

2 International League Against Epilepsy – the second period: 1953–1992¹

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Compiling a history of this second period of the International League Against Epilepsy's (ILAE) existence, more than the first, is complicated by the lack of crucial documents. The dearth of archival material is due partly to the organisational structure of the ILAE (at this time no central office or archive), partly because of the personalities of those involved and partly because, after 1960, *Epilepsia* emphasised its role as scientific journal more than its role as a record of ILAE activity. The records of the League were kept by the secretary-general and moved around the world with each change in administration and under such circumstances proved vulnerable. Bernard Christian (B. Ch.) Ledebøer, secretary-general from 1949 to 1957, was the medical director of the epilepsy centre at Heemstede, Netherlands, and devoted to the cause of epilepsy, but his personal life was turbulent. The collapse of one of his several marriages resulted in an ex-wife leaving her substantial wealth to a competing institution. The scandal of the divorce was too much for the Christian board of Heemstede, who asked Ledebøer to leave. This turn of events apparently soured Ledebøer towards the ILAE, and in his disgruntled state he is believed to have taken the League's archives home from where

they ultimately disappeared (Meinardi 2007). Minutes from September 1974 indicate that Otto Magnus, also embittered following arguments with the American members of the ILAE executive, 'did not wish' to transfer all of his accumulated documents. Henri Gastaut, who earlier had actually appealed to the readers of *Epilepsia* to help him replenish the lost archives, hardly did better.² Few records from his long tenure on the executive survive. The first determined effort to preserve the historical papers was made by Harry Meinardi. In the 1980s he centralised and indexed the available materials, and his collection became the kernel of the current ILAE archive. The archive, then consisting of boxes of papers, some dilapidated and damaged, was moved at least three times before finally travelling to a secure setting in Zurich in 2005.³

The historical archives of well-known neurologists who were ILAE leaders (e.g. Macdonald Critchley, Francis Walshe, Frederic A. Gibbs, Denis Williams, A. Earl Walker and Jerome K. Merlis), where they exist, also seem surprisingly quiet on the topic of the ILAE. One obvious reason is that the League was still a relatively

¹ Unless otherwise noted, sources for the information reported in this chapter are the ILAE's archive, based at the Swiss Epilepsy Centre in Zurich.

² 'I know', Gastaut wrote to [ILAE president A. M. Lorentz de Haas] in French on 18 January 1965, 'that I am an awful secretary. Oh, I have a certain talent for organising and instigating things and am totally devoted to the cause of epileptics and the study of epilepsy. But I am unfortunately undisciplined and lose everything and keep no archives ... For this reason I am hesitant to continue in the position of secretary-general of our League and would very much appreciate your advice on the matter. I say this not out of false modesty but so that you will tell me with your customary frankness what is best for our association!'

³ The archives are now stored at the Swiss Epilepsy Centre in Zurich, under a contract with the ILAE. The archives were in fairly good physical condition when they arrived in Zurich, with the exception of the files from 1993 to 1997, which had sustained substantial water damage. But no attempt had been made to keep the archives systematically after Meinardi's efforts, and they had become incomplete and disorganised. In 2006, Simon Shorvon suggested to the executive commission that Giselle Weiss go through the archives and index them. This was agreed, and Weiss reordered the archive and produced an annotated index over the next 12 months. The index was placed on the ILAE website in 2007. This was a major step for the ILAE. For the first time the documents are in a secure environment and an orderly state, in principle accessible to the public and to scholars.

minor organisation. The World Federation of Neurology (WFN) and the International Federation of the Societies of EEG and Clinical Neurophysiology (IFSECN), with whom the League shared many members, were larger and more influential.⁴ Until 1987, the ILAE meetings took place in the shadow of the larger congresses of the two societies (and previously the International Congresses of Neurology⁵), which typically drew thousands of participants, and were in essence little more than a day-long afterthought. In the early years, the ILAE conferences also played second fiddle to those of its American Branch (the American Epilepsy Society, AES) which had carried the League through the Second World War, even from an international perspective.⁶ Properly exploring the relative roles of these organisations in this period is beyond the scope of the present volume, which necessarily focuses on the League's own institutional story, seen from the inside. But it is worth bearing this early

context in mind to fully appreciate the ILAE's later development. For since the 1990s, the tables have almost completely turned. The IFSECN has ceased to exist and been replaced by the International Federation of Clinical Neurophysiology (IFCN), whose activities in relation to epilepsy have been completely eclipsed by those of the ILAE. The ILAE has also become totally independent of the WFN and now has a worldwide reputation.

The 1953 quadrennial ILAE meeting in Lisbon and the ILAE 1953–1957

The 1953 quadrennial meeting of the ILAE took place in Lisbon, Portugal, on 12 September 1953.⁷ The new Executive Committee was voted in at the General Assembly during the meeting and consisted of A. Earl Walker⁸

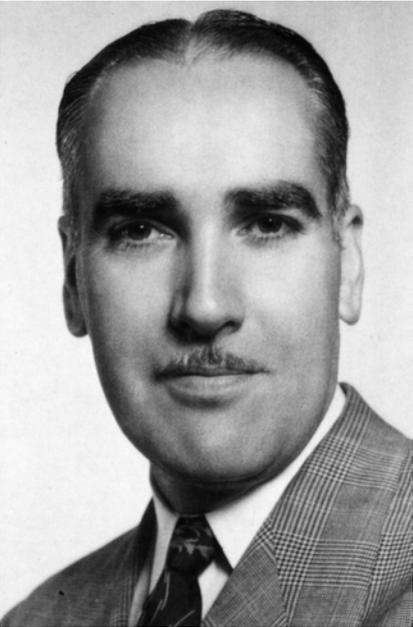
⁴ The World Federation of Neurology (WFN) was founded in 1957, initially with 26 delegates from 21 countries. At first it was rather overshadowed by the International Federation of Societies for Electroencephalography and Clinical Neurophysiology (IFSECN); but it soon grew into the predominant global neurological organisation it is today with over 25,000 individual members and 102 country chapters (China being the last country to join in 2007). The IFSECN itself was founded in 1947. It originally dwarfed the ILAE (and WFN) in size and influence, although petered out as a major force after the late 1980s. It has been resuscitated as the International Federation of Clinical Neurophysiology (IFCN), which now has 58 member societies from 55 countries (and in addition the 10 members of the International Clinical Neurophysiology Society, ICNS) and assets of approximately \$2 million. The IFCN owns the journal *Clinical Neurophysiology*, which was a reincarnation of the journal *Electroencephalography and Clinical Neurophysiology* (the EEG journal). The dropping of the term 'electroencephalography' from the title of the society and journal reflects the fall from grace of EEG and also the encroachment of the ILAE into old IFSECN territory. As an indication of its superiority over the ILAE in the 1950s, Gastaut turned down the presidency of the ILAE in favour of that of the IFSECN.

⁵ The International Neurology Congresses were the predecessor of the WFN conferences. The 1st congress was held in Berne 1931, 2nd in London 1935, 3rd in Copenhagen 1939, 4th in Paris 1949 and 5th in Lisbon in 1953. The WFN was formed at the 6th International Neurology Congress in Brussels. The ILAE has always been closely aligned with the international neurology movement, and indeed had attempted unsuccessfully to reform during the Berne meeting, and then did so successfully at the London meeting. The ILAE and IFSECN held their international meetings in concert with the International Neurological and WFN Congresses, the ILAE until 1987.

⁶ The AES during this period was an organisation that often considered itself 'semi-detached' from the international parent body. Its meetings were generally more scientific and of a higher quality than the ILAE meetings (and especially the Epilepsy International meetings, see below). Many members of the AES did not know that the organisation was part of the ILAE (a fact surprisingly still true today) nor that *Epilepsia* was the journal of the ILAE. Indeed, many thought it was the journal of the AES. So strong was the organisation that, for example, Canadian epileptologists considered the AES 'seamlessly' to represent their interests and thus saw no need to found a Canadian branch of the ILAE (Wada n.d.). For a long time, the event of the year for epilepsy specialists in Montreal was piling on to the train to attend the yearly AES meeting at the Roosevelt Hotel in New York.

⁷ The meeting was the 5th in the series of International Neurological Congresses. The 6th meeting, in Brussels, would be renamed 'Internationale Congrès des sciences neurologiques'. Ludo van Bogaert of Belgium, the secretary-general of the congress, wrote 'The 1957 Congress will be dedicated to the constructive coordination of neurosurgery, neuropathology, electroencephalography, clinical neurophysiology and even the activities of the International League Against Epilepsy' (Walker and van Alphen 2005, 16).

⁸ Arthur Earl Walker was born in 1907 in Winnipeg, Canada. Following early medical training in Edmonton and Toronto, he took up a residency in neurosurgery at the University of Chicago, which at the time was a fertile environment for neuroscience. He received additional specialty training in the United States and in Europe before being appointed head of the division of neurological surgery at Johns Hopkins Medical School in 1947. Walker's reputation had preceded him, as much for his 1938 monograph *The Primate Thalamus* (called 'monumental') as for his observation in 1946 that penicillin was a convulsive agent,



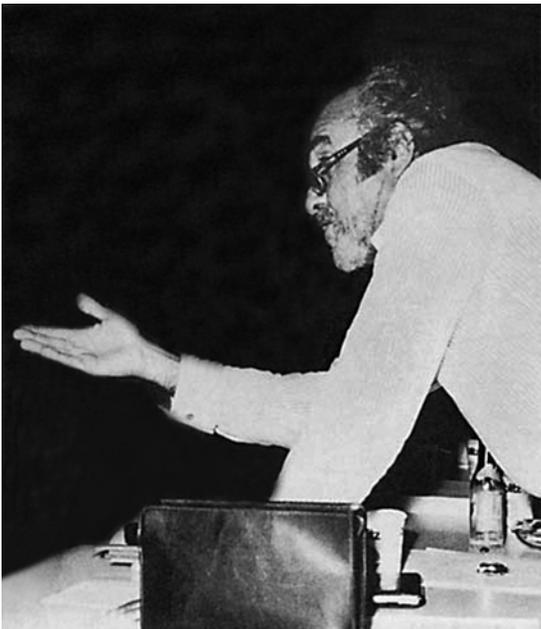
A. Earl Walker (1907–1995), president of the League from 1953 to 1961, ca. 1949. (Courtesy National Library of Medicine)

a finding of both clinical and research importance. At Hopkins, apart from the challenges of his institutional responsibilities, Walker developed a number of neurosurgical innovations, among them refinements to functional neurosurgery (such as electrocortigraphy) and temporal lobectomy. Walker was president for the ILAE for two terms, from 1953 to 1961. Together with Gastaut and Merlis he was responsible for resuscitating *Epilepsia* after it folded in 1956, although he personally was sceptical of the outcome. He was strongly committed to encouraging neuroscientists from developing countries, as is evidenced by his travels to South America on behalf of the League. He held positions in many other major organisations, and in 1965 was made president of the World Federation of Neurosurgical Societies. By all accounts a complicated personality and somewhat aloof, he was nonetheless much beloved by colleagues and students. He was an *éminence grise* of the American neurological scene and, working in concert with Penry, pretty well directed the pattern of American research and research funding in epilepsy at the time. Sadly, one of his children was killed in a freak bus accident in 1966. In 1972 Walker retired from Hopkins to Albuquerque, New Mexico. He died on New Year's Day, 1995, while riding as a passenger in a car driven by his wife (Niedemeyer 1995; Trufant 1996).

⁹ Henri Gastaut (1915–2005) is a near mythological creature in the history of international epilepsy and that of the ILAE, second only to Lennox in his devotion to the organisation and its journal. Born in Monaco to a family of modest means, Gastaut was an indifferent student but interested in everything. He dabbled by turn in banking

(president, United States), Henri Gastaut⁹ (president-elect, France), Dennis Williams (vice-president, England), Paulo

and politics (among other things) before embarking on medical studies in Marseilles where Henri Roger sparked his enthusiasm for neurology. In 1946 Gastaut went to Bristol, UK, to learn the basics of EEG with Grey Walter. On his return to France, he grew a beard (the result of a bet made with Antoine Rémond), traded his motorbike for a car and set up a small EEG laboratory at the Timone Hospital which rapidly attracted a group of French and foreign fellows eager to apply the new technology to the study of neurological syndromes. In 1949 Gastaut went to Canada for a brief sabbatical at the Montreal Neurological Institute with Wilder Penfield and Herbert Jasper. Back in Marseilles, with the aid of the Rockefeller Foundation, he began to build a research programme which culminated in 1961 in an INSERM unit in neurobiology. During this time he also created the Centre Saint Paul to treat epileptic children. Gastaut's contributions were innumerable and range from describing new EEG activities (such as lambda waves) to new forms of epilepsy (such as Lennox–Gastaut syndrome). He was deeply concerned with the naming of things (to wit, his classification of the epilepsies, formally begun in 1964) for which he realised a proper language was essential (hence his dictionary of the epilepsies, published in 1973). Gastaut trained generations of epileptologists, whose collective impact is known as the Marseilles 'school'. His Colloques de Marseilles, an enormously successful and influential forum for epilepsy, were held yearly from 1950 to 1980. Gastaut was committed to the international epilepsy movement. Not only did he found the French branch of the ILAE and help to form the International Federation of the Societies of EEG and Clinical Neurophysiology (IFSECN), but he realised the advantages to be gained by having major neurological congresses (including the ILAE) occur at the same time and place, and laboured tirelessly to make that happen. Gastaut was made president-elect of the ILAE in 1953 at the age of 38, but did not actually become president until 1969. In the interval he served as secretary-general of the League and as editor-in-chief of the journal. From 1961 to 1969 he held both offices concurrently. He is largely responsible for invigorating the ILAE and for bringing *Epilepsia* back to life following the Brussels congress in 1957. Gastaut made an indelible impression on people. His enthusiasm was catching, but he was occasionally high-handed and he had a quick temper. Robert Naquet has written that when, as a young researcher, he told Gastaut that he wished to be independent, it put a chill on their relations. Gastaut could, however, be equally (and charmingly) contrite, and many are the tales of him taking people to the opera or to dinner by way of apology. He was made dean of the Marseilles University Medical School just before the student uprising of 1968, which he managed with skill. Gastaut shared with his wife and longtime collaborator Yvette a passion for art, in particular a collection of skulls that now belong to the Vieille Charité Museum of Marseilles. He loved to sail. With his retirement in 1984, he left his professional life behind, appearing only rarely at meetings in France and Italy. He died at Marseilles aged 80, of cancer (Dravet and Roger 1996; Naquet 1996a,b; 1997; Lennox 1982).



Henri Gastaut (1915–1995), dominant ILAE figure of his times; he was the longest-serving member of the ILAE Executive Committee (1953–1977), and ILAE president 1969–1973.

Niemeyer (vice-president, Brazil), B. Ch. Ledebøer¹⁰ (secretary-general, Netherlands), H.P. Stubbe Teglbjærg¹¹ (treasurer, Denmark) and Jerome K. Merlis¹² (editor of *Epilepsia*, United States). The new administration

¹⁰ We know next to nothing of the early years and training of Bernard Christian Ledebøer (1897–1959). Harry Meinardi has described his major accomplishments in the *History of Neurology in the Netherlands* by Frederiks *et al.* (2002). Ledebøer was appointed medical director of the centre for epilepsy in Heemstede in 1930. His medical accomplishments there were many, including introduction of the ketogenic diet, cinematography (applied both clinically and for public education) and installation (in 1947) of the first Grass EEG machine in the Netherlands. But Ledebøer was also a superb organiser. During his tenure he managed to turn Heemstede from a residential care facility into a comprehensive centre with a hospital, a school and a network of outpatient clinics that extended throughout Holland. When Heemstede was taken over by the Germans during the Second World War, it was Ledebøer's plans and infrastructure that made it possible to transfer patients safely out either to their homes or to secure hiding places. Ledebøer joined the ILAE in 1946, first as vice-president and then in 1949 until 1957 as secretary-general. He emerges from the pages of *Epilepsia* as a fiercely committed if long-suffering member of the executive. Indeed, we have him to thank not only for what little we know of the history of those years but for ensuring its financial survival through loans from the Dutch branch. He had a stormy personal life, however, and its influence on his work was a factor in the loss of the League's archives up to that point.

signalled the end of William G. Lennox's long service to the League, and the group agreed to send him a telegram of appreciation.

