in the field of neurology, even older than the World Federation of Neurology (1931).

### References

Shorvon S, Weiss G, Avanzini G, Engel J, Meinardi H, Moshe S, Reynolds E, Wolf P. (2009) *International League Against Epilepsy 1909-1009: A Centenary History*. Chichester, Wiley-Blackwell.

## Edward Reynolds MD FRCP FRCPsych

Dr Reynolds qualified in medicine in 1959. He trained in neurology at the National Hospital for Neurology and Neurosurgery, Queen Square London from 1963 to 1969, and at Yale University, Dept of Neurology in 1090. He was elected a Fellow of the Royal College of Physicians of London in 1979 and a Fellow of the Royal College of Psychiatrists in 1985.

He was Consultant Neurologist to Maudsley and King's College Hospital 1974-1999; Founder and Director of the Institute of Epileptology, King's College 1994-2001; Chair of the Fund for Epilepsy 1992-2004; and is currently Honorary Senior Lecturer in Neurology at Guy's King's, St Thomas' School of Medicine, King's College University of London.

Dr Reynolds was Vice President of the ILAE from 1989 to 1993 and served as President from 1993 to 1997. During his presidency he initiated the Global Campaign Against Epilepsy and was Chairman of the campaign from 1997 to 2001.



# THE ORIGINS OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY



## Before and during the Second World War

**In Issue 3-2010 of IE News Ted Reynolds described how the ILAE and its journal *Epilepsia* were founded by a group of European neurologists and psychiatrists in Budapest in 1909, but, following a very encouraging start, ceased to exist after the outbreak of World War I in 1914. The story continues, looking at the period before and during World War II.**

The International League Against Epilepsy (ILAE) and *Epilepsia* were not revived until the summer of 1935, during the second International Congress of Neurology in London. That congress was dedicated to the centenary of the birth of Hughlings Jackson for which a special medal was given to the delegates. Epilepsy was therefore a main theme of the congress.

On the 31<sup>st</sup> July, 32 delegates with an interest in epilepsy, from 14 countries, met at Dormans Park Hotel, close to the Lingfield Colony in Surrey, and resolved to re-launch the ILAE and *Epilepsia*.

At a subsequent meeting, on the 2<sup>nd</sup> August in London, William Lennox (USA) was elected President, Louis Muskens (Netherlands) Vice President, HI Schou (Denmark) Secretary and Editor of *Epilepsia*, and Tylor Fox (Lingfield, UK) Treasurer. Muskens, who died in 1937, was the only link with the past. He had been the leading advocate of the revival of the League and he now proposed, wisely as it proved, an American President to avoid the catastrophic politics of Europe at that time.

Although the new vision of ILAE was similar to that of its original founders, there would now be a greater emphasis on the social and institutional care of patients with epilepsy, in part because of the large number of new neurological and psychiatric journals, since World War I, in which



epilepsy research could now be published.

The new second series of *Epilepsia*, published once a year from 1937 onwards, reflected this new policy, including reports of the activities of the League and of its Chapters.

At first, however, there were only three Chapters i.e. America (86 members), Britain (102) and Scandinavia (31), but with 29 members from countries without Chapters. By 1938 Chapters were also formed in the Netherlands and the former Czechoslovakia (now the Czech Republic and Slovakia).

It was agreed that the ILAE would henceforth meet every 4 years. The following meeting took place on August 24<sup>th</sup> 1939,

### Dormans Park Hotel, Lingfield

at the third International Congress of Neurology in Copenhagen, in the shadow of the Second World War, which broke out while the congress was taking place. Lennox described the banquet as a tragic affair. A new Constitution for the League was approved and the original officers were re-elected, the exception being KH Stauder of Germany who replaced the deceased Muskens as Vice President; although there was no Chapter in Germany with whom war was imminent.

Unlike the First World War, the League managed to survive the Second World War thanks to the continuing endeavours of its only active Chapter in America.

Although *Epilepsia* continued to appear annually, Schou found it impossible to edit the journal in Denmark and this task was undertaken by President Lennox.

Annual Chapter meetings continued in the USA with a research focus especially in the field of electroencephalography and new treatments with phenytoin and related anti-epileptic drugs.

Lennox also initiated a "Laymans League" in America of which there were nearly 2,000 members by 1946, a forerunner of later lay Chapters and IBE.

***In the next issue of IE News, it will be the turn of Harry Meinardi to continue his history on the origins of IBE.***

#### References:

Reynolds EH, *The John Hughlings Jackson 1935 Centenary Congress Medal*. *J.Neurol.Neurosurg. Psychiatry* 2005; 76:858-859.

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



The Hughlings Jackson centenary medal



# THE ORIGINS OF THE



## Part Three: The period 1946 - 1957

**In the first part of his series on the history of ILAE, which was published in Issue 3-2010 of IE News, Ted Reynolds described the foundation of ILAE and its journal *Epilepsia* in 1909. Part two of the story recounted the period before and after World War II. Now the story continues, looking at the period 1946 to 1957.**

In Issue 3-2010, I described the foundation and promising early years of ILAE, and its journal *Epilepsia*, from 1909 until the outbreak of the First World War, when it ceased to function. In Issue 1-2011, I reported the revival of ILAE and *Epilepsia* in London, and at the Lingfield Colony in Surrey in 1935, and its struggle to continue during the Second World War.



**WILLIAM G  
LENNOX  
1884-1960**

**He served continuously from 1935 to 1953 as President and/or Editor of *Epilepsia* ensuring the survival of ILAE during World War II and its post-war development.**

The ILAE survived the Second World War thanks to its American President, William Lennox, and the continuing activity of the USA Chapter, including the foundation of a Layman's League with over 2,000 members, a forerunner of later IBE Chapters.

By the end of the war ILAE had 3 Chapters i.e. in the USA (including members from Canada), the UK and Scandinavia.

The next business meeting of ILAE was held in New York in December 1946, in conjunction with the annual meeting of the American Chapter, together with the Association for Research in Nervous and Mental Disease. Two new Chapters were admitted - from Holland and Argentina. William Lennox was re-elected as its President and as Editor of *Epilepsia*. The journal was financially supported both by the American Chapter and by its affiliated Lay League but now, once more, had an international editorial board.

Hans Schou, from Denmark continued as Secretary General and Bernard Ledebøer, from Heemstede in Holland, emerged as Vice President. Ledebøer was later to become Secretary General - 1949 to 1957 - thus renewing the early influence, through Louis Muskens, of the Netherlands as a leading country in the epilepsy movement.

The ILAE next met in Paris in 1949 in conjunction with the International Neurological Congress, as in 1935 and 1939, but also with the relatively new International Society of Electroencephalography. McDonald Critchley from the National Hospital in London became the newly elected President. He was a distinguished neurologist, although he did not have a special interest in epilepsy. His appointment reflected the continuing close links between neurology and epilepsy and

he later became President of the World Federation of Neurology. William Lennox, however, continued as Editor of *Epilepsia* and also as "Honorary President" of ILAE, a well deserved but unique title, never since used. France was admitted as a 6th Chapter but the Scandinavian Chapter ceased to function over the next few years, perhaps with the departure of Schou. Sweden was later admitted in 1961 and Denmark in 1973.

A new era for ILAE began at the 1953 Congress in Lisbon, again in conjunction with the International Neurological Congress.



**HANS I SCHOU  
1886-1952**

**Secretary General and Editor of *Epilepsia* prior to and, briefly, after World War II, but based in Copenhagen during the war. His duties were limited by the occupation and largely undertaken by Lennox.**

A Earl Walker, a Canadian neuro-surgeon working at John Hopkins Medical School in Baltimore, was elected President (and again

for a second term in 1957), emphasising the growing links between epilepsy and neurosurgery, especially temporal lobectomy, which had been pioneered mainly at the Montreal Neurological Institute and the Maudsley Hospital in London. He too went on to become President of the World Federation of Neurosurgical Societies.

A new name to appear was Henri Gastaut, from Marseille in France, as “President Elect.” This was an entirely new constitutional post, perhaps created for him, but never to be repeated, because he had to wait until 1969 to become President, after first serving three terms as Secretary General!

Four new Chapters were admitted in 1953 i.e. Brazil, Chile, Japan and Peru. Thus South America now had as many chapters as Europe and a pattern was set for the steady growth of ILAE during the second half of the 20th century.

Also in 1953, William Lennox finally stepped down after 18 years of continuous service as President and as acting or de facto Editor of *Epilepsia*. He had ensured the survival of ILAE and the journal during the war, dominated their post-war development, and facilitated a novel Layman’s League in America with which he persistently lobbied in the USA for political recognition of the neglected needs of people with epilepsy.

One disappointment was that the Layman’s League withdrew its funding for *Epilepsia* in 1949, presumably to concentrate on social and political activity. The last issue of the second series of the journal appeared in 1950.

At the same time a new constitution for ILAE was being developed and was adopted at the 1953 Lisbon Congress. The objective of ILAE was now stated to be: “The advancement and dissemination, in

all countries, of knowledge concerning the epilepsies in every field; the encouraging of research into the cause and cure of the epilepsies; and the promotion of better treatment and care for persons suffering from these diseases.” Unlike the 1939 constitution, there was now no mention of “social aspects of the disease”.

These latter developments were probably some of the seeds that led to the later development of IBE in the 1960’s.

**Reference:**

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



# THE ORIGINS OF THE



## Part Four: The 50's and Early 60's

**In the first part of his series on the history of ILAE, which was published in Issue 3-2010 of IE News, Ted Reynolds described the foundation of ILAE and its journal *Epilepsia* in 1909. Part 2 of the story recounted the period before and after World War II. Part 3 dealt with the period 1946 to 1957. Now the story continues, with the birth of IBE.**

By the early 1950's ILAE had 10 chapters, including 4 in Europe - France, Great Britain, Netherlands and a non-functioning "Scandinavia"; 4 in South America - Argentina, Brazil, Chile and Peru; together with Japan and the USA.

The 1953 ILAE Constitution dropped any reference to a social objective and also stated: "The national branches should be primarily medical organisations, which may include in their membership laymen interested in the problems of epilepsy".

In the same year Bernard Ledebøer, who had been Medical Director in Heemstede in the Netherlands since 1930, and was now beginning his second term as Secretary General of ILAE, noted that three kinds of organisations in the "fight against epilepsy" had arisen in different countries:

1. Physicians
2. Lay-people
3. Mixed membership

He added: "Today it should be decided whether the League should restrict itself to the first group or whether it should be the uniting body for all the workers in the field of the fight against epilepsy. I can tell you that, personally, I am an advocate of the latter".

There is little doubt that tensions existed between scientifically and socially orientated physicians on the Executive in the 1950's, just as they had, periodically,

throughout the first 50 years of ILAE; this was a contributing factor to the founding of IBE in the early 1960's.

In the meanwhile there is a lack of documentation of the progress of ILAE between 1955 and 1961 for two reasons: ILAE's journal, *Epilepsia*, which in any case was only published annually, ceased publication from 1955. It was then revived in 1959 as a quarterly journal under a new editor, Sir Francis Walshe, a neurologist with a critical scientific track record as a former editor of the journal *Brain*. More seriously, with the death of Bernard Ledebøer in 1959 the archives of ILAE were mysteriously lost.

All we know for certain is that the quadrennial meeting of ILAE took place in Brussels in 1957 in conjunction with the 6th International Neurological Congress, the 4th International Congress of Electroencephalography, the 3rd International Congress of Neuropathology and the 1st International Congress of Neurological Surgery, an event which led to the foundation of the World Federation of Neurology.

The President of ILAE from 1953, Earl Walker, was a neurosurgeon and, surprisingly, he was re-elected in 1957 for a second term. This was something that has never happened subsequently, although there was a precedent with William Lennox. Even more surprisingly, Henri Gastaut, who was "President Elect" from

1953 to 1957, began the first of his two terms as Secretary General in place of Ledebøer, who died two years later, together with the archives. Although it would be interesting to know more about these political developments it seems clear that the medical and scientific approach was in the ascendency within ILAE, which is the backdrop to the initiation and development of IBE.

The details of the birth of IBE have been described by Harry Meinardi in an earlier article in this historical series (Issue 2-2010). In summary: As noted by Ledebøer, many countries had already established national associations of lay people in the post Second World War period.

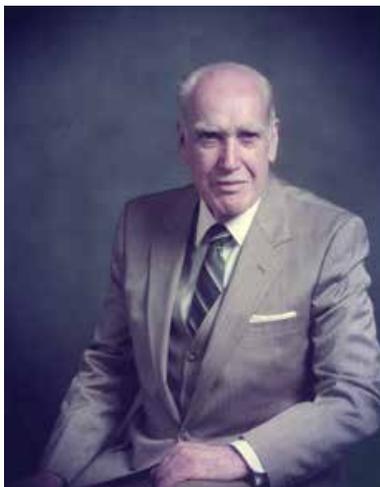
At the 1961 ILAE Congress in Rome, and on the initiative of the British Epilepsy Association, a Symposium was held on "The role of the lay organisation in the treatment of epilepsy". This led to the adoption of a formal proposal by Dr Mosovich (Argentina) to establish the IBE.

This was followed by discussions with the newly elected 1961-1965 ILAE Executive under its new President, Francis McNaughton, Head of the Montreal Neurological Institute in Canada, and including Henri Gastaut in his second term as the Secretary General. This initially led to the establishment of an informal IBE affiliated as the social arm of ILAE. It was run by a Board of Directors which included among

others, McNaughton and Gastaut as well as Ellen Grass (USA) and George Burden (UK), who later became President and Secretary General of IBE when it formally became an independent organisation with its own Constitution at the 10th World Congress of the International Society for Rehabilitation of the Disabled in Wiesbaden, Germany, in 1966.