Lennox had preserved the organisation during the war years and dominated its agenda. With him gone, the ILAE executive underwent a genuine change. Gastaut made his first appearance as president-elect, and he, too, would become an extremely active and powerful influence on the executive. (All in all, he would serve 24 years on the Executive Committee, including as president-elect, secretary-general, editor-in-chief, president and past-president.¹³) Gastaut

¹¹ Hans Peter Stubbe Teglbjærg was born in 1896. He grew up not far from Dianalund and knew Kolonien Filadelfia well. Following the end of his medical studies in 1921, he took up a post at the institute as a resident. In 1939 he became a consultant and chief of the epilepsy department. He wrote a thesis on investigations on epilepsy and water metabolism in 1936 and eventually became a renowned Danish authority on epilepsy. Stubbe Teglbjærg became associate editor of *Epilepsia* in 1948 and first joined the ILAE in 1949 as vice-president. He became treasurer in 1953. The job soon proved too much for him though, and it is not clear how much of his term he completed. For a time, Ledebøer, then secretary-treasurer, took up the slack. Stubbe Teglbjærg was active in the Association of Christian Danish physicians. He died in 1959.

¹² Jerome K. Merlis (1914–1982) held one of the first professorships of clinical neurophysiology in the United States. Born in New York, Merlis obtained his MD and an MS in neurophysiology at the University of Louisville, Kentucky, in 1937, and spent 1940/41 studying under John F. Fulton at Yale University. He went back to Louisville to start his independent career, and subsequently spent the years 1947–1956 heading up epilepsy centres first at the Cushing Veterans Administration Hospital in Massachusetts and then at the Boston V.A. Hospital. Notably, in 1956, he became professor of neurology and clinical neurophysiology at the University of Maryland, where he stayed until 1977. Merlis served on the ILAE Executive Committee from 1949 to 1973. Over that long span of time, he occupied every position (including president) but secretary-general, and was editor-in-chief of *Epilepsia* from 1953 to 1957. His obituary in the journal credits him with being a resurrecting force for *Epilepsia* in 1959. Moreover, Merlis chaired the ILAE Commission on Terminology and Classification from 1973 to 1977. He contributed significantly to experimental neurophysiology, clinical electroencephalography and the understanding of psychomotor epilepsy and its treatment (Glaser 1982).

¹³ The issue of whether one person should be allowed to stay on the Executive Committee for an extended period is one that continues to be debated. There is a tension which exists in many volunteer organisations. The need to renew and to encourage younger members is balanced by the fact that there are few talented individuals who are prepared, unpaid, to spend the time involved willingly. In 2005, it was decided that membership of the ILAE executive should be restricted to a maximum of 16 years. Another change was instituted – the president had to have been previously a member of the ILAE executive. This, with the 16-year rule, meant also that the president

Scheduling card for the 1953 Lisbon Congress. This includes the ILAE meetings, which were prominently placed on the programme with an invitation to all conference participants to attend. The conference also had a day devoted to excursions and ‘promenades’, a luxury no longer afforded in our less leisured times.

V^E CONGRÈS NEUROLOGIQUE INTERNATIONAL
PROGRAMME GÉNÉRAL (Résumé)

Dimanche 6	Inscriptions de 10 à 15 h. de 15 à 19 h.	Thé offert par le Comité Organisateur de 10 à 15 h.
Lundi 7	Inscriptions de 10 à 15 h. de 15 à 19 h. Réunion de la Ligue Internationale Contre l'Épilepsie de 9,15 à 10,15 h.	Ouverture Solennelle du Congrès avec la présence de Son Excellence le Président de la République, Société Géographique de Lisbonne. de 10 à 17 h. Réception des Congressistes par le Ministre de Lisbonne, Estufa Fria - Parc Edouard VII. de 17,30 à 18,30
Mardi 8	Séance Commémorative du Centenaire de von Monakow de 9,30 h. (Grand Amphithéâtre)	1 ^{er} Rapport de 10 à 15 h. Communications Libres de 15 à 19 h. Cours Supérieur de Neurologie- Projection de films de 15 à 17 h.
Mercredi 9	Toute la journée est libre pour excursions et promenades (par inscription)	
Judi 10	2 ^{ème} Rapport (Grand Amphithéâtre) de 10 à 15 h.	Communications Libres de 15 à 19 h. Cours Supérieur de Neurologie- Projection de films de 15 à 17 h. Réunion de la Ligue Contre l'Épilepsie de 15 à 19 h.
Vendredi 11	3 ^{ème} Rapport (Grand Amphithéâtre) de 10 à 15 h.	Communications Libres de 15 à 19 h. Cours Supérieur de Neurologie- Projection de films de 15 à 17 h. Réunion de la Ligue Contre l'Épilepsie de 15 à 19 h. Dîner officiel du Congrès au Casino d'Estoril de 19 h. à 22 h.
Samedi 12	4 ^{ème} Rapport (Grand Amphithéâtre) de 9 à 12 h.	Assemblée Générale Clôture du Congrès de 12 à 15 h. Réception offerte par leurs Excellences le Ministre de l'Éducation Nationale et le Ministre des Affaires Étrangères de 17 à 19 h.

Dimanche, 13 – Départ du train spécial pour Madrid à 8 heures. Pour des renseignements plus détaillés on devra consulter le Programme Général du Congrès. Le personnel et le bureau du Congrès se trouvent à la disposition des Congressistes, de 9 à 15 heures et de 11 à 19 heures, dans le Nouveau Hôpital Universitaire de Lisbonne (Hôpital Escolar). La Ligue Internationale Contre l'Épilepsie invite tous les Congressistes à assister aux Réunions scientifiques de la Ligue.

differed from Lennox in almost every way, and it is a pity that the terms of the two did not coincide: it would undoubtedly have been an interesting and possibly productive interaction. As it was, the link between European and American epileptology was maintained by president Walker, an academic neurosurgeon and respected doyen of the American epilepsy scene.

A copy of a preliminary programme of this quadrennial meeting of the ILAE survives, showing on its first page the emblem of the neurological congress: a medal featuring portraits in relief of Santiago Ramón y Cajal and Constantin von Monakow (the congress marked their centenaries). The congress itself had a glittering programme. Walshe led a major session on the parietal lobe, in which Critchley, Jean Lhermitte, H. Hoff and Derek Denny-Brown took part. On Friday, attendees could look forward to a dinner dance at the Casino d'Estoril. The programme also announced the schedule of a meeting devoted ‘exclusively’ to the ILAE. This was an extraordinary event, devoted to the new topic of temporal lobe epilepsy. Is it too much to suggest that its excellence and topicality possibly contributed to the establishment of the ILAE on the map of international meetings? The meeting itself was reported in *Epilepsia* by Ledebor (1953, 56–57), and was the subject of a recent editorial in *Epilepsia* (Shorvon

(who had to serve his term and then a term as past-president) has to be selected from those who were previous members by those who had previously served no more than 8 years – this restricted the list of potential candidates considerably.

2006).¹⁴ The League assembled in the amphitheatre of the new hospital of Lisbon, ‘a huge building’. The scientific meeting was devoted to the subject of temporal epilepsies,

¹⁴ As recorded in the editorial: ‘Few conferences in epilepsy can have been so productive or influential [as this one]. It successfully brought together the views of the intellectual leaders of the field and ... most of their conclusions remain uncontested even today, most of their controversies are unresolved, and most of their cautions should still be heeded. We can learn much, particularly from the unanimous rejection of the view that temporal lobe epilepsy is highly localized (a mistaken view often repeated today), and from the detailed neurophysiology that was presented. The importance of what we would now refer to as a neural network underpinning the seizures was fully recognized, as was the diffuse nature of the network involving rhinencephalic, diencephalic and neocortical structures, spread anatomically well beyond any lesion such as “incisural sclerosis”.’ Participants in this verbal discussion were A. Earl Walker, S. Obrador Alcalde, Murray Falconer, John F. Fulton. B. Fuster, K.W.E. Paine, G. Pampiglione, R.S. Schwab, A. Subirana, F.A. Gibbs, J. Guillaume, G. and Y. Mazars, H. Jasper, Birger Kaada, W.G. Lennox, Margaret Lennox and Otto Magnus. Masland and Wilder Penfield were not present but sent in written commentaries. Gastaut also proposed a ‘classification’ of temporal lobe seizures (an early sign of his interest in classification). Lennox was the only one to mention ‘febrile seizures’ as a possible cause of temporal lobe epilepsy and doubted that it was possible to subclassify temporal lobe seizures anatomically as Gastaut proposed – ‘the brain is too complicated and too well integrated to contain even a phase of epilepsy within a certain brain compartment’ – the anatomical localisation of seizures as a form of modern phrenology was one doomed to recur over and over again to this day. Fred Andermann attended the meeting and recalls the picture of Gastaut in his characteristic posture, standing bent forward over his papers, dominating the proceedings. The picture conjures an image to us of a golden eagle standing over his prey.

which was introduced by Gastaut who noted that he had devoted the last 5 years of his life to their study. The meeting had an interesting structure – taking the form of a series of expert discussions of an article circulated in advance by Gastaut. The article is divided into six sections, which Gastaut called critical studies. These were summaries of contemporary knowledge augmented by Gastaut's own data, and covered the following areas: clinical symptoms; electroencephalographic symptoms; correlations between the clinical and electroencephalographic symptoms; surgical anatomical findings; pathogenesis; and methods of treatment. The article concluded with a review of experimentally induced attacks of psychomotor or temporal epilepsy. This sparked a lively discussion which was published subsequently in *Epilepsia*.

The Executive Committee met on the night of Tuesday 7 September to prepare the next day's business meeting. Following an address by Critchley, the committee heard reports on the progress and financial position of the League. Chile, Japan and Peru were welcomed as new chapters, bringing the total number of branches to 10.¹⁵ A new constitution was ratified and would be sent to the members. It was, wrote Ledebøer, 'most important for the activities of the League in future' (Ledebøer 1953, 56). The 1953 constitution made no provision for a past-president, which meant that the year also marked the departure of Critchley.¹⁶ He later became president of the WFN and was a hugely influential neurologist – his absence from the ILAE diminished the contact between epilepsy and neurology, and the League thereafter tended to plough its own furrow, separate from its parent discipline.¹⁷ This was an active meeting: Walker was committed to cooperating with the World Health Organization (WHO)

¹⁵ These were Argentina, Brazil, Chile, France, Great Britain, Netherlands, Japan, Peru, Scandinavia, the United States and Canada.

¹⁶ Critchley was a generalist with no particular interest in epilepsy. He has left papers and has been the subject of biographical interest, but in these documents the ILAE hardly features at all – one presumes that he probably had no particularly strong attachment to the League. His appointment, however, would have certainly added worldwide legitimacy and authority to the organisation. Prior to his presidency, he was, apparently, active on behalf of the British branch: 'We understand that the secretary of [the British branch of the ILAE], Dr Macdonald Critchley (137, Harley-street, London, W.1), hopes to hear from other medical men who are interested.' At the time, the branch had 'over a hundred members' (Notes and news 1937, 823).

and with the United Nations Educational, Scientific and Cultural Organization (UNESCO). 'Between these meetings', wrote Ledebøer, 'the Office of the League was frequented by many persons who wanted information and/or wished to become members and subscribe to *Epilepsia*. Here also the possibilities of founding Branches in several countries were discussed.'

The same issue of the journal carried a lengthy secretary-general's report by Ledebøer (1953, 101–104).¹⁸ 'So far as I know,' he wrote, 'this is the first official report on the activities of the League as a whole ... which has been made since its foundation' [actually, it was not]. He lamented the 'lack of a well-functioning organisation' over the previous 4 years – which must have been insulting to Critchley who was a consummate organiser but, in stylistic contrast to Ledebøer, in a cool dispassionate way. The 'total lack of a constitution' and a 'binding regulation for the required finances' were specific weak points. He was, he said, 'considerably oppressed' with carrying on the League's task of attending to the world's 10 million epileptics in the face of limited resources. This was a slightly ridiculous position, and it is difficult to see what good Ledebøer's travelling, or indeed the ILAE, would have done for the 10 million. One can speculate that his unhappiness at this stage more reflects his personality and difficult personal circumstances. Despite the pledge by branches at the Paris meeting to send him one-third of their national income as payment of dues, few had met their obligations. His own institution had generously advanced half the cost of the secretariat year after year, but obviously after his departure would not continue to do so. He described at length his strategy for how the ILAE might go about tackling the fight against epilepsy – largely impractical, emphasising the social rather than scientific, and rather unfocused. In this context, he made a point 'as important as it is difficult', that the best possible organisational structure for achieving the League's

¹⁷ In the United States, epilepsy was then rapidly separating from neurology and establishing an identity as an independent subspecialisation. Conversely, in Britain, for instance, there was a concerted effort until the late 1970s to avoid subspecialisation of any area of neurology. The pros and cons of these different philosophical approaches continue to be argued.

¹⁸ This is an interesting document, throwing as much light on Ledebøer as on the ILAE. It takes the form of a long personal statement of beliefs, with many points that are not likely to have been shared by all the executive.



B. Ch. Ledebøer (1897–1959), the League's long-suffering secretary-general in the post-war years, ca. 1949. (Courtesy National Library of Medicine).

goals would be one that incorporated both physicians and laymen. He finished by recommending that *Epilepsia* continue its tradition of publishing 'almost everything about the literature on epilepsy [that] could be found' and encourage reports from the branches, but not focus on original articles. He finished with a grandiose flourish by misquoting Churchill.¹⁹

Ledebøer's report was prefaced by a brief and anodyne 'Letter from the President' by Walker. In it he stated that the constitution adopted at the Lisbon meeting 'should enable [the League] to function more smoothly and to fulfil its objectives with greater ease' (Walker 1955, 101). The ILAE's original constitution, formulated in 1912, had been dropped when the League disbanded at the outbreak of the First World War. After the League reformed in 1935, it created a new constitution. Dated 1939, the new statute was half the length of the original one and did little more than to name the ILAE and its officers, and to state that the League should hold meetings when it could and that chapters should pay dues as fixed "by the members or

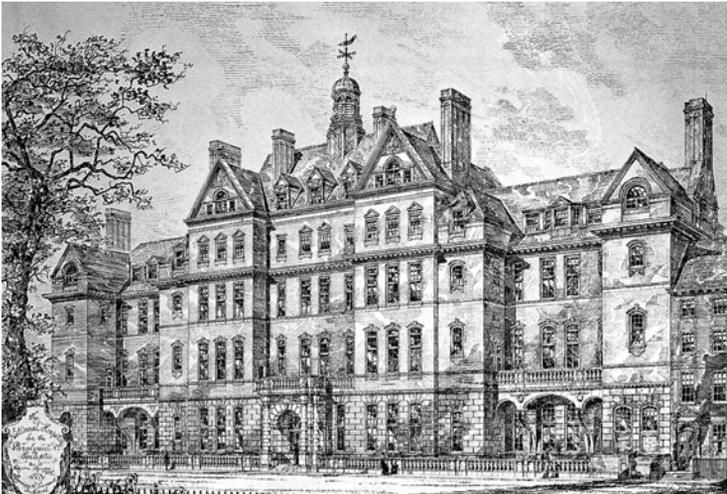
the officers from time to time' (Constitution 1940, 248). How the 1953 constitution was arrived at we do not know (see Appendix 5). It possibly reflects the organisational genius of Critchley, and it was very different from the 1939 version. It contained 13 carefully worded articles that covered everything from the name of the League to the location of its head office, to methods of working, to explicit requirements for dues and the appointing of special committees. The League would be administered by a General Assembly, a Committee²⁰ and an Executive Committee. Dues were set at \$5 (\$39 in today's dollars²¹) per member. Chapter dues would be one-third the sum collected from the members' dues, and would be payable to the treasurer of the League. Membership lapsed automatically on non-payment of dues (Constitution 1953, 113). Although considerably elaborated and constantly tinkered with over time, the core structure of the 1953 constitution remains today.

Following the meeting of the General Assembly, Denis Williams, the League's treasurer since 1946, transferred 'all the available funds', which had been frozen during the war, to Ledebøer in Holland. A personal appeal to the secretaries of delinquent branches 'did not lead to transfer of any proportion of subscriptions, possibly because of currency regulations' (a problem that was to recur not infrequently over the years). 'I have', he wrote, 'incurred no office expenses.' An accompanying 'working survey' shows that for the 4-year period September 1949–August 1953, the League's expenditure amounted to 10,809 florins (\$33,438 at current values), mostly for travelling. Income consisted of dues paid by the United States, Brazil, England and Scandinavia, as well as a gift from

²⁰ The 'Committee' was conceived to be the Executive Committee plus chapter vice-presidents 'who are the accredited representatives of their national branches'. This group would meet at the General Assembly. A confusing concept from the start, it was replaced in 1973 by the Council. The Council's function was to advise the executive in particular in ratifying new bylaws and in approving the appointment of the editor-in-chief of *Epilepsia*, and to handle matters normally under the jurisdiction of the General Assembly between assemblies. In 1997, the Council, too, was dropped from the constitution.