Thus IBE evolved from ILAE, just as earlier in 1909 ILAE had evolved out of International Medicine.

In the meanwhile, by 1965, the number of ILAE Chapters had risen to 19 with the addition of Austria, Bolivia, Cuba, Germany, Israel, Italy, Poland, Sweden (in place of Scandinavia), Switzerland and Uruguay.



**Notes:**

A Earl Walker (1907-1995) - pictured above. The last to serve as President of

ILAE for two terms (1953-1961). A Neurosurgeon who represented the neuroscientific wing of ILAE.

Bernard Christian Ledebøer (1897-1959), served two terms as Secretary General of ILAE (1949-1957). As Medical Director of a special centre for epilepsy in Heemstede, The Netherlands, he represented the socially inclusive wing of ILAE.

**Reference:**

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



# THE HISTORY OF THE



## Part Five: 1965-1973: Separation Anxiety

**As discussed in Part 4 (Issue 3-2012) the establishment of IBE, initially as the social arm of ILAE but, by 1967, as an independent organisation with its own constitution, was approved by the 1961-1965 Executive of ILAE. The 1965-1969 Executive was elected at the ILAE AGM during its quadrennial meeting in Vienna in 1965 in conjunction, as usual, with the International Congress of Neurology, the first Congress I ever attended. The new President was Albert M Lorentz de Haas from the Netherlands, but sadly he died in 1967 and was succeeded briefly by Jerome K Merlis (USA). Henri Gastaut (France) was now in his third term as Secretary-General and became an increasingly influential figure in the ILAE.**

Gastaut was the prime mover in trying to bring some order and global consistency into the definition and classification of seizures and epilepsies. Beginning with an International Symposium in Marseilles in 1964, a draft international classification of seizures was the main scientific theme for a joint session of the ILAE together with the Congresses of Neurology and Encephalography in Vienna a year later.

Gastaut now sought formal approval of the

ILAE by establishing the first ever ILAE Commission on Terminology and Classification to finalise the proposals and obtain the approval of the ILAE Executive and AGM. The ILAE Clinical and Electroencephalographic Classification of Seizures was published in *Epilepsia* in 1970.

This and its revised form in *Epilepsia* in 1981 have been among the most influential of ILAE activities and publications. Successive ILAE Commissions in 1985 and 1989 published initial and revised ILAE proposals for the more difficult and still ongoing task of the Classification of Epilepsies and Epileptic Syndromes.

Gastaut was finally elected President together with the 1969-1973 Executive at the ILAE Annual General Meeting (AGM) in conjunction with the Congresses of Neurology and Neurosurgery in New York in September 1969. Including his four years as Past-President from 1973 to 1977, he eventually became the League's longest ever serving Officer from 1953 to 1977 i.e. 24 years.

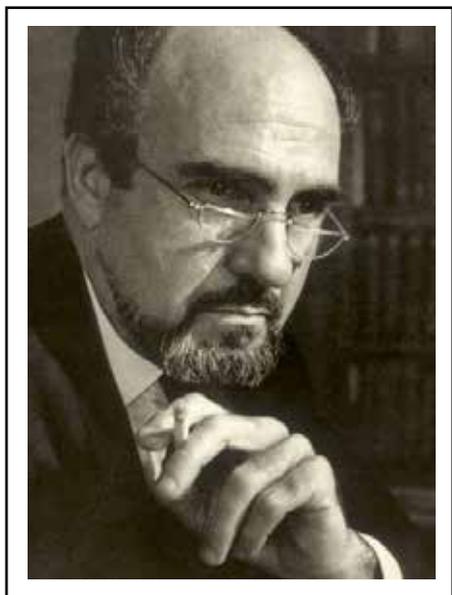
The new Secretary General was Otto Magnus from the Netherlands. Magnus *Henri Gastaut (1915-1995) from France, the longest serving officer in the History of ILAE, i.e. 24 years from 1953-1977.*

had agreed to edit *Epilepsia* on the death in 1967 of his fellow countryman, Lorentz de Haas, who had continued as Editor while he was President, as had Lennox in the past. With Magnus now Secretary General, Margaret Lennox-Buchthal from Denmark became Editor.

This Executive, with several strong personalities, did not function well and Magnus eventually resigned a year early in 1972.

There were several sources of tension. At the time, the Executive mainly concentrated on its scientific meetings and on *Epilepsia*. Magnus was motivated to bring the League to developing countries. Lennox-Buchthal and Magnus disagreed over the performance of Elsevier, the Dutch publishers of *Epilepsia*. David Daly (USA), in his second term as Treasurer, wished to exert more control over the League's finances. He objected to others, such as Magnus, raising money from generous Dutch sources for League purposes without more accountability.

The League, however, had limited resources of its own, not least because of poor communication with its Chapters, many of whom failed to pay their dues. In addition to the 19 countries listed in part 4 in this series, five new Chapters had





*Albert M Lorentz de Haas (1911-1967).  
The only President of ILAE to die during his  
Presidency*

been added by 1973 i.e. Czechoslovakia, Denmark, Norway, Portugal and Spain, making a total now of 24.

In the meanwhile, there had also been ambiguities and tensions over the relationship between the ILAE and IBE which had become an independent organisation in 1967. Some had objected to IBE appointing medical doctors to their Executive, which they felt confused and undermined the objectives of the separation.

However, in Europe ILAE and IBE began to work well together in establishing joint scientific and social conferences, firstly in Paris in 1967 and then in Dunblane, Scotland, in 1968, where I first met Harry Meinardi.

After the 1969 International Congress in New York these European Conferences continued in Marienlyst (1970), Amsterdam (1971) and London (1972). At the International Congress in Barcelona, in 1973, the relationship of ILAE and IBE was set on firmer and clearer foundations

by the establishment in the new 1973 Constitution of the ILAE of interlocking Executive Committees, with the President and Secretary-General of each organisation serving on the Board of the other.

This however also set the stage for a soon to be proposed re-integration of ILAE and IBE within just a decade of their separation! This will be the subject of the next instalment.

#### **References:**

1. Shorvon S, Weiss G, Avanzini G, Engel J, Meinardi H, Moshé S, Reynolds E, Wolf P. International League against Epilepsy 1909-2009: A Centenary History. Chichester, Wiley-Blackwell 2009.
2. Commission on Classification and Terminology of the International League against Epilepsy. Proposal for revised clinical and electroencephalographic classification of epileptic seizures. *Epilepsia* 1981; 22; 489-501.



# THE HISTORY OF THE



## Part Six: 1973-1981: Marriage and Divorce

**In part 4 (Issue 3, 2012) and part 5 (Issue 1, 2013) Ted Reynolds described how IBE evolved out of ILAE in the 1960's and how the two organisations established a practical working relationship.**

At the quadrennial International ILAE/ IBE Congress in Barcelona in 1973 David Daly, the former ILAE Treasurer, was elected President, with fellow American J Kiffin Penry as Secretary General and Karl-Axel Melin (Sweden), former Vice-President, as the new Treasurer.

In the December 1974 issue of the IBE Newsletter, Daly and Penry, together with Ellen Grass (also from the USA) and George Burden (UK), who were continuing as President and Secretary General, respectively, of IBE, published a "Declaration of Intent" for a much closer working relationship between ILAE and IBE under the joint umbrella of "Epilepsy International".

Initially the League and the Bureau would retain their separate identities but

Epilepsy International would act as their agent, with a view to eventual merger. This objective would save duplication, resources and costs, and facilitate greater fundraising.

Negotiations towards these goals encountered difficult practical issues relating to constitutional details; chapter membership and dues; commissions; Epilepsia and much else. Unfortunately, unrelated tensions between the four Officers resulted in the resignation of both Ellen Grass and George Burden and, by 1977, little progress had been made.

The next ILAE Executive was elected in 1977 at the ILAE/IBE Congress in Amsterdam, in conjunction with the 11th World Congress of Neurology. Kiffin Penry was now President with Francisco

Rubio Donnadieu from Mexico was Secretary General. At the same time Mexico, Canada and the Dominican Republic were admitted as League Chapters.

IBE now also had a new Executive with Harry Meinardi (Netherlands) as President and Richard Grant (UK) as Secretary General.

Both Executives gave renewed impetus to the Epilepsy International project and a new target date for merger, subject to Chapter approval, was set for 1981 at Kyoto. The League and Bureau Executives constituted the Board of Directors of Epilepsy International with the two Presidents, Secretaries General and Treasurers as the Executive Committee of the new organisation.

The plan for a single office was imple-



*Ellen Grass, Founding President of IBE.*



*George Burden, Founding Secretary General of IBE.*



*J Kiffin Penry, ILAE Treasurer 1973 -1977 and President 1977-1981*

mented in 1978 at a neutral, but expensive, site in Geneva, Switzerland, where Richard Gibbs, another American, took up his new role as "Executive Director". The London office of IBE closed. The League had no fixed office and relied on the, largely voluntary, efforts of its Secretary General.

The Geneva Office soon fell apart for lack of funding and communication difficulties. Richard Gibbs returned to the USA in 1979 and was released from his contract in 1980. The Epilepsy International office was moved to Milan, where Patsy McCall-Castellano (USA) and her husband, Francesco Castellano (Italy), both Officers of IBE, were based and where Patsy acted as temporary voluntary Executive Director for Epilepsy International.

At the Epilepsy International Symposium in Kyoto in 1981, the IBE voted in favour of a merged Epilepsy International but the ILAE General Assembly voted against in a ratio of 2 to 1.

It was clear that many in the League were unimpressed with the proposed merger. They felt that the Board of Directors of Epilepsy International had not been acting as an agent for ILAE but had been running and controlling the League, largely under the influence of the Bureau. Duplication had not reduced but had, in

fact, increased; money had been wasted on an expensive office and staff in Geneva; and fundraising had not increased. The League's Treasurer, Karl-Axel Melin, was concerned about ILAE's dwindling finances.

After the negative 1981 vote, some in the Bureau and a few in the League, including the new 1981-1985 President, Mogens Dam (Denmark) still hoped that Epilepsy International might be salvaged with better communication with the Chapters, which had certainly been poor. The wounded, and not yet legitimised, Epilepsy International limped on for four more years, until it was finally disbanded at the next quadrennial Epilepsy International Symposium in Hamburg in 1985.

In retrospect, it is very surprising that so soon after the emergence of IBE from ILAE in the second half of the 1960's a new, largely Anglo-American, proposal to integrate them should evolve in the mid-1970's, partly driven by the same IBE Officers who had successfully campaigned for, and established, an independent IBE.

Although no doubt well intentioned, it was undermined from the start by serious practical challenges; poor planning and communication; personality clashes and financial disputes. It was a marriage that was never consummated and ended in divorce.

Many lessons can be, and were, learned by both ILAE and IBE, who have continued to work successfully together since then as independent but interlocking organisations. This unhappy story diverted much of the attention, and energy, of ILAE between 1973 and 1981. The annual European Conferences, which had been initiated by IBE in 1967, now continued at Brussels in 1974; Berlin in 1975; and Dublin in 1976.

After 1977, international conferences continued annually under the label of "Epilepsy International Symposia" and were held at Vancouver in 1978; Florence in 1979; and Copenhagen in 1980. Only two new Chapters - Colombia and Finland - joined ILAE at Kyoto in 1981, bringing the total number of Chapters to twenty-nine.

One new initiative by the ILAE Executive was a Commission on Antiepileptic Drugs, in addition to the Commission on Classification and Terminology, discussed in part 5.

Preceded by a Pharmacological Advisory Committee led by Treasurer Daly in 1970, the first Commission, from 1973-1977, was chaired by Maurice Parsonage (UK), with whom I served as secretary.

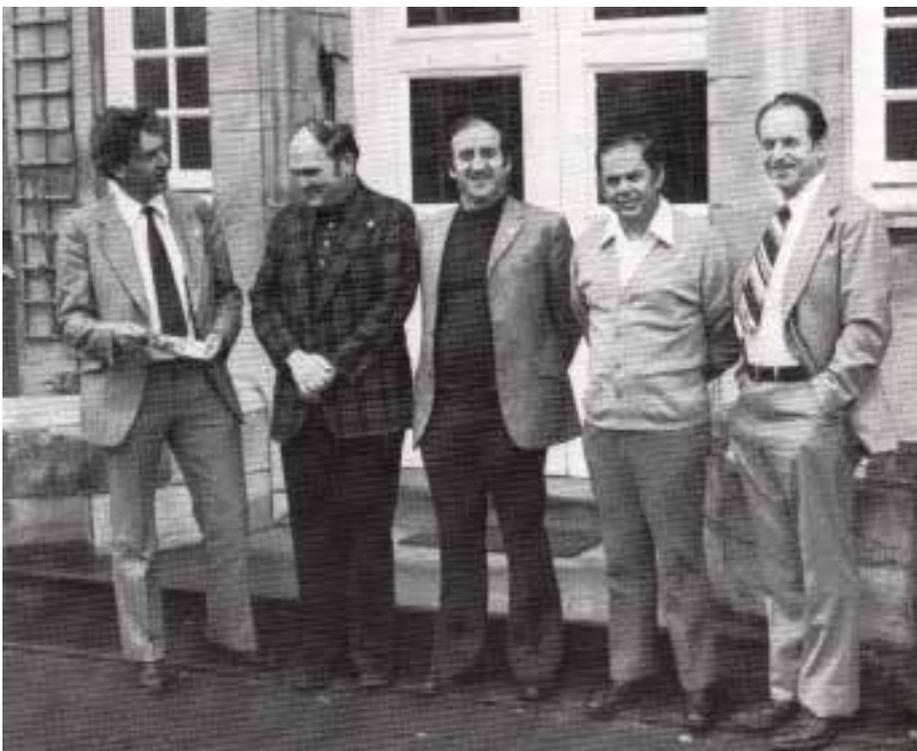
The driving force, however, was Kiffin Penry, who, as Head of the Epilepsy Branch at the National Institutes of Health in Washington, spearheaded the scientific and political campaign to improve the availability, evidence and better use of currently available antiepileptic drugs, and to develop new antiepileptic drugs.