²¹ In this chapter, here and there we have, as a point of calibration, converted original currencies into current values using the American Consumer Price Index (CPI) converted into 2007 dollar values. The data are taken from tables published on www.measuringworth.com, where an explanation of the measures is also given. We make these comparisons only up to the mid-1980s. Thereafter, they cease to be of any particular interest.

¹⁹ A controversial view, not shared by the executive, and see Chapter 7 for a discussion of the role of *Epilepsia*.



National Hospital for the paralysed and epileptic, Queen Square, London, in 1885. The hospital is one of the most celebrated in the world. It was founded in 1860 for the alleviation initially of epilepsy and paralysis, and among its early physicians were famous names in epilepsy: John Hughlings Jackson, Sir David Ferrier, Sir William Gowers and Sir Victor Horsley (1857–1916). The name has changed several times (now the National Hospital for Neurology and Neurosurgery), but the hospital remains on the same site and in the same building, which was completed in 1885, and with a large epilepsy practice. At least 20 ILAE Executive Committee members worked in the hospital at some point in their career. (Courtesy Wellcome Library, London)

Meer en Bosch of 5,000 florins. Debt outstanding to Meer en Bosch, as well as expenses still to be paid, amounted to 2,140 florins (Williams 1953, 105). In other words, at the time, the ILAE was in deficit and dependent on loans.²²

It is important to recognise that at this time the ILAE was a very small organisation. Membership had only just risen to 10 chapters, and there cannot have been many individual members (we estimate fewer than 600).²³ Reports from the branches from 1953, published in *Epilepsia*, help somewhat to flesh out the picture of the League's activities. Abraham Mosovich of Argentina, who had been waylaid en route to Lisbon by an emergency operation, apologised for 'not being able to contribute more in the financial aspect' of the ILAE, but also suggested 'that a fixed contribution' for all the branches might be in order. Paolo Niemeyer, president of the Brazilian chapter (founded in 1949), reported that his league now numbered 109 members. Among other activities, the chapter had produced 'a model for the clinical and neurological examination of the epileptic patient'. Moreover, the statutes had been changed to include a class of lay members, with a view to creating a new source of income. W. Aldren Turner, who had been instrumental in founding *Epilepsia*, contributed two sentences for the British league. The French chapter's report, which was unsigned, stated that

the branch had 'temporarily given up social action ... in order to bring all its efforts to bear on the medical and scientific aspects of the fight against epilepsy'. It was also focusing on 'spread[ing]' *Epilepsia*. A film on epilepsy commissioned by the French league in 1951 had been shown to many audiences of physicians throughout France.



Paulo Niemeyer (1914–2004) of Brazil, a noted epilepsy surgeon and ILAE vice-president from 1953 to 1957, in 1996. (Courtesy Elza Márcia Targas Yacubian)

²² These were apparently made without the expectation that they would be paid back (H. Meinardi, personal communication).

²³ Even these were not all 'official' and some contributions were tiny; most did not pay their dues.

Gastaut had presented a report at a meeting on electroencephalography (EEG) in Marseille in 1952, which must have been one of his early forays into an area about which he would later write voluminously. Despite persisting financial constraints and a government whose response was of a 'rather platonic character', the Netherlands branch reported a fairly high level of outreach activity. An 'epilepsy day' was held every year and proved to be popular. A small legacy left by L.J.J. Muskens enabled the printing of popular folders and screening of an epilepsy film 'all over the country' (Reports from the Branches 1953, 108–110).

A year later, Ledebøer reported in *Epilepsia* that the League had applied to and been accepted as a member by the Council for International Organizations in Medical Sciences (CIOMS).²⁴ Cuba had joined the ranks of the branches. Belgium, Israel, Spain, Austria and Italy were working to create branches, with varying levels of difficulty. The outlook for the League's financial situation was hopeful, following ratification of the new constitution in Lisbon. Unfortunately, the treasurer, H.P. Stubbe Teglbjaerg, had fallen ill from overwork, putting a halt to all financial activities. The only dues received were those from the Netherlands. Once again, Meer en Bosch had come to the ILAE's aid with funds. Ledebøer had organised the mailing of 40 letters to branches and individual members to stimulate contributions (Ledebøer 1954, 111–112). The reports in *Epilepsia* revealed some signs of activity from other chapters.²⁵

²⁴ The CIOMS was established jointly by the World Health Organization (WHO) and UNESCO in 1949 to coordinate medical congresses and to provide a global forum for discussion of biomedical advances. The liaison with the ILAE was short-lived. In 1965, then president McNaughton announced to the General Assembly that, as affiliation to the CIOMS brought no advantages, the ILAE would be resigning as a member.

²⁵ The page preceding Ledebøer's report bears a photograph of the League's 'president-elect' Henri Gastaut along with two brief paragraphs describing his lecture tour to Brazil, Uruguay, Argentina, Chile, Peru, Ecuador and Colombia, during which visit he also took time to stump for the League (Henri Gastaut 1954, 110). The annual meeting of the British branch had drawn some 60 members and guests. In its first year, the Cuban league already had almost 40 members and had held four meetings. For 1954, the French branch was planning two meetings on basic physiological and anatomical problems in epilepsy. Coincident with the first of the meetings, which was to take place in November in Paris, the French league was planning a meeting devoted to the social aspects of epilepsy, to be chaired by Ledebøer. The Japanese league had been busy with scientific studies. F.H. Glastra van Loon reported that the Netherlands branch had

The 1955 volume of *Epilepsia* carries no further news from Ledebøer, only the text of a president's report by Walker stating that trips he had made to South America and Europe had revealed much interest in the activities of the League. Walker announced that a newsletter²⁶ would be sent to all branches beginning 1956 whose purpose would be 'to keep the members throughout the world abreast with the clinical and research advances in epileptology'. He drew attention to the research being carried out in the United States on anticonvulsive drugs which would be reported at a forthcoming meeting of the American League Against Epilepsy in New York that December (Walker 1955, 109). One of Walker's stop-offs on his tour was Rio, where the Brazilian league was hosting an international symposium on electrocorticography. At its annual meeting, the British league had heard a discussion on epilepsy and the motorist,²⁷ and enjoyed an 'admirable lunch'. The Cuban branch had sponsored two conferences, including one on the social aspects of epilepsy sponsored by Ellen Grass.²⁸ The French league

received a token subsidy from the government – a sign of interest at least – and that the annual epilepsy day had been attended by 100 medical specialists. The American branch had voted to appoint a special committee to 'draft ideal legislation for epileptic patients' and to push for its adoption. The American league was also concerned to reduce competition between epilepsy organisations in the States.

²⁶ So far as we know, this newsletter never materialised.

²⁷ The topic for the following year was to be epilepsy, marriage and parenthood.

²⁸ Ellen Grass (1914–2001) was born Ellen Harriet Robinson in Taunton, Massachusetts, and educated at Radcliffe College. She became interested in brain function and in 1935 began graduate study in the department of physiology at Harvard Medical School. There she met Albert Grass, an electrical engineer who had been asked by Frederic Gibbs to 'build three channels of EEG amplifiers to drive the Western Union Morse Code inkwriting undulator' (cited in Zottoli 2001, 219). Ellen and Albert were married in 1936, and shortly thereafter Albert's EEG machine was employed by Frederic and Erna Gibbs, William G. Lennox and Hallowell Davis in pioneering studies of epilepsy. Together in 1945 the Grasses founded the Grass Instrument Company to provide high-quality equipment to researchers in the neurosciences. The success of the company led first to a trust to support research into the brain, and, in 1955, to the establishment of the Grass Foundation to advance neurophysiology and related fields. Among other activities, the foundation created the Grass Fellowship Program to enable neuroscientists to train for a summer at the Marine Biological Laboratory in Woods Hole. Ellen Grass helped to create both the Epilepsy Foundation of America and the IBE, and in so doing made an incalculable contribution to the volunteer epilepsy movement around the world. She was president of the IBE from its inception until 1977. She died in Quincy, Massachusetts (Pedley 2007).



International Colloquium of Electrocorticography in Rio de Janeiro, 1955. From left to right: Abraham Mosovich, Henri Gastaut, Aristides Leão, A. Earl Walker, Bartolomé Fuster, Paulo Niemeyer, Carlos Vilavicencio. All were important figures in the evolving ILAE, which then as now had an important presence in Latin America. (Courtesy Elza Márcia Targas Yacubian)

now had over 100 members and stated, in a rather startling reversal of its previous policy, that they now wished to ‘reduce its efforts in purely scientific activities and to increase its activities in the social sphere’. It had accordingly created a commission to work with the Directorate of Social Hygiene of the Ministry of Public Health and Population. The branch was also mulling over whether to accept a private gift to create a new medical teaching institute for epileptic children (Reports from the Branches 1955, 110–114).

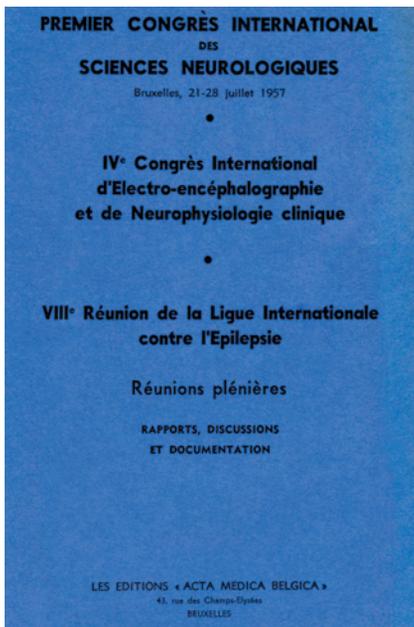
ILAE 1957–1961 and the 1957 quadrennial meeting in Brussels

From 1955 to roughly 1961, the ILAE fades from the public record. The main reason is that between 1956 and 1959, *Epilepsia* ceased publication (see Chapter 7). ‘The supply of articles failed,’ wrote Lennox later (Lennox and Lennox 1960, 2:1035). Because the journal served as the main source for disseminating news of the League’s goings-on, its shutting down has created another lacuna in the ILAE’s history.

One can imagine, however, that in 1955, the League executive was preparing for the next General Assembly, in Brussels, planned to coincide with the 6th International Neurological Congress. Also meeting at the same time were the 4th International Congress of Electroencephalography, the 3rd International Congress of Neuropathology

and the 1st International Congress of Neurological Surgery (Aarli 2007).²⁹ Billed as the First Congrès International des Sciences Neurologiques, the congress was a deliberate (and successful) attempt to launch a World Federation of Neurology. The founding of the WFN would have implications for the ILAE for years to come. No account survives of the League’s business dealings in Brussels, although the scientific presentations on epilepsy appear in volume 3 of a five-volume proceedings edited by van Bogaert and Radermecker (1959). In his president’s report of 1955, Walker had provided a glimpse of what was to come: ‘The [ILAE] has been given a very favourable spot in the programme for the 1957 International Neurological Congress’, he wrote. ‘It has been assigned the first morning (Sunday) for its symposium which will probably be on certain aspects of temporal epilepsy. This will enable the League to hold a meeting without competition from any other society, and should promote considerable interest in its activities’ (Walker 1955, 109). In the event, the League seems to have had an entire day (although joint with the International EEG Congress), at least based on the undated programme presented in the proceedings, with a programme that extended beyond temporal lobe epilepsy and with addresses from over 25 speakers including Critchley, Buchthal, Grey Walker, Gibbs, Penfield and Gastaut.

²⁹ The word ‘sciences’ was a late addition to the title of the meeting to mollify neurosurgeons, who were feeling marginalised (Walker and van Alphen 2005, 16).



At the time of the League's 8th meeting in Brussels in 1957, *Epilepsia* had temporarily ceased publication. (Courtesy Royal Association of Medical Scientific Societies of Belgium)

At Brussels, a new slate of ILAE Executive Committee members was brought on board: Walker remained president; Gastaut assumed the secretary-generalship³⁰; Merlis became treasurer; and Sir Francis Walshe, of England, was appointed editor-in-chief of the journal.³¹ If other positions were included, we do not know of them. Such archival material as exists during this time concerns primarily the journal (see Chapter 7).

ILAE 1961–1969 and the quadrennial meeting in Rome, 1961

The ILAE held its 9th meeting in Rome on 10 September 1961, and there the General Assembly was held. It lasted only half an hour but was enough time to bring in a

³⁰ According to Margaret Lennox-Buchthal, Gastaut refused the presidency in 1957 to become president of the Federation of EEG and Clinical Neurophysiology. He eventually became president of the League in 1969.

³¹ The makeup of the executive is known through 'a collaborator of the former secretary-general' (Meinardi 1999, 24).

new Executive Committee: Francis L. McNaughton³² (president, Canada); Bartolomé Fuster (vice-president, Uruguay); A.M. Lorentz de Haas³³ (vice-president and editor, *Epilepsia*); Gastaut (secretary-general and editor, *Epilepsia*). Merlis remained as treasurer.

In 1959/60 *Epilepsia* was resurrected in a fourth series, and with it, the window of sorts on to the League was opened once again.³⁴ Lennox had died in the interim, and the journal began with his obituary, written by Frederic Gibbs. The first issues of *Epilepsia* contained a plea to the national branches of the ILAE, as well as this announcement: 'At the last General Meeting of the league a new secretary-general (Henri Gastaut) was appointed. Unfortunately, in connection with the subsequent death

³² Francis Lothian McNaughton was born in 1906 in Montreal. The son of a physician, he studied medicine at McGill and neurology at the National Hospital, Queen Square. His primary interests were epilepsy and head pain. In 1957 he took over the department of neurology at the Montreal Neurological Institute and brought his pacific nature and kindness to bear in building its international reputation. McNaughton assumed the presidency of the ILAE in 1961. He was an active servant of the League during his tenure, and a faithful cheerleader for it afterwards. He was one of the small group originally chosen by Gastaut in the early 1960s to develop an international classification of the epilepsies. He was the vice-president of the American Neurological Association, the president of the Canadian Neurological Society and the third president of the American Epilepsy Society. A connoisseur both of art and of music, McNaughton also had an abiding concern for human justice, medical and otherwise. He died in 1986 at the age of 80 (Andermann 1987).

³³ Albert M. Lorentz de Haas (1911–1967) was the grandson of the physicist Hendrik A. Lorentz, who shared the Nobel prize in 1902 for his work on magnetism and light. Albert trained in medicine in Utrecht and had a brilliant early career. In 1951, he was awarded a Rockefeller Foundation fellowship to work under Lennox at Harvard, and there met Merlis and Cesare Lombroso, who were also fellows. In 1955, he succeeded Ledeboer as medical director of Meer en Bosch, the famous epilepsy centre in Holland. The League then was in effect a small club, and Lennox, Merlis and Ledeboer were all at one time ILAE president or general-secretary. In 1961 Lorentz de Haas became vice-president of the ILAE, and in 1965 its president, holding these posts and the managing editorship of *Epilepsia* in tandem. Lorentz de Haas had a fine intellect, was an erudite and serious person and was apparently easy to get on with, unlike perhaps his predecessors Walshe and Ledeboer. His life, though, was cut short by the recurrence of malignant disease, first treated in 1962. He died after a relatively short illness in October 1967 at the age of 56 (Magnus 1967).

³⁴ Although, as the editor made clear, primarily as a scientific journal and not as a vehicle for the publication of ILAE minutes or material (see Chapter 7).

of his predecessor (B. Ch. Ledeboer), the archives were lost completely. The secretaries of each organisation are therefore requested to supply the present secretary-general [Gastaut himself] with information about the structure and running of their organisations, together with the names of the members of the board, the number of ordinary members, and the scientific and social activities' (Appeal 1961, 100).³⁵

The scientific programme, which was sketched briefly in *Epilepsia*, ran from 9am until half-past noon, and included presentations on EEG, differential diagnosis, epilepsy in the different stages of life and social aspects of epilepsy in childhood. The speakers were R. Vizioli, Joseph Roger, M. Vigouroux, W.F. Caveness, P. Passouant, P. Kellaway, Th. Alajouanine, P. Castaignes and A.M. Lorentz de Haas (Ninth Meeting 1961, 101). Why Gastaut is not on the programme is not clear. He did present at the neurological congress in a session on neurological diseases associated with cardiopulmonary disorders. He was just completing his presidency of the IFSECN.