He stimulated many symposia and publications on the subject, including the authoritative multi-author "Antiepileptic Drugs", which ran to five updated editions by 2002.

The ILAE Commission on Antiepileptic Drugs has continued to the present time, more recently under the broader title of "Therapeutic Strategies", and has remained one of the most influential ILAE initiatives.

#### References:

1. Shorvon S, Weiss G, Avanzini G, Engel Jr. J, Meinardi H, Moshé S, Reynolds E, Wolf P. International League against Epilepsy 1909-2009: A Centenary History. Chichester, Wiley-Blackwell 2009.
2. Parsonage M. Guest Editorial. *Epilepsia* 1984; 25: 405-407.



**Members of the Executive Committee of Epilepsy International in 1978.** From left to right Harry Meinardi, IBE President; J. Kiffin Penry, ILAE President; Richard Grant, IBE Secretary General; Francisco Rubio Donnadieu, ILAE Secretary General; and Richard Gibbs, Epilepsy International Executive Director.



# THE HISTORY OF THE



## 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 bylaw 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 bylaws. 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 na-

tional 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 Donnadiou (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



# THE HISTORY OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY



## Part 8: 1993-1997: Global and Regional Development

**In part7 (Issue 1, 2015) Ted Reynolds described eight years of consolidation of ILAE following the end of Epilepsy International. Now the story continues....**

Beginning at the IBE/ILAE International Epilepsy Congress in Oslo, 1993 I was privileged to serve as President of the 1993-1997 ILAE Executive, together with Peter Wolf (Germany) as Secretary General and Pete Engel (USA) as Treasurer.

An immediate objective was to improve the lines of communication within a fast growing ILAE. For the first time we had a staffed office for the Secretary General, who was supported by Mrs Irene Kujath. In 1994 we produced the first of our ILAE Annual Reports and in the same year initiated our twice-yearly newsletter, *Epigraph*, under the editorship of Simon Shorvon (UK).

In January 1996, *Epilepsia* expanded to a monthly journal under our new editor, Tim Pedley (USA). Subscription rates for the journal were reduced and at the same time a pilot trial of a low cost quarterly *Epilepsia Digest*, for developing countries, was started under the editorship of Rajendra Kale (India). Plans were developed for an ILAE website.

These necessary improvements in internal communication were associated with a remarkable increase in the number of Chapters of ILAE from 39 in 1993 to 62 by 1997, a growth rate of over 50% in 4 years. The 23 new Chapters were: Bulgaria, Burkina Faso, Croatia, Egypt, Georgia, Greece, India, Ireland, Jordan, Latvia, Lithuania, Macedonia, Moldova,

Romania, Russia, Saudi Arabia, Slovakia, Slovenia, Taiwan, Thailand, Tunisia, Turkey and Ukraine. Although one third of the 62 Chapters were in Europe, by now every continent was represented and the ILAE had become a truly global organisation on which, as had been said of the British Empire, the sun never set.

Likewise the number of delegates attending the International Congresses had grown from approximately 2,000 in Oslo (1993) and Sydney (1995) to nearly 5,000 in Dublin (1997).

The rapid growth of ILAE was also reflected in the activities of 15 Commissions and 2 Sub-Commissions, including new Commissions on developing countries, economics, neuroimaging and outcome measurement.

The rapid global growth of ILAE required the introduction of regional structures and activities. Having the largest number of chapters, the first Regional Commission was on European Affairs, chaired by Simon Shorvon (UK). The objective was to improve co-operation and communication in epilepsy services, teaching, research and regulatory affairs. Unusually this Commission reported both to the Executive and to a new European Advisory Council, consisting of one delegate from each European Chapter and chaired by Peter Wolf (Germany). This led to the first ILAE European Epilepsy



*Simon Shorvon, ILAE Vice-President, first Editor of Epigraph and first Chairman of the Commission on European Affairs.*

Congress in Oporto in 1994, followed by The Hague in 1996. A first Regional ILAE Asian and Oceanian Epilepsy Congress was held in Seoul in 1996, following which a new Commission on Asian and Oceanian Affairs was established, chaired by Masakazu Seino (Japan).

The objectives were the same those in Europe with the additional goal of promoting more Chapters in the Region.

These two Regional Commissions were the forerunners of later Regional Commissions in other parts of the world, including Latin America which already had a tradition of "Pan American" congresses.

## **ILAE/IBE/WHO Global Campaign against Epilepsy: "Out of the Shadows"**

The ILAE and the IBE are Non-Governmental Organisations (NGO's) affiliated to the World Health Organization (WHO). Every December the WHO invites the Presidents of ILAE, IBE and all neurological and neuroscience-related NGO's to Geneva for an exchange of information. After two such meetings it occurred to me that a more productive partnership with the WHO might be possible. I therefore returned to Geneva on 15 January 1996 together with my ILAE colleague, Pierre Jallon (Switzerland), Chairman of the Commission on Developing Countries, to meet Professor J Costa e Silva, Director of the WHO Division of Mental Health, together with his colleague, Leonid Prilipko (Russia), Chief of the Unit on Neuroscience, and Professor Li Shichuo, the Chinese delegate on the WHO Executive Board who had a special interest in epilepsy. My proposal of a Global Campaign for the global problem of epilepsy, aimed especially at developing countries, where recent evidence suggested 60 to 98% of patients were not receiving any effective treatment, the so-called treatment gap, was encouragingly endorsed that day. Throughout the 1993-1997 Executive period relations between ILAE and IBE were excellent. After some initial financial concerns, IBE soon supported ILAE and the WHO in planning the Global Campaign. President Hanneke de Boer



*Photo top right: Launch of the 2nd Phase of the Global Campaign, Geneva, February 2011, chaired by WHO Director General, Dr Gro Harlem Brundtland.*

*Above from left: Ted Reynolds, President ILAE; Shichuo Li, Chinese delegate on the WHO Board; Hanneke de Boer, President IBE; Leonid Prilipko, WHO Unit on Neuroscience. Global Campaign launch, Geneva, June 1997.*



(The Netherlands) became a dedicated supporter of the Campaign.

The first step in the summer of 1996 was a conference on "Epilepsy in Developing Countries" held in Geneva on 6 and 7 June. This focused on the needs of people with epilepsy in developing countries with the help of colleagues from many such countries (Jallon 1997). The ILAE/IBE/WHO Global Campaign Against Epilepsy: "Out of the Shadows" was announced at the Hague and Seoul congresses in September 1996.

The campaign was formally launched in Geneva on 19 June 1997 in the presence of the ILAE, IBE and WHO leadership, together with leaders of related NGO's, and supported by John Bowis, former Minister of Health in the UK and now a member of the European Parliament.

Two weeks later, on 3 July, the campaign was again launched at the International Epilepsy Congress in Dublin with the support of Mary Robinson, the Irish President. A highlight of that congress was a session on "The Politics of Epilepsy", with John Bowis (UK), Senator Tony Coelho (USA), Senator Joe Doyle (Ireland) and Mary Banotti, MEP (Ireland).

The Mission Statement for the campaign is "To improve the acceptability, treatment, services and prevention of epilepsy worldwide".

Objectives are:

1. to increase public and professional awareness of epilepsy as a universal, treatable brain disorder;
2. to raise epilepsy on to a new plane of acceptability in the public domain;
3. to promote public and professional education about epilepsy;

4. to identify the needs of people with epilepsy on a national and regional basis;
5. to encourage governments and departments of health to address the needs of people with epilepsy, including awareness, education, diagnosis, treatment, care, services and prevention.

A programme of global, regional and national activities were initiated which will be discussed in the next and subsequent instalments of this History.

The on-going Campaign has recently culminated in Resolution (EB136/SR/14) by the WHO Executive Board on February 2nd this year urging all member states to develop national healthcare plans for epilepsy management, particularly in low and middle-income countries (see EI News 2015, issue 1) and which has now received global national support and approval by the General Assembly of WHO (World Health Assembly) on May 26th this year (see the current issue of EI News).

### **References.**

1. Jallon P. Epilepsy in developing countries; ILAE Workshop Report. *Epilepsia* 1997; 38: 1143-1151.
2. Reynolds EH. President's report (1993-1997). *Epilepsia* 1998; 39: 1128-1130.
3. WHO Press Release. Bringing epilepsy out of the shadows. A Global Campaign is launched. WHO/48, June 19th 1997. [http://www.who.int/entity/mental\\_health/neurology/epilepsy/Press\\_Release\\_WHO\\_48\\_1997\\_en.pdf?ua=1](http://www.who.int/entity/mental_health/neurology/epilepsy/Press_Release_WHO_48_1997_en.pdf?ua=1)



# THE HISTORY OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY



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## Part 9: 1997 – 2001: Professionalism and the Global Campaign

**In part 8 (Issue 2, 2015) Ted Reynolds described the rapid growth and regional development of ILAE between 1993 and 1997, culminating in the launch of the ILAE/IBE/WHO Global Campaign. Delayed due to a special article in Issue 4, 2015, to mark the passing of Hanneke de Boer, we are now pleased to present the next instalment....**

At the International Congress in Dublin in 1997 the new ILAE Executive included Jerome Engel Jr (Pete) (USA) as President, Peter Wolf (Germany) in his second term as Secretary General, and Guiliano Avanzini (Italy) as Treasurer.

The ILAE continued its rapid expansion. By 2001, 19 further chapters were added, - Albania, Armenia, Azerbaijan, Estonia, Honduras, Iraq, Jamaica, Kyrgistan, Lebanon, Malaysia, Malta, Nepal, Paraguay, Philippines, Qatar, Senegal, South Korea, Syria and Zimbabwe. In eight years the ILAE had doubled in size from 39 Chapters in 1993 to 81 in 2001.

### **Professional Management and Communication**

Pete Engel and the new Executive realised that the increasing size of the ILAE and the scale of its proactive global commitments, some in collaboration with IBE and WHO, required a more professional approach to administration and financial management than could be provided by unpaid volunteer officers rotating every four years.

By 2001, the ILAE had scattered assets worth nearly three million dollars and an annual budget approaching one million dollars. Partly guided by Walt Schaw, a self-employed consultant in Leadership

and Management, the Executive employed Peter Berry of Association Resources in the USA, where the ILAE is registered as a non-profit organisation, to establish a central accounting system and an investment policy to ensure the ILAE's financial security into the future. For the first time, annual audits were undertaken. A proposal to establish a permanent administrative office, perhaps in Europe, was discussed, but a decision was postponed for the 2001-2005 executive committee to consider.

In view of the growing size and financial importance of ILAE/IBE biennial International Epilepsy Congresses and the increased number of intervening ILAE and IBE Regional Congresses, Richard Holmes, based in Dublin, was appointed as International Director of Meetings to oversee financial, scientific and political control of these events for both the League and the Bureau. The international congresses continued in Prague in 1999 and Buenos Aires in 2001. The third and

fourth European Regional Epilepsy Congresses were held in Warsaw in 1998 and Florence in 2000, respectively. The second and third Asian and Oceanian Regional Epilepsy Congresses were in Taipei in 1998 and New Delhi in 2000. The first official Latin American Epilepsy Congress was



*Pete Engel, ILAE President 1997-2001*

in Santiago de Chile in 2000. More local conferences continued or were initiated by Mediterranean, Pan Arab and Pacific Rim Chapters.

A new contract was signed with Blackwell for the publication of the highly successful *Epilepsia* journal under the continuing editorship of Tim Pedley (USA). This guaranteed a reliable source of income for ILAE for a further 5 years. Responsibility for *Epilepsia Digest* for developing countries passed to Blackwell to undertake in local countries.

*Epigraph* continued to be published twice or three times yearly, now in colour and later on-line, under the editorship of Simon Shorvon (UK). Plans for the ILAE-IBE website portal under Rajendra Kale (UK and India) continued but were delayed when the idea of a joint initiative with the British Medical Journal could not be agreed.

### Regional Development and Commissions

The process of regional development, begun under the previous executive committee (see part 8), continued with the European Commission chaired by Martin Brodie (UK) and the Asian and Oceanian Commission chaired by Masukazu Seino (Japan). New commissions were established for Latin America, chaired by André Palmi (Brazil) and for the North American Continent chaired by William Theodore (USA). Plans were developed for an African Commission to be implemented by the next executive committee.

Peter Wolf (Germany), as Secretary General and chairman of the European Advisory Council, established Eureka as an independent, but ILAE affiliated, educational organisation responsible for epilepsy education throughout Europe, but especially in the Eastern Europe, including educational activities during ILAE European Epilepsy Congresses.

Pete Engel reorganised the Scientific Commissions of ILAE into Resource Commissions, including Neurobiology, Psychobiology, Neurosurgery and Paediatrics; and Problem-orientated Commissions, including the Burden of Epilepsy, Developing Countries, the Search for Epilepsy Genes, Diagnostic Strategies and Therapeutic Strategies.

The goals and activities of these commissions were, to a large extent, relevant to and directed towards the flagship of almost all League activities i.e. the ILAE/IBE/WHO Global Campaign Against Epilepsy



*Launch of the Second Phase of the Global Campaign: Dr Ted Reynolds, ILAE Past President and Past Chairperson, Global Campaign; Dr Gro Harlem Brundtland, Director General WHO; Hanneke de Boer, IBE Past President and Past Chairperson Global Campaign; and Professor Pete Engel, ILAE President.*

to improve the acceptability, treatment, services and prevention of epilepsy worldwide.