The league was obviously gathering momentum. In 1962, *Epilepsia* reported the founding of the Michael Stiftung and its awarding of a prize to investigators younger than 45, which was open to German authors and would be awarded at the time of the ILAE congresses (also a sign of the restitution of Germany into the international community). The March issue of 1964 carried the text of the first William G. Lennox Memorial Lecture, given by Herbert Jasper (Jasper 1964).³⁶

Founding of the International Bureau for Epilepsy: the 'social' arm of the ILAE

During the General Assembly in Rome, a development of the greatest importance to the history of the epilepsy movement occurred: the proposal to found the International Bureau for Epilepsy, initially as the 'social arm of the ILAE'. The League was criticised for paying too little attention to the social and behavioural side of epilepsy (see Chapter 6). George Burden, general secretary of the British Epilepsy Association, later reported that the

³⁵ An extraordinary situation; but it is clear that the ILAE executive had at this stage really no idea exactly how many chapters were in place or who were the officers of its chapters. This is a remarkable level of disorganisation.

³⁶ This actual lecture was given to the American Epilepsy Society on 5 December 1963.

The Netherlands Branch (*Federatie voor Epilepsie-bestrijding*) has adopted an attractive emblem of its own, in the form of a stylized wave-and-spike . In the words of the Secretary, Dr. Otto Magnus, the emblem itself has a symbolic character, the "spike" representing epilepsy, and the "wave", the fight against it. This emblem has already been adopted by the French National Branch of the League, and Dr. Magnus has suggested that other National Branches which have no emblem might adopt it. Your Executive has reached no decision, but this suggestion should be sent to all the national branches for their consideration, in the coming year.

The origin of the ILAE logo.

British Epilepsy Association had been permitted to hold, during the Rome Congress, a meeting on the role of lay organisations in the treatment of epilepsy.³⁷

In what has become known as the Mosovich motion, the president of the Argentinian ILAE chapter proposed setting up a separate association that would cooperate closely with the League. It would be called the International Bureau for Epilepsy (IBE), and so it was that the IBE was established – at a conference of the ILAE – as the ILAE had been established at the international medical congress. The IBE emblem – a candle (at the time the emblem of the British Epilepsy Association) – was also adopted for the international organisation and remains. (The League's own emblem, the 'spike and wave', originated as the logo of the Dutch branch. Discussion of it first appears in the *Epilepsia* account of the 1965 congress in Vienna. It did not figure on ILAE congress programmes until 1976.)

The move to create the IBE echoed Ledeboer's earlier call for unity, and no doubt would have pleased him. From this very time, a debate has endured about whether, and to what extent, lay and professional people should work together in the same organisation. In the United States, a laymen's league had been existence since 1940, founded by Lennox, but had become fragmented. The combined 1959/60 volume of *Epilepsia* carried a brief announcement of the establishment of the American Epilepsy Federation, 'an effort to unite the entire lay epilepsy movement' (Announcement 1959/60, 232). According to Burden's report of Ellen Grass's presentation, this was the result of a survey of existing groups made in 1957 by the American Branch of the ILAE which recommended consolidating groups.

³⁷ Three addresses were made by Lorentz de Haas (medical director of the epilepsy centre at Meer en Bosch), Ellen Grass (president of the American Epilepsy Federation) and Irene Gairdner (of the British Epilepsy Association), each giving details of the lay organisations of their countries, followed by brief presentations by Karl-Axel Melin of Sweden, Abraham Mosovich of Argentina and Kilgour of the Scottish Epilepsy Association about facilities in their own countries (then as now, Scotland seems semi-detached from England).

Ellen Grass (1914–2001), a co-founder of the International Bureau for Epilepsy (middle); to her left is Frederic Gibbs and far right is Erna Gibbs, 1953. In 1955, Ellen and her husband Allen founded the Grass Instrument Company, which developed and manufactured EEG machines. These were sold worldwide. Despite the great international success of their enterprise, the Grasses maintained a personal interest in epilepsy and had a remarkable reputation for personal service and philanthropy. (Figure 2 from S. Zottoli, *Biological Bulletin* 2001, 201:218–226. Reprinted with permission from the Marine Biological Laboratory, Woods Hole, MA)



Henri Gastaut and the international classifications of epileptic seizures and of the epilepsies

During the 4-year term of the executive, another major development was set in motion by secretary-general Gastaut, namely a classification scheme for epileptic seizures (Table 1). This scheme was badged with the ILAE name, and as such over the next decades catapulted the League into the consciousness of neurologists around the world, in a way that had not been previously possible. This remains one of the most enduring and important achievements of the ILAE.

The interest in classification first appeared publicly on 1–2 April 1964, when Gastaut called together a group of 120 members of several European branches³⁸ which met in Marseilles to discuss a possible international classification of seizures. According to Gastaut, the discussion was lively with a presentation of a preliminary classification by a group representing the European chapters (Gastaut 1969a).³⁹ At the time, there were various incoherent

and incompatible classifications of seizures, and Gastaut's (brilliant) idea was to standardise these, under the flag of the ILAE.⁴⁰ He rightly realised that a uniform system of diagnostic terms was essential for effectively studying and treating the disease. At the end of the meeting, the group had come up with a preliminary scheme (Gastaut *et al.* 1964, 297). This classification was then submitted to a Commission on Terminology consisting of representatives of the European and American branches of the league, the WFN (J. Radermecker) and of the IFSECN (W. Storm van Leeuwen).⁴¹ How the commission came

³⁸ Gastaut used the term 'branch' not 'chapter', and this appellation, reflecting perhaps Lennox's visualisation of the ILAE as a trunk (the executive) and branches, sadly is now lost. The British branch remained a branch until 2004 (a deliberate imperative of the then president, Tim Betts) when for no particular reason the name was changed. We would like to see the term resuscitated as an echo of the organic and close-knit nature of the ILAE.

³⁹ The group consisted of Gastaut (chair), Hans Heinrich Landolt (Swiss branch), Desmond Pond (later Sir Desmond Pond, British branch), A. Subirana (Spanish branch) and R. Vizioli (Italian branch).

⁴⁰ An article by Richard Masland in *Epilepsia* in 1959/60 summarised a number of classification schemes, including an earlier version of Gastaut's, and suggested 'a classification based on the coding system in the Standard Nomenclature of Diseases ... which would categorise patients into three main groups, i.e. "central epilepsy", "partial epilepsy" and unlocalised seizures of known or unknown etiology' (Masland 1959). A preliminary, undated draft of the preface to the 1964 article in *Epilepsia* states that the Marseilles group chose to classify 'epileptic attacks' rather than 'the epilepsies' because the former was simply more feasible.

⁴¹ The Commission on Terminology was the very first in a long line of ILAE committees and commissions on special topics. How the members of the commission were appointed is unknown, but they were very likely chosen by Gastaut unilaterally. The members of the first commission were: W.F. Caveness, Gastaut, Landolt, Lorentz de Haas, McNaughton, Magnus, Merlis and Pond. Within a year it was enlarged to include M. Gozzano (Italy), J. Kugler (West Germany), P.M. Saradzisvilli (USSR), Z. Servit (Czechoslovakia), T. Wada (Japan) and A. Earl Walker (United States – representing the World Federation of Neurosurgical Societies).

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Table 1 The various versions of the ILAE classification* of seizures, and of the epilepsies and epileptic syndromes, published in *Epilepsia* between 1964 and 1989.

Year	Classification of seizures	Comment	Classification of the epilepsies	Comment
1964	A proposed international classification of epileptic seizures (5:297–306)	Classification for ‘general adoption by neurologists’ with a one-page intro. by Gastaut. Includes a ‘Summary form classification’	n/a	n/a
1969	Clinical and electroencephalographic classification of epileptic seizures (10:S2–S13)	‘Modified and perfected’ version of the 1964 seizure classification. The ‘Summary form classification’ has been abandoned (‘too short and too different’). Masland’s alternative classification was also published	Classification of the epilepsies (proposed) (10:S14–S28)	Draft classification of the epilepsies with commentary published in <i>Epilepsia</i> in advance of the 1969 quadrennial meeting to promote discussion
1970	Clinical and electroencephalographic classification of epileptic seizures (11:102–113)	Identical version to the 1969 publication. It had been submitted to the ILAE General Assembly in 1969, and now carried the ‘recommendation’ of the ILAE and others. It appears to have been reprinted simply for convenience	Proposal for an international classification of the epilepsies (11:114–119)	Revised proposed classification of the epilepsies based on discussions at the 1969 quadrennial congress in New York. Merlis invites ‘comments and criticisms’
1981	Proposal for revised clinical and electroencephalographic classification of epileptic seizures (22:489–501)	Revision to the 1969 classification of seizures representing the work of two commissions since 1975 and based on ‘new technology’ (study of videotapes). It was ‘approved’ by the ILAE in 1981	n/a	n/a
1985	n/a	n/a	Proposal for classification of epilepsies and epileptic syndromes (26:268–278)	Intended as a ‘complement’ to the classification on epileptic seizures accepted by the ILAE General Assembly in 1981 and to reach consensus on the ‘apparently irreconcilable opinions of different schools about syndromic classifications and terminology.’ Begins by considering the 1970 classification of the epilepsies
1989	n/a	n/a	Proposal for revised classification of epilepsies and epileptic syndromes (30:389–399)	A ‘consensus statement’ based on experience with the 1985 classification of epilepsies ... ‘suitable for mutual exchange of ideas’

* The stimulus for Gastaut’s classification for the epilepsies was actually a request in 1968 by WHO for a classification to supplement its glossary of epileptological terms, an effort Gastaut had been involved with since 1964. ‘Gastaut’s’ dictionary was published by the World Health Organization in 1973. The Commission on Classification and Terminology (1989) was considering updating and expanding Gastaut’s dictionary. It is not clear what happened to this effort. In 2001, however, the Task Force on Classification and Terminology published a ‘Glossary of Descriptive Terminology for Ictal Semiology’ (Blume *et al.* 2001).

Henri Gastaut and colleagues at the Marseilles Colloquium of 1964. The Marseilles colloquia were most important events in the history of epilepsy. Run mostly by Gastaut himself, these colloquia were held almost every year, from 1950 to 1980, each attracting up to 500 participants. They had his personal touch and were a launching pad for his important initiatives. The 9th colloquium, in 1962, was the first meeting to be devoted to status epilepticus and led to a new chapter in the study of this condition. The first draft of the ILAE classification of seizure types was unveiled at the 1964 colloquium.



into being is not quite clear. But that it already existed in 1963 is evident in a circular letter from Gastaut to the 'six' other members enclosing a crude outline of a classification and requesting 'brief' critiques.⁴² The Commission next met on 11–13 May 1964 for a 3-day session to discuss the Marseilles proposal at Meer en Bosch. The product of the Meer en Bosch meeting – 'avoiding neologisms as far as possible and points of view too new or outrageous' – was subsequently published in *Epilepsia* (Gastaut *et al.* 1964). The pace was very fast, and the next step was to introduce the classification at the League's upcoming congress in Vienna in 1965:

The International League Against Epilepsy takes pleasure in announcing its Quadrennial Meeting in Vienna on September 5th, 1965. Subject is the discussion of a proposed terminology and classification of the epilepsies, to be formulated by an international commission under the auspices of the ILAE, the World Federation of Neurology and the International Federation of EEG Societies ... The printed text of the proposed classification will be sent two months in advance to all registered members of the International Congresses of Neurology and of Electroencephalography. All members of both congresses are cordially invited to take an active part in the discussion. (Announcements 1964, 376)

The classification was accordingly circulated to all the participants of the ILAE meeting, and reprints of the classification (the 1964 *Epilepsia* paper) were sent to 14,000 neurologists by the secretary of 8th International

Congress of Neurology and the International Federation of EEG societies. Gastaut was ecstatic for it meant that neurologists and electroencephalographers around the world would see the classification. He also asked neurologists who were members of a national neurological society for comments. Gastaut presented the classification on 5 September 1965 to a joint meeting of the 8th International Neurological Congress and the quadrennial meeting of the ILAE. As he wrote: 'All criticisms formulated during this meeting and those addressed by 170 neurologists directly to Gastaut, were used to correct the scheme of classification which was then sent back to the members of the Commission on Terminology'. The speed at which this was carried out was a hallmark of Gastaut's energy and method. He involved as many other persons and organisations as possible, but managed always to have his own opinion prevail – in his characteristically quasi-democratic autocratic style.

The revised scheme was then reviewed in New York on 30 November 1967 by the ILAE executive, joined by Earl Walker. All these discussions yielded a further draft, although there was no agreement on certain details, for instance the differentiation and terminology of absence seizures (how like today!); whether these should be known as typical/atypical absence (Gastaut's preference) or petit mal/petit mal variant or not differentiated at all; whether somato-inhibitory seizures should be included; whether déjà vu and jamais vu were apperceptive or dysmnestic or intellectual manifestations. The ILAE executive were counting angels on the head of a pin, and the delay must have greatly annoyed Gastaut. In any event, the new version of the classification was published in 1969 (Gastaut 1969a).

⁴² Gastaut's own letter is undated. But Lorentz de Haas answered as early as 9 May 1963.

The classification received the strong recommendation of the Executive Committee and was presented to the General Assembly and republished (unchanged) in 1970 in *Epilepsia*. Presumably it was approved by the General Assembly, although this is not actually stated anywhere that we can find.⁴³

By then Gastaut had moved on, and now was considering the question of a classification of the epilepsies, as well as a classification of epileptic seizures. In the same 1969 supplement as the classification of seizure type, Gastaut added a personal paper (Gastaut 1969b) presenting a provisional ‘classification of the epilepsies’, as he put it, ‘a classification which some regard as rash, or outdated or even useless. Perhaps its chief advantage is that it can serve as the anvil on which critics can hammer out a classification of higher value’ (S15). This was formulated in a manner similar to the classification of seizures. Gastaut prepared a draft, sent it (in August/November 1968) to the officers of the League, the members of its fledgling Commission on Terminology, and experts of the WFN and the IFSECN attached to the commission, and asked for comments within a month. The commission would then meet at a time sufficiently early to permit publication of the draft in *Epilepsia* before the quadrennial meeting of the League in September. This was a punishing schedule, and may have been deliberately chosen so by Gastaut to prevent too much dissent. But this time there seems to have been serious opposition from the commission members (‘one-third considered my suggestions unacceptable and delays and reservations prevented one-third of the persons consulted from informing me of their opinion’), and the commission meeting was not called. Undeterred, Gastaut submitted his draft directly to the New York quadrennial meeting and published it in *Epilepsia* before the meeting.⁴⁴ In reporting the process in the journal, Jerome K. Merlis (who assumed the ILAE presidency following the death of Lorentz de Haas) described the follow-up to this:

⁴³ The publication in *Epilepsia* in 1970 of the classification is preceded by an introduction by Gastaut outlining (his version of) its gestation, and the classification is tagged by the statement that it is ‘Recommended by the International League Against Epilepsy, the World Federation of Neurology, the World Federation of Neurosurgical Societies and the International Federation of Societies for Electroencephalography and Clinical Neurophysiology’ (Anon. 1970, 112).

It was obvious that detailed discussion at this meeting [general assembly at the New York quadrennial meeting] would be impossible, due to the strictures of time. In the belief that some preliminary discussions were essential if what appeared to be irreconcilable differences of approach and viewpoint were to be resolved, I, as President of our League, attempted the impossible. With the cooperation of the Presidents of the International Federation of Societies for Electroencephalography and Clinical Neurophysiology, the World Federation of Neurology and the World Federation of Neurosurgical Societies, an International Commission for Classification of the Epilepsies was appointed and arrangements were made to meet in New York, on September 20, one week before the quadrennial meeting. (Merlis 1970, 115)

The discussions occupied the whole day. As Merlis wrote, ‘The initial period could be described as chaotic, with many divergent approaches being presented and with frequent interruptions of speakers by, sometimes, rather warm disagreement. Nevertheless, as time went on, a core of agreement on certain basic principles seemed to emerge and, once this became apparent, the discussions proceeded with surprising ease. I think I can say that, despite being hoarse and tired at the end of the day, many, if not all, of the participants felt that it had been an instructive, productive and exhilarating experience’ (Merlis 1970, 114). The proposal was then presented to the ILAE meeting on 27 September 1969 and the General Assembly on the same day. The revised classification was published in *Epilepsia* in 1970 (11:114–119). Further revisions were made to the classification of epilepsies in 1985 and 1989. To complicate matters, the classification of epileptic seizures first published in 1964 and revised in 1969 was revised again in 1981.⁴⁵ As Merlis had said, the classification is not ‘fixed for all time ... As our knowledge

⁴⁴ In the same issue, Masland (a future president of the WFN) published his own ideas on classification – suggesting an aetiological classification and a revision of both seizure and epilepsy classifications into a single uniform scheme in four divisions: by aetiology, seizure patterns and EEG, anatomy and modifying factors (age, circadian, hormonal, reflex). Actually, to our eyes, this is a more sensible classification than the new Gastaut version, but needless to say, it was not adopted.