### Global Campaign Takes Off

In part 8, I described the background, concept and objectives of the ILAE/IBE/WHO Global Campaign Against Epilepsy to bring epilepsy “out of the shadows”, which was launched in Geneva and Dublin in June/July 1997. The strategic aims of the campaign included:

1. raising public and political awareness and understanding about epilepsy,
2. encouraging and supporting Departments of Health to address the needs, treatment, services and care of people with epilepsy nationally.

In phase 1, the first four years of the campaign, the emphasis was on the first aim by increasing awareness, creating acceptance, and improving education through global, regional and national activities.

Soon after, a new Director General of WHO, Dr Gro Harlem Brundtland, boosted the campaign by approving, in 1999, a so-called “Cabinet Paper”, which raised the status of the campaign to the highest level within the new priorities of the reorganised WHO. Epilepsy is the first neurological disorder to be accorded this status and was at the forefront of WHO’s 2001 World Health Day and Report on mental and brain disorders.

At the regional level in 1998 the German government sponsored a conference in Heidelberg of more than 100 professionals, patients/public, and politicians from all over Europe, which led to the publication and promotion of the European Declaration on Epilepsy. Similar regional declarations, based on the European format,

were subsequently developed in Africa (Senegal), Latin America (Chile), Asia and Oceania (India) and North America (USA), all in 2000. More than 1,200 experts from more than 100 countries participated in these regional conferences and declarations. The European Declaration called for and led to the preparation of a “White Paper” on epilepsy for Europe, launched at the European Parliament by John Bowis MEP on March 22<sup>nd</sup> 2001. At the national level as many as 50 countries in all continents expressed a wish to join the campaign with their own “out of the shadows” initiatives.

All of these achievements led to a formal high profile launch of the second phase of the campaign in Geneva on February 12<sup>th</sup> 2001, led by the Director General, with the participation of senior WHO staff; the Regional Mental Health Officers of all six WHO regions; John Bowis MEP, representing the European Parliament; as well as the leadership of ILAE and IBE, representatives of national chapters and of other neuroscience NGO’s, including some ambassadors to WHO. The objectives and outcome of phase 2 will be discussed in the next instalment. The speech of Dr Gro Harlem Brundtland, made at the launch, can be viewed as a milestone in the social history of epilepsy.

### References

1. Engel P. *President’s Report. Epigraph 2001; 1: 1-3.*
2. Reynolds EH. *ILAE/IBE/WHO Global Campaign “Out of the Shadows”: Global and Regional Developments. Epilepsia 2001; 42: 1094-1100.*
3. Reynolds EH (Ed). *Epilepsy in the World: Launch of the Second Phase of the ILAE/IBE/WHO Global Campaign against Epilepsy. Epilepsia 2002; 43 (supplement 6): 1-46.*



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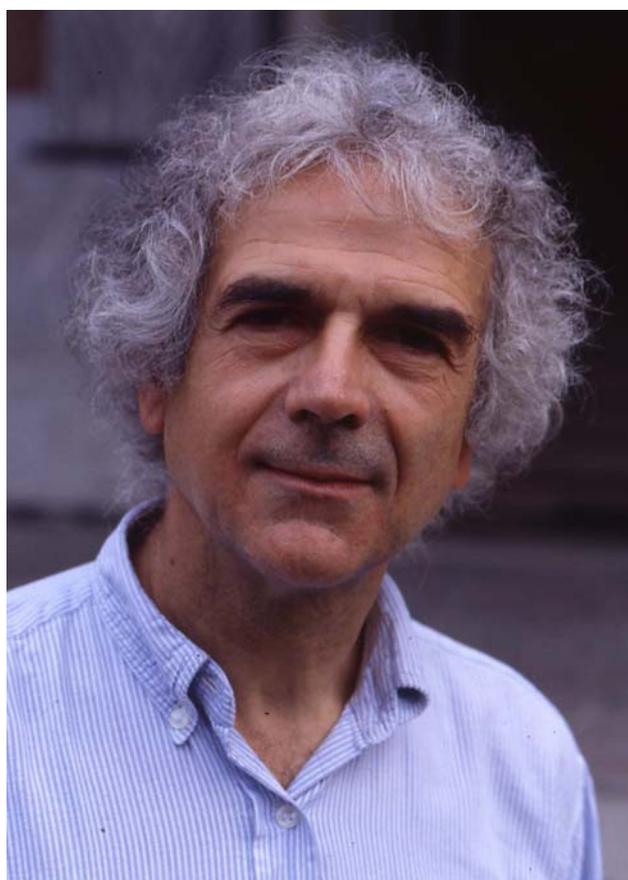
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## Part 10: 2001 – 2009: Accelerating towards the Centenary

In part 9, Ted described the administrative changes necessitated by the rapid growth of ILAE and the commensurate scale of its activities, including the launch of the second phase of the ILAE/IBE/WHO Global Campaign against Epilepsy in Geneva in February 2001. In this, the final article of the series, he takes us to 2009 and the celebrations to celebrate ILAE's centenary.

A compilation of the 10 articles that comprise the series are available on the IBE website <http://www.ibe-epilepsy.org/publications/other-publications/>



*Giuliano Avanzini, ILAE President 2001-2005*

### 2001 – 2005

At the International Congress in Buenos Aires in May 2001, the new Executive was led by Giuliano Avanzini (Italy), with Natalio Fejerman (Argentina) as Secretary General and Ley Sander (UK) as Treasurer.

President Avanzini's priorities included developing and strengthening the regional activities of ILAE, to take account of differing cultural and socio-economic requirements, while at the same time improving communication and interaction between national Chapters, regional structures and the Executive, thus enhancing the Global Campaign. With this in mind he established Task Forces for regional, sub- and inter-regional organisation. Beginning at the ILAE European

Congress on Epileptology in Madrid in 2002, he also initiated annual Chapter Conventions at alternating Regional and International Congresses, which considerably increased the involvement of Chapters in the policy development and ongoing activities of ILAE at all levels.

A new administrative Headquarters of ILAE, with two permanent assistants under Executive Director Peter Berry, was now established in Brussels, because Europe had the largest number of Chapters. This Office supported Executive interactions with Chapters and Regions in all activities of ILAE except finance, which remained the remit of the Hartford, Connecticut Office. Communication was also improved by a new ILAE website, now under Information Officer, Simon Shorvon (UK), together with the continuing roles of *Epilepsia*, led by new editor, Robert Fisher (USA), and of *Epigraph* (Ley Sander, UK). Simon Shorvon also facilitated the establishment of an International Epilepsy Resource Centre at the Swiss Epilepsy Centre in Zurich, an idea promoted by past president, Pete Engel (USA). This also became the temporary home of the ILAE Archives.