⁴⁵ The 1969 classification of epileptic seizures appeared again in *Epilepsia* in 1970 (11:102–103). These versions are identical. The 1970 publication was simply reprinted as part of the report of the 1969 quadrennial meeting of the League.

of the epilepsies increases, it will undoubtedly require modification, not only as to criteria, but in fact, in its whole organisation' (Merlis 1970, 117).⁴⁶ As time passed, further amendments were made to the classification (see below). Indeed, at the time of writing the commission is currently devising a major revision. The name of the Commission on Terminology was changed to the Commission on Terminology and Classification.⁴⁷ It is the League's first and oldest commission.

The 1969/1970 ILAE classification of seizure type became universally adopted, no doubt in large part due to Gastaut's untiring promotion and his intelligent use of WHO, WFN and other organisations. Moreover, the tagging of the classification with the ILAE name was a publicity coup for the ILAE. By virtue of the classification scheme, the ILAE became synonymous with professional authority in epilepsy. In our opinion, this single activity did more than any other to catapult the ILAE into the top position in the world of epilepsy.

⁴⁶ The commission realised that it would be important not to 'intermix classification of seizures and classification of epilepsies', although, in fact, that is precisely what happened, and generations of epileptologists ended up being confused.

⁴⁷ The commission ran until 1993 and was then reconstituted as a Task Force in 2005 and remains active to this day.

⁴⁸ Hans Heinrich Landolt was the only Swiss member of the Executive Committee in modern times. Born in 1917 to a prominent Swiss family, he grew up in the Italian-speaking part of the country. He was talented enough at the piano to be playing concert halls in his teens, but decided instead on medicine as a career. He inspected prisoners' camps in Germany and England for the International Red Cross during the Second World War, at the conclusion of which he went to La Salpêtrière in Paris for neuropsychiatric training. In 1949 he moved to the Schweizerische Anstalt für Epileptische (today the Swiss Epilepsy Centre) as an intern, and took over as head when the medical director, Friedrich Braun, died in 1954. Landolt was a modest person who preferred the care of his patients to the bustle of scientific activity. Nonetheless, he made recognisable contributions, in particular his observation of 'forced normalisation' of the EEG. He disdained the blind application of statistics to the detriment of thinking. But he was no luddite, and lobbied effectively (and in the face of a small budget) to modernise his institution in keeping with William G. Lennox's concepts regarding the management of epilepsy. He served in the League only as vice-president, from 1965 to 1969, although he appears to have been a voice of moderation, especially vis-à-vis the desire of some members of the ILAE to abandon the relationship with the IBE. He was also one of the early members of Gastaut's classification group. Landolt died in 1971 (Hess 1971).

ILAE 1965–1969 and the 1965 quadrennial meeting in Vienna

The next ILAE General Assembly was held in the Hofburg, Vienna, on 9 September 1965. The new Executive Committee was voted in and comprised A.M. Lorentz de Haas, Netherlands, president and editor of *Epilepsia* (replaced in 1967 after his death by Merlis); Hans Heinrich Landolt,⁴⁸ Switzerland, vice-president; David Daly,⁴⁹ United States, treasurer; and Francis L. McNaughton, Canada, past-president.⁵⁰ Gastaut remained as secretary-general.

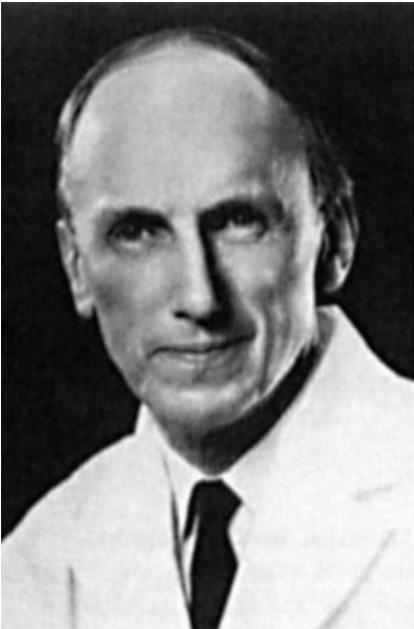
The meeting was a momentous occasion, not least as it was the first meeting at which the IBE played an integral role, as Gastaut's correspondence attests. It is hard to tell from the archives whether Vienna could properly be called a 'joint' meeting, though by 1967 that was certainly the case. Indeed, holding joint international congresses lies at the heart of the ILAE mission, and although threatened from time to time in subsequent years, the concept has been retained since its inception. The ILAE and IBE standing shoulder to shoulder, with the visible product of a joint international congress, has been a powerful force in the field of epilepsy – exerting influence far greater than would be possible by either organisation alone.

⁴⁹ David Daly (1919–1991) received his medical degree at the University of Minnesota in 1945, and worked both at the Mayo Clinic in Rochester and then at the Barrow Neurological Institute in Phoenix, Arizona, before moving to the University of Texas in Dallas where he chaired the department of neurology from 1966 to 1973 and remained until 1984. As a professional, Daly specialised in studies of epilepsy and EEG, and he helped to pioneer the use of videomonitoring. He was also a consummate public servant. In the 1960s, along with J. Kiffin Penry and a young James Cereghino, he worked on the Surgeon General's Advisory Committee on the Epilepsies, chaired at the time by Houston Merritt – just one of his many committee and study section activities. Together with Kiffin Penry and Ellen Grass, Daly was instrumental in getting Congress to authorise the Commission for the Control of Epilepsy and Its Consequences in 1974. He was president of the American Epilepsy Society and the American EEG Society, and a director of the Epilepsy Foundation of America. Daly was a fixture on the ILAE executive from 1965 until 1981 as treasurer (for two terms), then president and past-president. Juhn Wada credits him with having supported the formation of the Canadian branch of the League. Described as honest but pugnacious, he clashed openly with officers of the both the League and the Bureau at several different reprises (Cereghino 1994).

⁵⁰ The concept of past-president must have been introduced informally around this time. It did not exist previously, and it does not appear in the constitution until 1973.



Hofburg, Vienna, ca. 1965. The Hofburg was the site of the 1965 ILAE congress. It had been the residence of the sovereigns of Austria for over 600 years and an important location in the history of events in Europe. The ILAE session comprised a single-day workshop on Gastaut's proposed classification of the epilepsies. (Image from the American Geographical Society Library, University of Wisconsin-Milwaukee Libraries)



Francis McNaughton (1911–1967), nicknamed 'St Francis' for his pacific nature.

The preparations for Vienna were carefully scripted by Gastaut, as his communications to the executive reveal. In one such missive addressed to 'my dear friends', dated 13 June 1965, Gastaut detailed the agenda. In addition to the officers, the Executive Committee meeting would include Landolt, the local congress organiser, Gilbert Glaser (at the request of McNaughton, then president) and

David Daly ('if he accepts to be treasurer'). The scientific meeting was to be held on Sunday 5 September, from 9am to 1pm. Gastaut also envisaged a lunch which perhaps might be open to the representatives of the international branches, provided the treasurer had no problem with it ('two or three times the guests!'). Since he had no time to arrange the invitations, he asked McNaughton to do them. The General Assembly would take place on Thursday 9 September, from 9am to 3:30pm. Gastaut had asked the local organiser to state on the programme that the General Assembly would be followed by a discussion to find common ground on an international classification of epileptic seizures. 'That,' he wrote, 'is in response to the request of Dr Merlis that the General Assembly be made as attractive as possible to draw the maximum number of people.' An even more detailed plan for the Executive Committee meeting was attached, at the top of which Gastaut had typed the French equivalent of ILAE: 'L.I.C.E.'. Among the items for discussion was the form of the League's international meeting: whether it ought to continue as a simple half-day affair at the beginning of the neurology congress or expand to a more independent one- or two-day event. The sole constitutional item on the agenda was the elimination of the position of president-elect, for the reason that it was impractical to decide the president 4 years before the start of his term.

An unsigned report in the journal described the proceedings after the fact. Walker and Richard Masland weighed in on the importance of defining terms unambiguously for the proposed classification of epileptic

seizures. A film on absences collated by Gastaut was to be made available, with text in several languages. A statement sent in by the treasurer for the period June 1961–June 1965 and read to the assembly showed total income for the League of \$6,372 (\$41,863 in 2007 values), including a balance brought forward of \$2,266. Peru, Germany, the United States, Netherlands, England and Switzerland had paid dues. Japan had sent dues for 1956–1961, although for reasons not specified, the amount was not credited. Expenses came to \$2,381, mostly associated with *Epilepsia*. As the new treasurer, Daly was faced with the perpetual problem of annual contributions from the national branches. The French branch, for example, had not paid its dues for several years, and it was hoped that Gastaut's influence could be brought to bear in remedying the situation. McNaughton suggested that with the help of Lorentz de Haas, it might be possible to draw up an official list of the current executives of the national branches; it was also hoped that a regular newsletter might help to bring closer contacts that would encourage dues paying (General Assembly 1965, 348–350).⁵¹

On 7 July 1966, Lorentz de Haas wrote a letter to the members of the Executive Committee updating them on various matters of business. He was by this time suffering from advanced melanoma. 'Since, as you know [although many did not],' he began, 'illness has kept me from working for more than three months, my activities for the [ILAE] have also been interrupted. Today, however, I have the pleasure of asking your attention for the following points.' The first issue concerned possible modifications to the constitution, as resolved in Vienna. He suggested, among other things, a mechanism for having national



H.P. Stubbe-Teglbjaerg, ILAE treasurer 1953 to 1957.
(Courtesy National Library of Medicine)

organisations provisionally approved by the Executive Committee rather than having to wait until the next General Assembly for admission. The position of 'president-elect' was to be replaced by 'past-president'. 'Editors' of *Epilepsia* 'might be members of the Committee; the managing editor might be a member of the Executive Committee.' He raised the question of multiple terms for the secretary-general and the editors and managing editor of the journal. Individual members should have an advisory vote; sponsoring members no vote. The Committee should meet at least once every 4 years. An article covering the IBE might be introduced.

Lorentz de Haas then discussed the Bureau at length. He recapped the rationale and circumstances of its founding. 'The Bureau has since carried out a variety of tasks and developed laudable activities,' he wrote. 'It is perhaps understandable that the Bureau has done so in a position of considerable independence. The question, however, is whether this independence has not assumed proportions reaching farther than has ever been the intention of the Committee of the International League.' Already, friction had arisen between the secretary-general (Gastaut) and the head of the Bureau (George Burden), particularly concerning the appointing of 'medical' officers to the

⁵¹ The report contained the following additional details: McNaughton had kicked off the assembly with the report of the League's activities. The constitution, he said, needed to be revised. He also proposed that communications between the branches be promoted via a 'personal' newsletter to be created as a supplement to *Epilepsia*. The managing editor of the journal reported that 200 papers had been contributed since the launch of the fourth series, and that one-third of the papers came from the United States. Subscriptions had roughly doubled. Hope was expressed that, at the next General Assembly, more time would be given to reading papers. Austria, Bolivia and Poland were accepted as new members. Two individual members were announced: Mogens Lund (Denmark) and Karol Matulay (Czechoslovakia). Gastaut, Ellen Grass and George Burden discussed the ILAE and IBE and concluded that the 'exact functions and relationships' between them needed urgently to be sorted out.

board of the Bureau without notifying the League. There was no denying the interweaving of medical and social factors in epilepsy, and the need to attend to both. But the League felt keenly that its turf was being encroached upon. 'While we may gratefully acknowledge all that the International Bureau in London has so far done, we must bear in mind (as must the Bureau) that it is closely linked to the League and owes its appellation "International" to the League. Should the Bureau fail to understand this, then the League could in fact establish another bureau at any time, anywhere in the world.'⁵²

The executive was quick to respond, although opinions on all issues were mixed.⁵³ 'As regards the General Assembly,' wrote Merlis from Baltimore on 13 July, 'the circumstances are such at the quadrennial meetings that there is not a fair representation from all national branches ... This means that it would be unfair to have the General Assembly have any voting power since a large contingent from the U.S., for example, could easily control a majority of the votes ... The matter of the International Bureau of Epilepsy is a difficult one. As I recall, at the Rome meeting, there was a definite feeling by many that the bureau should not be an integral part of the International League but should be in symbiotic relation to the League.' That same day, Gastaut responded, 'As for the International Bureau, I agree with everything you wrote in your letter. I am also very happy to see that you have finally decided to broach the matter. You know that for a long time I have considered that the Bureau's insufferable independence diminishes the effectiveness of the League, and that this competition between two organisations that have the same goals is ridiculous and

intolerable.' He had no quibble with the constitutional proposals. David Daly answered at length on 25 August, going systematically through many of the 'categories and terms never precisely defined' in the constitution. 'In retrospect,' he wrote vis-à-vis the Bureau, 'perhaps the League erred initially in not defining formally the relationships of the Bureau to the League ... I gather the Bureau has become a creature with a life of its own ... The League should clarify its relationships with the Bureau prior to any attempt to amend the League's constitution ... In the event that members of the Bureau do not accept such proposals then the League would have only the recourse of withdrawing any financial and moral support of the Bureau's activities.'

Another round of detailed correspondence followed beginning in October. In a letter to the Executive Committee dated 5 October 1966, Lorentz de Haas proposed new changes to the constitution, taking into account the responses he had received. A suggestion that the secretary-general of the Bureau be an ex officio member of the League's executive had been unanimously agreed to. Daly had raised the question of a nominating committee, 'to clarify the mode of proposing candidates'. Finally, Lorentz de Haas said, the relations to the Bureau had developed in a favourable manner, especially following a meeting between Burden and 'a representative of the Dutch Branch' in Wiesbaden. (According to an announcement in a 1967 issue of *Epilepsia*, the first official meeting of the IBE council took place at Wiesbaden. Before that time, the Bureau had existed only informally.) The constitution of the Bureau would stipulate that it was to act as the Bureau for Social Affairs of the League. The Bureau agreed to seek advice from the League on medical matters (indeed, the Executive Committee of the League would be the Medical Advisory Committee of the Bureau), and Burden had abandoned a proposal that the ILAE's branches contribute financially to the Bureau. Lorentz de Haas finished by asking what amount of money the League could place at the disposition of the Bureau. In a letter dated 8 November, Daly deferred the question to the executive.⁵⁴ Lorentz de Haas died on 4 October 1967, and Merlis took over as president for the remainder of the term.

⁵² In other words, the Bureau would have to accept its 'obligations [to submit] to a measure of control by the Executive Committee of the International League and [consult] the International League on all strictly medical problems and appointments'. He finished by apologising for a delay in publishing *Epilepsia*, and made some comments regarding the promised newsletter: '[The newsletter suggested] by Dr McNaughton has by no means been forgotten. However, there is little sense in starting publication of such a newsletter unless we are sure it can be continued. The new items will have to be supplied by the national branches, few are which are particularly active. In this context it is my intention to address a letter to all branches; so far I have been unable to do this, but I have recently received the addresses of a number of officers at national branches which I had been expecting.'

⁵³ By the standards of today, Lorentz de Haas' comments seem patronising. It is not clear how the IBE responded.

⁵⁴ At the time, Daly said the League's account, which was in Phoenix, Arizona (Daly himself was based in Texas), came to \$4,435. Eventually, the League agreed to give the Bureau \$500 (\$3,194 in 2007 dollars) a year (Announcements 1967, 71).