*Peter Wolf, President 2005-2009*

By 2005, a further 16 Chapters joined the ILAE, of which China, representing about one fifth of the world's population, was a significant diplomatic achievement. The others were Bangladesh, Belgium, Costa Rica, Cyprus, Hong Kong, Kazakhstan, Kenya, Mongolia, New Zealand, Nicaragua, Pakistan, Singapore, South Africa, Tanzania and United Arab Emirates.

On a more negative note the decision to move, at short notice, the International Congress in 2003 from Tunis to Lisbon because of political considerations following the 9/11 attacks in the US, was a setback for ILAE relations with Africa. Plans for an ILAE Commission on Africa were again put on hold.

### **2005 – 2009**

At the AGM at the International Epilepsy Congress in Paris in 2005 new constitutional amendments, relating mainly to election procedures, were approved. Peter Wolf (Germany), who was the ILAE Constitutional expert during his 8 years as Secretary General, was now President, supported by Solomon Moshé (USA) as Secretary General and Martin Brodie (UK) as Treasurer. Peter Wolf prioritised the

development of regional educational structures and programmes. He had already established the European Epilepsy Academy (EUREPA) in 1996 and an Asian Academy (ASAPE) in 2003 and he advanced these models, in conjunction with the ILAE, in other regions with the help of a Global Education Commission, summer schools, residential courses, distance learning and fellowships. Other priorities included translational research and a new Epilepsy Care Commission to co-ordinate with the Regional Commissions (Asia/Oceania, Eastern Mediterranean, Europe,

Latin America, North America) and the ILAE/IBE/WHO leadership in advancing the Global Campaign.

The 2007 International Epilepsy Congress was held in Singapore, where Uganda was admitted as a Chapter. Throughout the period 2001 to 2009, ILAE/IBE Regional Epilepsy Congresses were held in each of the above regions alternating with the biennial International Congress, as ILAE accelerated towards its Centenary at the International Epilepsy Congress in Budapest in 2009. At Budapest six new Chapters i.e. Ghana, Guinea, Mali, Palestinian Territories, Uzbekistan and Vietnam, joined the League, bring the total past 100 to 103 in its Centenary year.

### **ILAE/IBE/WHO Global Campaign, Phase 2 (2001 - 2009).**

As described in Part 9, the success of the first four years of the Global Campaign led to a high profile launch of the 2nd phase in Geneva on February 12th 2001 led by the Director General of WHO, Dr Gro Harlem Brundtland. A central feature of phase 2 was Demonstration Projects, initially in regions of Brazil, China, Senegal and Zimbabwe. The methodology of these

projects included epidemiological assessment, case finding, educational and social intervention, and treatment by primary care workers. The ultimate objective was to examine the causes and to reduce the treatment gap; and to develop models of epilepsy treatment and care for integration into national health policies in nearby developing countries.

The largest and most successful project was in six provinces of China. In an initial survey of 55,000 people the lifetime prevalence of epilepsy was seven per thousand and the prevalence of active epilepsy was 4.6 per thousand (87% convulsive). Only 25% had had regular antiepileptic treatment. These findings led to a large community-based intervention trial of phenobarbitone in 2,455 patients with convulsive seizures (median frequency 10 per year and mean duration of epilepsy 15.5 years).

After two years of treatment one quarter were seizure-free and 72% experienced at least a 50% reduction in seizure frequency. So successful was this simple protocol, undertaken by specially trained primary care workers under the supervision of neurologists in rural communities with limited resources, that this approach was extended to 10 further locations in China and incorporated into a national programme (Wang et al, 2006).

Similar but smaller scale successful outcomes attended the Senegal and Brazil projects, but that in Zimbabwe was undermined by a deteriorating political situation. In the meanwhile several more developing countries initiated similar community-based projects, including Congo, Georgia, India, Indonesia, Maldives, Myanmar, South Korea and East Timor. Related global projects of the Campaign during this period included an Epilepsy Atlas describing epilepsy services available throughout the world; a study of epilepsy and stigma in China and Vietnam; and a global review of legislation related to epilepsy.

Finally, by 2009, 103 countries or chapters had initiated local or limited projects of various kinds under the umbrella of the Global Campaign. In view of the scale and success of the Chinese Demonstration Project, it was appropriate that China took the lead with the co-sponsorship of 17 other countries, in stimulating the General Assembly of WHO to unanimously approve in May 2015 Resolution WHA 68.20, which urges all member states to develop national healthcare plans for epilepsy management, particular in low and



*Some of the present and past Officers and Commission Chairpersons of ILAE attending the 2009 Centenary gala event in Budapest*

middle income countries, thus promoting the 5th and final objective of the Global Campaign (see Part 8, IBE Newsletter, Issue 2, 2015 and Covanis et al 2015)

### **A century of achievement**

Thus, stemming from small, mainly European, origins in Budapest in 1909, the leadership and membership of ILAE met again, together with IBE, at the International Epilepsy Congress in Budapest in 2009 to celebrate a century of achievement. Despite interruptions and setbacks, mainly due to two world wars, the League had grown into a truly global organisation with over a hundred national chapters, representing every continent. In partnership with the IBE, which it had spawned half a century earlier, and more recently

with the WHO, ILAE has continued to fulfil its founding fathers objectives at national, regional and global level i.e. “The League will devote itself to special projects on behalf of epileptics, and to finding a cure and means of prevention, as well as providing aid and social rehabilitation. Nor will the League neglect experimental research and comparative physiopathology, or laboratory work, which is essential for elucidating a series of problems as those raised by the origin, evolution and nature of seizure disorders, with their attendant range of somatic and psychic complications”. (see Part 1, IE Newsletter, Issue 3 - 2010). In the 1973 Constitution of ILAE these objectives were crystallised as:

1. the advancement and dissemination throughout the world of knowledge

concerning the epilepsies;

2. the encouragement of research concerning the epilepsies;
3. the promotion of prevention, diagnosis, treatment and care for all persons suffering from these disorders;
4. the improvement of education and training in the field of the epilepsies.

While proudly acknowledging the progress of the first century of ILAE, all in ILAE, IBE and beyond will be aware that there are still enormous challenges in the century ahead to continue the promotion and fulfilment of these objectives on behalf of people with epilepsy throughout the world.

### **References**

- Avanzini G. *ILAE's regional approach and the electoral process. Epigraph, Issue 2, 2004.*
- Covanis A, Guekht A, Shichuo Li, Shakir R, Perucca E. *From Global Campaign to global commitment: The World Health Assembly's Resolution on epilepsy. Epilepsia 2015; 56: 1651-1657.*
- Shorvon S, Weiss G, Avanzini G, Engel J, Meinardi H, Moshe S, Reynolds E, Wolf P. (2009). *International League against Epilepsy 1909-2009: A Centenary History. Chichester, Wiley-Blackwell.*
- Wang WZ, Wu IZ, Ma XY et al. *Efficacy assessment of phenobarbital in epilepsy: a large community-based intervention trial in rural China. Lancet Neurology 2006; 5: 46-52.*
- Wolf P. *ILAE President's mid-term report. Epilepsia 2008; 49: 531-534.*