Opening ceremony of the 1969 World Congress of Neurological Sciences (the ILAE met on the last day of the congress) at the Hilton Hotel in New York City. The ILAE held its meeting jointly with the congress, for which epilepsy was also one of three main themes. The ILAE meeting took place on 27 September 1969, and it was here that the ILAE classification of epileptic seizures was finally approved. (Image courtesy of the World Federation of Neurosurgical Societies)



ILAE 1969–1973 and the 1969 quadrennial meeting in New York

The ILAE General Assembly, held on 27 September 1969 at the New York Hilton Hotel, was the last to be reported in *Epilepsia* (General Assembly 1970). The assembly followed the ILAE's scientific meeting, which was subsequent to the week-long meeting, at the same location, of

the World Congress of Neurological Sciences. According to minutes of the League Executive Committee meeting in New York in December 1965, the programme had been prepared by a committee of the AES in consultation with the president and executive of the ILAE.⁵⁵ That said, the schedule of talks appears to have been surprisingly European: of 17 speakers listed on the programme, only three (Daly,⁵⁶ White and Taylor) were American. Gastaut

⁵⁵ On 2 December 1965, Gastaut, McNaughton, Merlis and Daly had met as the Executive Committee in New York. Also present were a Dr Sanseigne, research director at Parke, Davis; and Richard Schmidt and Preston Robb, president and president-elect of the AES, respectively. According to minutes drawn up by McNaughton, Gastaut turned his absence film over to Sanseigne, who agreed on behalf of Parke, Davis to see it completed. Although there was no discussion regarding the future use of the film, the executive officers felt that the League should take the initiative in producing or promoting films that illustrate the types of seizures included in Gastaut's international classification. The idea was to get financial support from pharmaceutical companies, as was being done in Europe in at least two cases. Together with Schmidt and Robb, the discussion turned to the 1969 quadrennial meeting of the League in New York. The AES would be drawing up the programme in consultation with the president and Executive Committee of the International League. A preparatory meeting was to be held in New York in June 1967. On 20 March 1967, McNaughton wrote Lorentz de Haas to ask how the purported plans for an Executive Committee meeting in New York in June were coming along. On

26 April, Lorentz de Haas responded, in a detailed letter, that he had himself never intended to organise such a meeting, and that, all things considered, he would prefer not to go on account of his 'personal circumstances' and not wishing to leave his small son. If McNaughton, who was going to go anyway (on account of a WFN meeting), wished to meet with Merlis and Daly informally, it could be useful. 'Much depends on the question whether our proposals with regard to the arrangements to be made for the International League during the congress in 1969 will be accepted by the other organising societies. Prof Gastaut will speak on this subject to Drs Yahr and Merritt on May 19th and his expectations with regard to the presumable result of their talk were optimistic.' As it happened, no meeting took place in June. Instead, the Executive Committee gathered on 30 November 1967 in New York where, joined by Earl Walker, they reviewed the latest draft of Gastaut's classification of epileptic seizures (Gastaut 1969a, S2). By then Lorentz de Haas had died.

⁵⁶ Daly did not attend the General Assembly supposedly due to illness. We do not know whether he actually was at the scientific session.

headlined the session with a presentation on classification of the epilepsies (see Chapter 9).

At the General Assembly a new slate of officers was submitted and passed: Gastaut, president; Merlis, past-president; Karl-Axel Melin,⁵⁷ Sweden, first vice-president; Luis Oller-Daurella, Spain, second vice-president; Otto Magnus, Netherlands, secretary-general; and Margaret Lennox-Buchthal, Denmark, managing editor of *Epilepsia*. Daly remained as treasurer.

A number of topics were discussed. The idea for the newsletter fizzled out, and despite a proposal made earlier by Lorentz de Haas that communications be included with 'Announcements' in the journal,⁵⁸ these were largely limited to prizes and forthcoming congresses. Fortunately for the history of the League, around this time archival materials had begun to accumulate, although they are thin through the early 1970s. Merlis opened the New York meeting by remembering Lorentz de Haas, and proceeded to give a brief review of the activities of the League. He named as principal responsibilities the preparation of the international congresses and the development of *Epilepsia*. Merlis thanked Otto Magnus for stepping in to maintain the journal during the illness and after the death of Lorentz de Haas,⁵⁹ and he welcomed Magnus's successor, Lennox-Buchthal. The ILAE and the IBE were

cooperating nicely, as evidenced by two joint symposia, one held in Paris in October 1967 and the other in Dunblane, Scotland, in June 1968.

Questions were raised about whether epilepsy specialists could become individual members of the ILAE (they could⁶⁰) and whether lay organisations could become members (they could not). Asked whether special rules governed qualifications for national branches for admission, Merlis replied that the rules had evolved over time. Currently, he said, national associations applying to become a branch of the ILAE had to submit statutes and bylaws and a list of officers and active members. Membership of Bulgaria as a branch was approved.

The location of the League's next international congress would be Barcelona, in conjunction with the International Neurological Congress there in 1973. The assembly agreed to publish the plans for the event as soon as possible so that research centres could direct their activities accordingly. The ILAE intended to make planning international meetings and fighting epilepsy in developing countries a priority. In these activities it would cooperate with the Bureau and, if possible, with other organisations. Otto Magnus gave a forward-looking appraisal of the journal. For whatever reason, the revision of the constitution did not make it onto the agenda, and would have to wait until 1973.

ILAE treasurer David Daly was absent due to illness, but a succinct report covering 1966–1969, signed by him, appeared in the minutes of meeting published in *Epilepsia* in 1970. As of 1 January 1970, the League had \$4,636 (\$24,749 in 2007 dollars) in its account in Phoenix, Arizona. Contributions (presumably dues) for those years ranged from \$150 in 1966 to \$917 the next year. Contributions for 1969 had been \$303. The account had drawn \$761 in interest. Expenses for 1967 and 1968 were mostly for the classification commission meeting and the League's \$500 contribution to the IBE. All of the 1969 expenses, totalling \$1,443, appear to have been for the New York meeting.

⁵⁷ Karl-Axel Melin was born in Gothenburg in 1915. He received his medical degree from the Karolinska Institutet in Stockholm. He developed an interest in epilepsy during his subsequent training in paediatrics. In 1953, he took up a position at the Stora Skondal, a hospital for patients with epilepsy, and spent the remainder of his career there. Melin helped to found the national lay organisation for epilepsy in Sweden, which led to his involvement with the IBE from its inception in 1961. He served as a vice-president of the League from 1969 to 1973, and treasurer from 1973–1981. The early 1970s coincided with a clash of cultures between the Americans and Europeans on the ILAE executive. Otto Magnus, as secretary-general, felt especially aggrieved by the Americans' focus on the bottom line and disregard for process, and in 1972 he left. From that time, and up to the Barcelona congress in 1973, Melin assumed Magnus's duties. Melin died in 1992.

⁵⁸ On 26 April 1967, Lorentz de Haas wrote Francis McNaughton, 'The suggestion of a Newsletter, made by you at the time, keeps occupying my mind. Should it appear in *Epilepsia*, like the one in *Neurology*, or separately as a loose pamphlet? In the former case it would not reach all the branches of the League. In case it should be published separately, I wonder how the expenses should be met and in what way publication should take place ... For the time being I think the most feasible solution would be to give some extension to the communications under the heading Announcements in *Epilepsia*.'

⁵⁹ Between 1961 and 1969, Lorentz de Haas and Henri Gastaut, in addition to their other functions on the executive, shared the editorship of *Epilepsia*. It is not clear how this situation came to be, although there was precedent for it in the examples of William G. Lennox and H.I. Schou.

⁶⁰ Article IV of the ILAE Constitution.

Like Ledebøer before him, Otto Magnus was able to keep the secretariat going and to cover the expenses of his travel from a contribution of the Netherlands branch and other sources. And he had, in fact, been tremendously active on behalf of the ILAE. At a meeting of the executive on 5 September 1971, Melin suggested that extra-League expenses and contributions be shown more clearly in the secretariat's accounts. At the same meeting, a proposal was made (subject to the future approval of the treasurer, who was not present) to have the European branches make use of a banking account that the secretariat now had in Wassenaar. But dues collection remained a source of frustration and the League's financial reporting haphazard. Officers spent more than was reflected in the financial statements. Dues payments do not appear on the statements.

Indeed, dues were hard to get even from branches as strong and well organised as Germany and Switzerland. The tone at the Executive Committee meeting in Venice in October 1972 was one of frustration. Merlis suggested that chapter vice-presidents should be more active. Magnus had been attending branch meetings to stir up awareness of the League, but to little avail. Daly, the treasurer, did not even have the addresses of the treasurers of many of the branches. Moreover, he objected to 'individual solicitation and use of funds in the name of the League without budgetary control by the Executive Committee'. Magnus countered that the treasury's contribution to the secretariat was miserly, and that without grants made to him by the Dutch branch, the Dutch Medical Research Organization and Hoffman-La Roche,⁶¹ the secretariat's activities would have been severely curtailed.

These financial details are important, for they go to the core of what kind of governance and pursuits the ILAE wanted. As the debate grew increasingly heated,

Daly took particular aim at travel to exotic locations. Lennox-Buchthal backed Daly, saying, 'Other organisations just arrange congresses and nothing more. You do not need a travelling secretary-general.'⁶² Magnus pointed to the ILAE's responsibility towards people suffering from epilepsy in developing countries. Melin chimed in that it was the 'inactivity of the League [that] gave rise to the setting up of the Bureau'. Financial realities had to be faced, said Merlis: 'For Barcelona for instance we have a budget without any reference to expenses for a program of speakers.' 'Epilepsia and the international congresses are important,' rejoined Henri Gastaut. Merlis proposed a special programme for epilepsy at Barcelona, for which a special fee could be charged. Daly and Magnus discussed the difficulty of meeting travel expenses for speakers, and the possibility that pharmaceutical and other companies might be willing to provide funds given the prominence of antiepileptic drugs on the programme. The meeting reached an agreement of sorts: Magnus had a preliminary budget for the congress on which the executive agreed in principle; Daly would try and formulate an overall budget for the League's fiscal year, to run from September to September.⁶³

Resignation of the secretary-general

As these exchanges make clear, there were grave philosophical differences between the American and European members of the executive (especially Magnus). The roll-call of the 1971 Executive Committee meeting is particularly telling. Present: Melin, Oller-Daurella, Magnus. Apologies: Gastaut, Merlis, Daly, Lennox-Buchthal. The situation was to come to a head soon after over the fate of *Epilepsia*.

The reorganisation of the journal following the Brussels Congress of 1957 had not begun auspiciously. A committee of three (Gastaut, Walker and Merlis) was charged with looking into continuing publication of the journal. Neither Walker nor Merlis thought that the journal was worth the effort. But Gastaut prevailed,

⁶¹ In his Report of the Secretary-General of the Executive Committee dated 3 September 1971, Magnus gratefully acknowledged 'a grant for Sw.frs 3,000 – from F. Hoffmann-la Roche & Co. in Basle for the purpose of supporting the organisation of the International Meeting on Epilepsies in Sao Paulo' [Roche was the manufacturer of the benzodiazepine drugs, by then widely used in epilepsy in Europe]. He also concluded, 'It will be clear that the League can only hope to fulfill its many obligations if it succeeds in obtaining financial support on a more regular base and on a larger scale. Branches are urgently requested to transfer their annual contribution regularly in due time ... In view of the above discussions have been started with various organisations and companies, such as pharmaceutical companies producing antiepileptic drugs.'

⁶² Lennox-Buchthal also uttered what now appears, by the situation today, to be a striking understatement: 'The journal could perhaps in the future give the League some income.'

⁶³ The League's rubber fiscal year is a source of great confusion in trying to trace its financial history. Over time it has gone from December to December, September to September, June to June and back to December with variations in between.



Karl-Axel Melin (1915–1992) was ILAE treasurer from 1973 to 1981.

and on 4 July 1958, Elsevier (a Dutch publisher), as the only firm willing to take on *Epilepsia*, was appointed as publisher. Magnus was a strong supporter of Elsevier and on very good terms with its management. In 1969, Lennox-Buchthal was appointed as *Epilepsia* editor, and relations between her and the publisher rapidly deteriorated. The details of this clash are discussed in more detail elsewhere (see Chapter 7). Suffice it to say here that a series of price increases and publication delays caused serious irritation among the executive, especially to Walker and Merlis, as well as Lennox-Buchthal. There was also the threat that if Elsevier persisted in raising prices, the ILAE would lose its bulk subscription from the AES, which constituted one-third of the total subscriptions. The minutes of the ILAE Executive Committee in Venice in October 1972 record David Daly as even mentioning a plan of the AES to start a new journal.⁶⁴

In the light of all this, Lennox-Buchthal proposed abandoning Elsevier and moving publishers. A switch to an American publisher would also mean the exclusive use of English. This all proved too much for Magnus, who had already clashed with Lennox-Buchthal over the appointment of the editorial board and the publication of supplements, and a series of violent arguments followed

on this point. A second problem had also reached crisis point, namely Magnus's habit of securing funds from the pharmaceutical industry (Hoffman-La Roche) and from Dutch charitable sources for his travel, and not reporting these to the ILAE centrally. Wording from a memorandum by Daly dated 11 September 1972 was included in the executive minutes which stated: 'In the past I have personally questioned the wisdom of what appeared to be individual solicitation and use of funds in the name of the League without budgetary control by the Executive Committee. For this reason I record a formal objection that the Secretary-General continuing such activities.'

In an undated circular letter to chapter vice-presidents written subsequent to the Executive Committee's meeting in Venice on 3–4 October 1972, Magnus announced that he had resigned as secretary-general. Without going into details, he gave as reasons his differences with Lennox-Buchthal over the management of the journal; the League's financial policy in general and the criticisms of the 'treasurer' regarding expenses in particular; the priority given to developing countries; and the future direction of the League. But on 4 December 1972, Magnus wrote to Luis Oller-Daurella, 'As for my resignation, the matter is not as simple as you think. Anyway, I never intended to continue as secretary-general beyond Barcelona. And as you probably know, some members

⁶⁴ The ambivalence of the AES towards the ILAE is long-standing. Lennox once wrote of the name of the lay counterpart to the American League Against Epilepsy (the precursor to the AES), 'It seemed to some any new name should retain the word League for token identification with the International organisation' (Lennox and Lennox 1960, II:1036). Repeatedly in the League's history, because it was bigger and had better meetings, the AES has been able to direct decisions (especially) regarding the journal simply by idly threatening to discontinue its bulk subscription. The relationship is not without irony, for lead members of the AES have always sat on the Executive Committee of the international organisation, and every American officer of the League to date, and two Canadians (Wada and McNaughton), have also served as president of the AES. Americans historically have taken special objection to what they perceive be the dominance of Europeans on the Executive Committee, which manifests especially in the recurring debate over the nationality of the editor-in-chief of *Epilepsia* (see Chapter 7). Fred Dreifuss was insistent that the editor of *Epilepsia* should be an American with voting rights to balance the perceived predominance of Europeans on the executive (J. Engel, personal communication). *Epilepsia* was indeed widely considered in that time to be the journal of the AES.

of the Executive Committee refused to have me serve the League in any other function.' Magnus's handwritten notes from a meeting in London in July 1972 also indicate that he was concerned about what he saw as growing rivalry between the League and the Bureau which could only be avoided either by integrating the two into a single organisation or by more clearly distinguishing between them. Melin would take over the responsibilities of the office of secretary-general until the Barcelona congress. Magnus's breach with the ILAE was complete: after he left, he had nothing further to do with it.

These growing pains notwithstanding, in contrast to Ledebøer's lament of 1953, the ILAE was now starting to look like a functioning organisation. The 1953 constitution had made an enormous difference in providing a structure, and this helped; but the real progress was made by the efforts of Gastaut and others in promoting ILAE activity. One of the League's stated resolves at the New York General Assembly was to concentrate on international meetings. In October 1967, the ILAE and IBE had organised a meeting together in Paris. That meeting and one before it were de facto considered to be the first two so-called European Symposia. These meetings, which emphasised the social aspects of epilepsy, would in future be held annually between the ILAE's quadrennial congresses, and would continue to be organised jointly by the League and the Bureau. The 3rd European Symposium occurred in Marienlyst, Denmark, in 1970 and, beginning that year, the Executive Committee deliberately chose its meeting to coincide with it. The 4th European Symposium on Epilepsy in Amsterdam the next year was pronounced a great success and drew 376 active participants from 25 countries. A 5th European Symposium on Epilepsy was planned for London in July 1972 and would focus on the medical and social implications of prevention in epileptic disorders (Osler Library Archives).

The League stayed true to its intention to make fighting epilepsy in developing countries a priority. In June 1970, the Executive Committee had approved a plan to sponsor an International Meeting on Epilepsy to be held in São Paulo in conjunction with the Pan American Congress of Neurology in October 1971. The meeting was prepared together with the IBE, and featured a programme on recent developments in the treatment of the epilepsies. The speakers were Merlis, J. Kiffin Penry,⁶⁵ Dieter Janz, Luis Oller-Daurella and Magnus. The League also organised a meeting on epilepsy in Latin America, and during it

set up a Committee for Latin America (which seems not to have lasted) to foster activities in that part of the world. São Paulo would be a test case for making use of congresses of neurology and tropical medicine in developing regions to arrange special meetings on epilepsy. A planned workshop for June 1971 in Kampala, Uganda, on managing the epilepsies, also to be organised with the IBE, never happened because of the coup in that country. Instead, the League and the IBE planned a travelling seminar on epilepsy in seven African countries for the spring of 1972. It was, said Francis McNaughton, now the Canadian representative to the League, in a progress report dated 1971, 'an interesting experiment' that would be receiving financial support from ICI (Great Britain) and other sources (McNaughton 1971).

The League recognised early on that there were advantages to be had through cooperating with other organisations. Immediately following the war, it had sought cooperation with the WHO and CIOMS, which

⁶⁵ J. Kiffin Penry (1929–1996) came from humble origins (his father ran a hardware store). Penry obtained his medical degree in 1955 from Bowman Gray School of Medicine at Wake Forest University, proving himself a stellar student, and completed his residency training in neurology at Boston City Hospital. In those early years he was so influenced by Richard Masland and Martin Netsky and later Derek Denny-Brown that he named his three sons after them. Penry served in the US Air Force both in the States and in Japan, and in 1966 was hired by Masland to build a section on epilepsy at National Institutes of Health, where he became a powerhouse. There was little in clinical epilepsy that did not interest him. He pioneered the simultaneous use of EEG and videomonitoring in the classification and diagnosis of epilepsy. He recognised early the importance of measuring serum levels of antiepileptic drugs, and was instrumental in getting the FDA to approve the therapeutic use of valproate in the United States. He initiated several series of textbooks, including *Basic Mechanisms of the Epilepsies and Antiepileptic Drugs*. Penry's initial involvement with the ILAE was as secretary on the League's first Commission on Antiepileptic Drugs. He became secretary-general in 1973, and president in 1977. In this, as in other activities, Penry was a dynamo, a person you did not easily say no to. His presidency coincided with the decision of the League and the Bureau to merge into Epilepsy International, and although the effort failed, he was one of its most ardent advocates. In 1979 Penry left the NIH to return to Bowman Gray, where he established a series of minifellowships which, as of 1996, had trained 2,200 fellows. In 1994, a conference titled *New Frontiers in Epilepsy Research* was held at Wake Forest University in Penry's honour. Summaries of the symposia were published in *Epilepsia*. Penry suffered all his life from diabetes. The disease became increasingly troublesome, and he died at 66, long before his time. His death was preceded by the tragic death of one of his sons in 1981 which greatly affected him (Dreifuss 1996; Kelner 1996; Cereghino 2007).



J. Kiffin Penry (1929–1996), a major figure in the ILAE: secretary-general 1973–1977 and president 1977–1981.

was established jointly by WHO and UNESCO in Brussels in 1949 as a non-governmental scientific organisation, among other things to coordinate congresses. In New York, the League had vowed to work with other organisations in planning international meetings and in its plans regarding developing countries. Now, it wished to approach the WFN. The WFN had already been closely involved in helping Gastaut to draft the classification of epileptic seizures. Since 1935 the League had traditionally tried to schedule its quadrennial meetings to coincide with the WFN's World Congress of Neurology. But the League was after a more official association. Macdonald Critchley, who had led the ILAE from 1949 to 1953, was then the president of the WFN and an obvious point of contact. On 2 June 1971, Magnus wrote to Critchley to 'explore the possibilities of establishing closer collaboration between the WFN and ILAE'. Magnus's proposal was less a rationale than a statement of common concerns. These included the League's interest in the developing world and a closer working relationship with WHO⁶⁶; its participation in congresses sponsored by the WFN; and the pharmacology

⁶⁶ WHO officially recognised the ILAE in 1971.

of antiepileptic drugs. Both organisations could benefit. The WFN had no liaison committee with the League, said Magnus. Moreover, 'amongst the research groups of WFN a research group on ... epilepsy [is] lacking'. He suggested that the forthcoming ILAE Congress in Barcelona in 1973 might offer a forum for discussion, and he invited Critchley to show the letter to the WFN's executive committee. Critchley wrote back on 7 June saying that he would welcome a 'small liaison committee' between the two organisations and would put the question to his council of delegates in Barcelona. He requested the names of nominees. By September 1971, Critchley had appointed an eight-member committee as WFN representatives for the liaison committee.⁶⁷ On 5 June 1972 Magnus circulated a letter to J. Armbrust Figueiredo (Brazil), J.F. Henriksen (Oslo), G. Loeb (Genoa), Merlis and Pond (naming Gastaut and himself ex officio) asking if they would serve on the committee 'to coordinate activities of WFN and ILAE not only with regard to international or regional congresses, but also with regard to special projects in the field of epilepsies to be sponsored jointly by WFN and ILAE'. The League's archive is silent on the further workings of the committee. But it must have made progress. For Article V(2) of the new constitution of the ILAE, ratified in Barcelona in 1973, specifies that its international congresses should ordinarily be held 'at or near the place of the International Congress of Neurology'. This arrangement served for a long time, although by the 1980s it became impractical.

ILAE 1973–1977 and the quadrennial congress in Barcelona

The 12th International Congress on Epilepsy was held in Barcelona on 9 September 1973. What we know of the League's business during the event comes from a draft of minutes of the General Assembly (with much crossing out) which survives in the League's archives. No minutes were printed in *Epilepsia*. Henri Gastaut opened the

⁶⁷ E. Bay (Duesseldorf), Eddie Bharucha (Bombay), T.O. Dada (Lagos), Dr Narabayashi (Tokyo), Fred Plum (United States), with Critchley himself and Henry Miller serving ex officio. They were all leading neurologists in their regions. Eddie Bharucha was, for instance, a pioneer of epilepsy in India and the leading neurologist in Bombay. He remains to this day respected and loved.

assembly, and in his comments on the ILAE's activities of the previous 4 years emphasised relations with WHO. A roll call of branches revealed 38 votes present.⁶⁸ Denmark, Norway and Portugal were unanimously accepted as full members. Reports by the secretary-general, treasurer and managing editor of *Epilepsia* followed without contest. J. Kiffin Penry presented a report of the extensive work of the ILAE Commission on Antiepileptic Drugs.⁶⁹ Harry Meinardi proposed a committee for developing countries, a long-standing request that was finally realised in 1981. A new constitution was adopted that, for the first time, included a set of bylaws. Even more significant, the new statute 'interlocked' the executive committees of the ILAE and the IBE by making the president and secretary-general of each organisation an ex officio member of the other's executive.

The treasurer complained about the lack of factual information from the branches which had prevented him from being able to properly consider the budget for the coming 4-year period or the annual dues. This refrain was to become a familiar one in future years. But the real surprise of the meeting was yet to come. In consultation with the Executive Committee and various branches, Gastaut had worked out a slate of officers that had been circulated by the general-secretary on 19 June 1973. Gastaut asked the General Assembly to vote for the full slate, but they refused. Instead, it was decided to vote for one officer at a time. Daly was unanimously elected president, Penry secretary-general and Melin treasurer. Lennox-Buchthal remained as managing editor of the journal. Gastaut's original candidate for first vice-president was J. Kugler (Munich). But the German branch advanced a second candidate, Dieter Janz (Berlin). Kugler received 8 votes, Janz 11, there were 8 registered abstentions and 9 voting delegates not present. The event constituted the first time that a slate of officers proposed by the Executive Committee was not completely accepted, and Gastaut

took it as a personal affront (Meinardi 1999). Indeed, for some time after, the effects of the argument impaired the close relationship of the League with a man who had perhaps done more than any other to increase the influence, visibility and authority of the organisation.

Over the years, communicating with the branches of the ILAE had proved problematic in the best of times. Now, as the League was expanding, dissemination of news was important not only to recruit new branches but also to give existing ones a stake in the League's activities and overall survival. During 1973, the office of secretary-general had been consumed with defining the chapters and the membership of the ILAE, generating proposals for more effectively achieving the goals of the constitution and making plans for increasing the number of active chapters. At more than one reprise, the League had had to rebuild its address lists from scratch. In 1972, when Merlis as past-president took over from the departing Magnus, Melin gave him a 'small package of active correspondence' and advised him that the rest would have to be obtained from Magnus. In the event, Magnus delivered only a fraction and held on to the rest of the archives. Nevertheless, over several months, Merlis was able to establish a roster of the officers of the ILAE chapters. He also sent each



David Daly (1919–1991), ILAE president 1973–1977, and treasurer 1961–1973.

⁶⁸ According to the constitution in force at the time, each delegate was entitled to 1 vote for every 100 professional members in good standing in his/her chapter. Any fraction over 50 was worth an additional vote. No chapter could have more than 4 votes.

⁶⁹ Appointing commissions is the prerogative of the president. All existing commissions are dissolved with the advent of a new administration, and then reconstituted (or not). Some commissions, like the Commission on Antiepileptic Drugs and the Commission on Classification and Terminology persisted over many executives. Others have proved ephemeral.

officer a questionnaire and managed to tabulate founding dates, number of members, amount of annual dues and so on, and circulated the information to the Executive Committee. Communications could not be established with the chapters in Israel and Peru.⁷⁰ The ILAE's efforts in recruiting chapters were to be aided by a new multilingual worker, devoted to the cause of epilepsy, based in Washington, who would serve both the Bureau and the League. The new constitution provided for individual membership in countries where there was no chapter. Merlis recommended that individual memberships be sought in a number of countries until active local chapters could be established. Merlis's chapter-promoting activities extended beyond those sponsored by the League. In September 1973 he travelled to Merida, Venezuela; Bogotá, Columbia; Panama City; and Mexico City to advise on behalf of the Pan American Health Organization on field studies related to the epidemiology of epilepsy. He also visited Rio de Janeiro in February 1974, where he met with Abraham Mosovich of Argentina and discussed the challenges of organising chapters in Latin America.

Around this time, the League also realised it had an image problem in that its administration did not properly reflect its international constituency. With the exception of Paulo Niemeyer, of Brazil, who served as a vice-president on the Executive Committee from 1953 to 1957, since 1935 the ILAE's officers had been exclusively European or American. Meeting for the first time after their inaugural year in office on 19 September 1974, at the Europa Hotel in Brussels, on the occasion of the 6th European Symposium, the new executive welcomed Francisco Rubio Donnadiu of Mexico as second vice-president. (Mexico did not officially become a chapter of the ILAE until 1977. But Rubio Donnadiu was an individual member, and thus entitled to hold office.) In making his presidential report, David Daly said that the appointment fulfilled the ILAE's mandate for having a truly international organisation. The symposium's scientific programme took place in the William Lennox Centre at Ottignies and was titled 'Total Care in Severe Epilepsy: A Challenge to All Disciplines'. Daly, Harry Meinardi, Ellen Grass, O.M. Jones (Wargrave, England), Mogens Lund and Melin each led a plenary session. Sessions 3 and 4 consisted of case presentations representing epilepsy treatment in the United States, England, France, Holland and Belgium. IBE

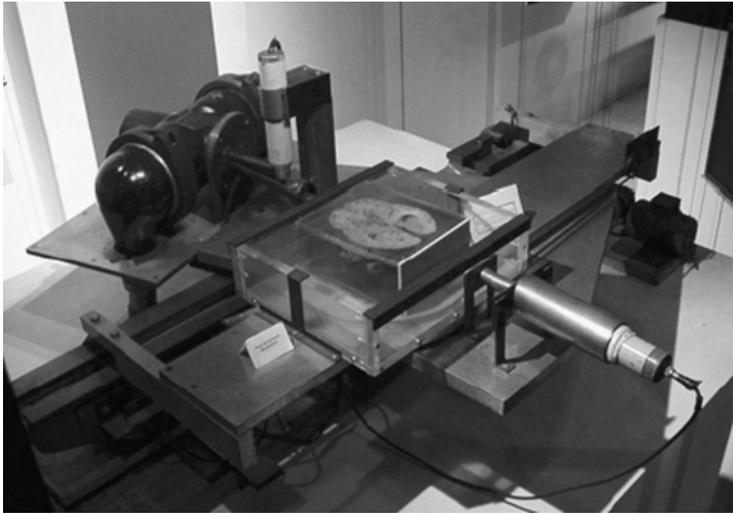
⁷⁰ The heads of both the Israel and Peru chapters had died.

lecturer Madison Thomas of Salt Lake City gave a talk on classification of the epilepsies. J. Kiffin Penry summed up and closed the two-day meeting. A third day consisted of visits to a number of residential centres for epilepsy, namely the Atelier Protégé and the William Lennox Centre (both in Brussels), the Institute Sante Amadeus (Moortsel, Antwerp) and La Porte Ouverte (Blicquy).

The League executive next met coincident with the 7th European Symposium in Berlin. With regard to organisational matters, only a preliminary programme for the event survives. The scientific content was published by Georg Thieme Publishers, Stuttgart, in 1976 as *Epileptology: Proceedings of the Seventh International Symposium on Epilepsy Berlin (West), June 1975*. The symposium lasted from 19 to 21 June, and dealt with two themes: treatment and rehabilitation of the outpatient with epilepsy (chaired by Daly); and methods and techniques in clinical epileptology (chaired by Hermann Doose and Meinardi, and in a separate session by Dieter Janz). On the afternoon of 19 June, participants were offered a choice of visits either to the Red Cross Institute at Kladow or the Berufsförderungswerk in Berlin. The ILAE Executive Committee meeting took place just before the symposium, on 18 June, in the Hotel Schweizerhof. Penry reviewed his activities in building chapters, which involved sending letters in Spanish to more than 100 people in Mexico, in response to which he received applications from at least 35. He had spoken to people in the Soviet Union as well, but medical organisations such as the ILAE could not be developed under the Soviet constitution. Argentina had become inactivated, and reactivating it was not straightforward as the country had not fulfilled the requirements of the constitution. In a separate agenda item, Henry Gastaut reported that he had visited China for 3 weeks in 1973 and found the Chinese interested in epilepsy, but that attempts to correspond with them had not been successful. He went on to discuss the relationship of the ILAE and WHO, which he described as 'very good', although the organisation seemed not particularly keen on providing monetary support for epilepsy projects. The afternoon session of the executive was given over to talk of future symposia and congresses. In coordinating the Berlin symposium, the IBE and the League had named a scientific committee⁷¹ to

⁷¹ The committee comprised Dieter Janz (Berlin, chairman), Hermann Doose (Kiel), Mogens Lund (Copenhagen), J. Kiffin Penry (Bethesda) and George Burden (London, secretary).

The original test rig for a CT scanner, ca. 1968, from the EMI laboratories of Godfrey Hounsfield. Godfrey Hounsfield, a British electrical engineer, received the 1973 Nobel Prize in Physiology or Medicine for his development of CT scanning. He worked for the EMI company (the early instruments were known as EMI scanners). The first human CT was taken in 1968, and the first clinical scanner was installed in 1971. (Source: E.C. Beckmann, CT scanning in the early days. *British Journal of Radiology* 2006, 79:5–8. Reprinted with permission)



be concerned solely with scientific aspects of the meeting, and a local arrangements committee was organised to take care of all the other details. This formula would be carried over to the League's next quadrennial congress in Amsterdam in 1977, a milestone in the ILAE's history, and has been retained ever since.

For reasons unknown, no minutes survive of the next executive meeting, on the occasion of the IBE/ILAE 8th International Symposium on Epilepsy, held in Dublin from 12 to 15 September 1976. ILAE secretary-general Penry published the proceedings (Raven Press, 1977). This book contained a loose, short letter signed by David Daly acknowledging that its publication had been made possible by a grant from Geigy Pharmaceuticals. Organisers of the symposium are announced as Epilepsy International (ILAE; IBE) and the Irish Epilepsy Association. The venue was the Conference Centre of the Burlington Hotel on Upper Leeson Street. Henri Gastaut gave the IBE Lecture on the use of the 'EMI-scan' in epilepsy. A series of post-graduate training courses were offered separately for medical participants; EEG assistants; teachers, employment officers and social workers; and lay organisation personnel. The theme of the scientific programme was new approaches to therapy, and included plenary talks on long-term control of seizures (Meinardi), behaviour modification and rehabilitation (Olaf Henriksen, Oslo) and intensive monitoring (Penry). A fourth plenary session on the needs of developing

countries was moderated by Liana Bolis of WHO, with keynote presentations by G. Arjundas (Madras), B.O. Osuntokun (Ibadan, Nigeria) and Remy Rada (Merida, Venezuela). Participants also had a choice of visits to St Patrick's Hospital (founded by Jonathan Swift in 1745) and Dr Steevens' Hospital, or the AnCo Industrial Training Centre in Balleyfermot.

The ILAE Antiepileptic Drug Commission and WODADIBOF

As the age of consumerism dawned, and as the organisation grew in the late 1960s, the ILAE had become for the first time a body that government and industry listened to in relation to epilepsy therapy. This was partly indicative of the changing social environment and the growth of lobbying, but also of the outstanding quality of the League's leadership, particularly Penry and, later, Fritz Dreifuss. The influence led to the recognition by industry that interaction with the ILAE could improve market share. It was also demonstrable in concrete terms by the increasing involvement of industry in ILAE international congresses.

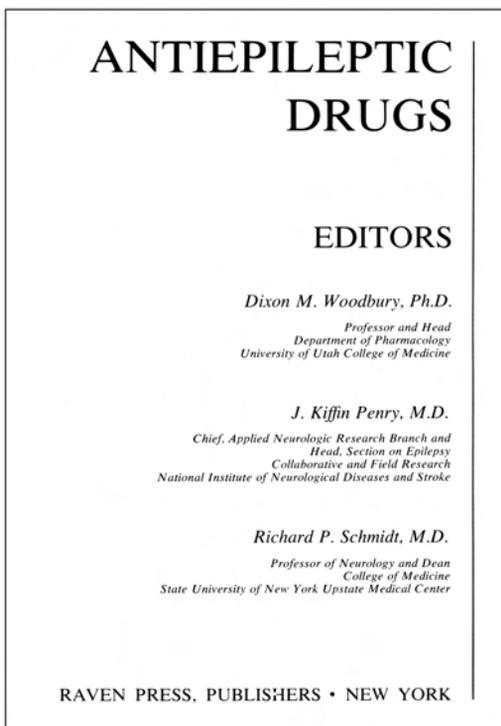
Two League activities in this realm are of particular note. The ILAE Commission on Antiepileptic Drugs (Table 2) was one of the earliest ILAE commissions (only the Commission on Classification and Terminology is older) and, it can be argued, its most important. The first commission was set up in June 1970, under the chairmanship of David Daly, who was then the ILAE

Table 2 Antiepileptic drugs, 1909–2009: dates of introduction into clinical practice.

1909	Drugs in widespread use were bromides (various salts and combinations, including chloral hydrate, borax, belladonna and zinc salts). Other drugs and herbal remedies included hyoscyne, strophanthus, digitalis, atropine, glycerophosphates, stramonium, strychnine, calcium chloride, atropine, nitroglycerine, veronal, cannabis, conium, wolfsbane and opium
1912	Phenobarbital
1913	Crotalin
1937	Vital dyes
1938	Phenytoin
1946	Trimethadione
1947	Mephenytoin
1949	Paramethadione
1950	Phenethylnate
1950	Corticosteroids and ACTH
1951	Phenacemide
1952	Metharbital
1952	Benzchlorpropamide
1953	Phensuximide
1954	Primidone
1957	Methsuximide
1957	Ethotoin
1958	Ethosuximide
1962	Sulthiame
1963	Diazepam
1964	Chlordiazepoxide
1964	Carbamazepine
1967	Valproate
1971	Clonazepam
1979	Clobazam
1985	Progabide
1989	Vigabatrin
1989	Zonisamide
1990	Lamotrigine
1990	Oxcarbazepine
1993	Felbamate
1994	Gabapentin
1995	Topiramate
1996	Tiagabine
1999	Levetiracetam
2004	Pregabalin
2007	Stiripentol
2007	Rufinamide
2008	Lacosamide

ACTH, adrenocorticotrophic hormone.

treasurer.⁷² At its inception, the commission had two published goals: to promote increased knowledge of currently available antiepileptic drugs and to improve the application of this knowledge in the treatment of epilepsy; and to foster the development of new antiepileptic drugs with great efficacy or with equal efficacy but less toxicity



The textbook series *Antiepileptic Drugs*, begun in 1972 by J. Kiffin Penry and others reached five editions, the last in 2002.

than those currently available (Penry 1974). The commission initially met annually,⁷³ and soon was a force to be reckoned with. The first meeting, in Scottsville, Arizona, in September 1971, was part of a conference organised by the Epilepsy Branch of the National Institutes of Health (NIH), which resulted in the publication of the first edition of the book *Antiepileptic Drugs* (the book reached its fifth and last edition in 2002). In 1973, the commission also published a set of influential guidelines for the clinical testing of anti-epileptic drugs. By 1974, it had made recommendations about repository antiepileptics and laboratories for the determination of antiepileptic drugs

⁷² The members of the first commission were all to become highly influential players in the field of antiepileptic drug therapy and in international epilepsy affairs: David Daly, Dieter Janz, Harry Meinardi, J. Kiffin Penry and Carlo Alberto Tassinari. Fritz Buchthal acted as consultant to the commission.

⁷³ The first meeting was at the Camelback Inn, Scottsdale, Arizona, on 11 September 1971, the second at the Statens Sykhus for Epileptikere, Sandvika, Norway, on 25–26 September 1972 and the third at the Gesellschaft für Epilepsieforschung, Bethel, Bielefeld, on 28–30 May 1973.

in serum. It had reviewed surveys of antiepileptic drug regimens used by clinicians in France and the United States, and had held the first Symposium on Antiepileptic Drugs.⁷⁴ Owing to the involvement of Penry, most of the commission's work in the early years was closely aligned with that of the NIH Epilepsy Branch. For instance, the commission endorsed the work of the branch, reviewed the NIH survey of pharmaceutical firms, the so-called Coatsworth report, and therapeutic drug-monitoring workshops. Over its first 4-year term, stimulated by Penry's extraordinary energy, the commission became a powerful voice in the field of drug therapy. In its second term (1974–77), the commission established two annual prizes.⁷⁵

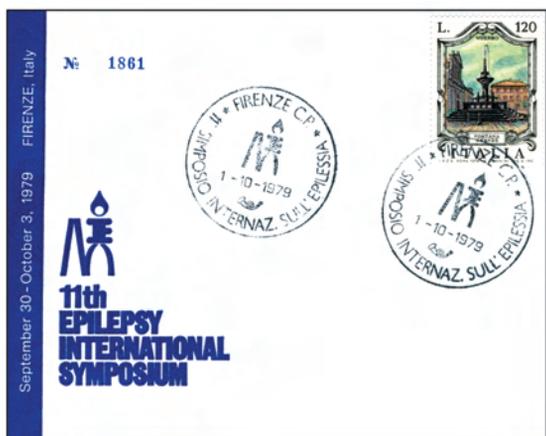
⁷⁴ Held during the 12th International Congress of Epilepsy in Barcelona in September 1973.

⁷⁵ The first of these prizes was for the best-controlled trial in epilepsy (the Ciba-Geigy Award), and the second (the Epilepsy Research Award) for the outstanding contribution to the clinical pharmacology of antiepileptic drugs (administered by the American Society for Pharmacological and Experimental Therapeutics, ASPET). The first Ciba-Geigy Award was awarded to Jim Cereghino, the second to N. Simonsen (1976) and the third to A. Troupin (1977). The 1978 award was not given owing to a lack of qualifying papers. For 1979, none of the selected papers received a majority vote. The award was given again in 1981 to Nancy Temkin and in 1983 to Lennart Gram, and then faded out. A separate award called the Ciba-Geigy-ILAE-IBE Epileptology Prize, introduced in 1993, offered 20,000 Swiss francs for outstanding achievements in both the medical and social aspects of epileptic disorders. The first award was announced at the opening ceremony of the Oslo conference, where it was followed by a very promotional speech by the Ciba-Geigy representative. This turn of events led to protracted soul-searching at a number of joint meetings of the ILAE and IBE executives both over the name of the prize and its comprehensive nature. The award was given a second time in 1995 in Sydney to Fritz Dreifuss. In 1997, following the fusion of Ciba-Geigy and Sandoz, the renamed Novartis ILAE/IBE Epileptology Prize was awarded to Richard Mattson. Following a hiatus of several years, Novartis agreed to sponsor a prize of 60,000 Swiss francs for specific achievement in basic medical or social research. In 2001, Sam Berkovic was the awardee of the Novartis ILAE/IBE Epileptology Prize. Re-named again the Novartis Prize for Epilepsy Research, in 2005 the award was given in Paris to Jeffrey Noebels. The current status of the award is, however, uncertain. The Epilepsy Research Award has been given yearly since 1978 (the first winner was Alan Richens and the most recent, in 2007, Robert Schwarcz), and the ILAE is named on ASPET's website as sponsoring the \$2,000 award and being represented on the award committee. But the League has complained about not being consulted on the choice of awardee. A third prize (the Syva Award) was launched in 1985, but was abandoned within a few years due to failure of sponsorship. All these awards suffered from a general lack of publicity and awareness, confusion about the mechanisms of evaluation and a lack of consistent sponsorship.

One focus of the second term was chronic toxicity, and Ted Reynolds published a landmark paper on the topic (Reynolds 1975). The third commission modified its objectives (Anon. 1982) to promote the dissemination of information about epilepsy; acquire information about antiepileptic drug usage in various countries; promote application of ILAE guidelines to clinical trials; define a list of high-quality clinical centres; and promote collaborative studies. Some progress was made on all fronts, but the commission's activities were not on a par with those of the Penry years. The third and fourth commissions published an interesting list of drug availability in developing countries – finding 'the present situation alarming'. This constituted one of the first forays of the ILAE into the question of treatment in developing countries, which culminated in setting up the Global Campaign Against Epilepsy (see Chapter 8) (Third and Fourth Commissions on Antiepileptic Drugs 1985). A major task of the Fourth Commission was the production of a *Glossary of Antiepileptic Drugs*, which was eventually published in 1991.⁷⁶ Other guidelines also appeared (Commission on Antiepileptic Drugs 1991, 1993, 1994). In 1989, the Fourth Commission also undertook the task of updating the *Guidelines for the Clinical Evaluation of Antiepileptic Drugs*, first published in 1975. Like its predecessor, this document was based on a workshop (held, with representatives of the regulatory authorities present, in November 1985), and would prove an important influence on the parameters for drug trialling by the US Food and Drug Administration (Anon. 1989). The later commissions also produced reports, but by then many bodies were focusing on therapeutic issues, and the ILAE commission had rather lost its energy and its way. Lennart Gram, chair of the Sixth Commission, wrote bitterly to the executive that he could not get any of the commission members to come up with ideas or be active in any way. When Jerome (Pete) Engel, Jr. was made president, the commission was discontinued and its work taken over by the new Commission on Therapeutic Strategies.

A second ILAE initiative worth noting in the treatment domain is the series of Workshops on the Determination

⁷⁶ This project became very delayed and expensive, souring relations somewhat between the commission and the ILAE executive. Cereghino had suggested publishing the glossary as a supplement of *Epilepsia*, and eventually it did appear as a supplement in 1992 (supplement 2), but only after an earlier letter had been sent to all subscribers apologizing for the delay.



Commemorative postcard designed for the Epilepsy International Symposium in Florence, 1979.

of Antiepileptic Drugs in Body Fluids (under the rather clumsy but memorable acronym WODADIBOF). Between 1972 and 1979, four WODADIBOFs took place, and they helped drive the clinical chemistry agenda, at least in so far as it evolved in hospitals and universities. The first workshop, in Noodwijkerhout, Netherlands, in 1972 dealt with methods for quantitatively determining antiepileptic drugs. The second in Bielefeld, Germany, in 1974 dealt with the clinical pharmacology of antiepileptic drugs. The third was held in Exeter in 1977 and focused on therapeutic drug monitoring, and the fourth, in Oslo in 1979, covered clinical applications of antiepileptic drug monitoring. In 1972, Alan Richens started the first quality control scheme for antiepileptic drug measurements in London. The importance of this step was quickly recognised, and soon Richens was providing an international service. Another workshop was set up – the Workshop on Laboratories for the Determination of Antiepileptic Drugs in Serum – which first met in New York in November 1972, but as far as we can tell was a one-off event. A few years later, the NIH Epilepsy Branch, together with the American Epilepsy Society, set up an antiepileptic drug quality control programme throughout the United States and Canada based on methods discussed in the NIH-sponsored publication *Antiepileptic Drugs: Quantitative Analysis and Interpretation* (Pippenger *et al.* 1978). The ILAE Commission on Antiepileptic Drugs was also intimately concerned with therapeutic drug monitoring and published its own guidelines in 1993 (Commission on Antiepileptic Drugs 1993).

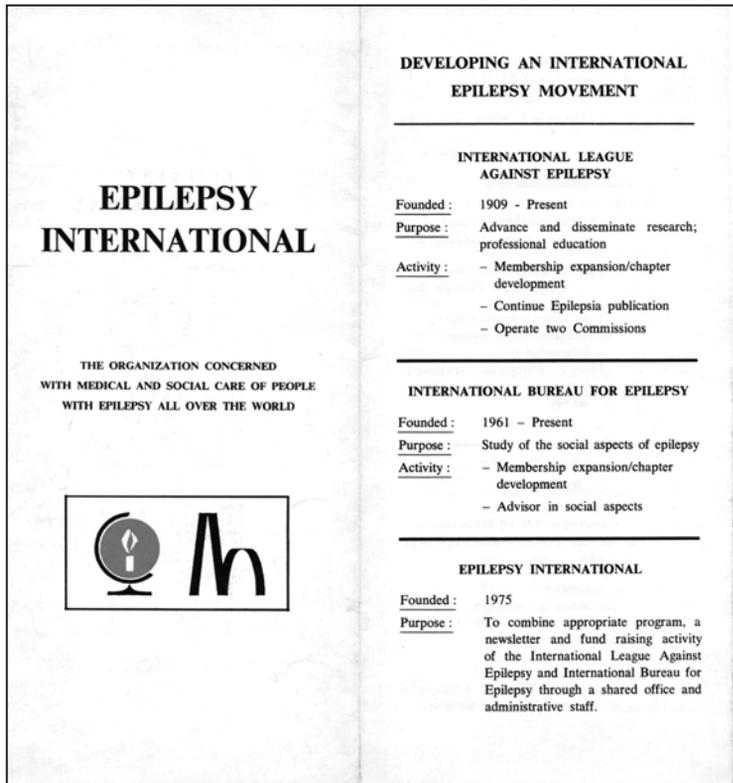
Epilepsy International and the proposed integration of the ILAE and IBE

The programme for the 1976 Dublin meeting contained a cryptic notice that signalled a new, important phase in the shared history of the League and the Bureau: ‘Shortened texts of the papers presented at the symposium are to be published by Epilepsy International as an inexpensive soft cover volume at an early date’ (see above). As far back as the 1950s, B. Ch. Ledebøer had advocated that the most salutary organisational structure for the League would be one that combined physicians and laymen. In September 1971, at a joint meeting in Amsterdam, the ILAE and the IBE considered integrating into an ‘International Epilepsy Foundation’. This would be an enormous step and over the next 8 years consumed a great deal of energy and engendered bitterness and contention. The reasons were fundamentally philosophical although the practical advantage of a shared secretariat and staff and the efficiencies this might bring were also discussed. In Brussels in September 1974, Penry told the League’s Executive Committee that the presidents and secretaries-general of both the League and the Bureau had met in Bethesda in June and formulated ‘long-range plans of more intimate cooperation [that] will be discussed later’. At the same meeting, Ellen Grass, president of the IBE, quoted some of the questions she heard regularly in soliciting funds: ‘Isn’t there more than one organisation? ... What do they do that you don’t do? Are you quarrelling with one another? ... Just what is it all about? We’re confused.’ In short, the League and the Bureau had decided to embark on a new joint working concept aimed at advancing each other’s purposes while minimising overlap.

It seems that the idea of a complete merger was thought initially to be too great a step, for the December 1974 issue of *IBE Newsletter* contained the first public notice of the concept, a Declaration of Intent (signed by David Daly and Penry for the ILAE and Grass and George Burden for the IBE) laying out the principles of cooperative action between the League and the Bureau.⁷⁷ An undated brochure titled ‘Epilepsy International: Developing an International Epilepsy Movement’ states as the project’s purpose (c. 1975) ‘to combine appropriate programme, a

⁷⁷ At the founding of the Bureau, the League agreed to support it to a total of \$500 per year. The League failed to make these payments in 1973 and 1974. Following a lengthy discussion, the executive agreed to make ‘a single final payment of \$1,000 to the bureau’.

Epilepsy International was an ill-fated attempt to combine the strengths of the ILAE and IBE into a single organisation. In particular, beginning in 1978, the joint ILAE/IBE quadrennial congresses were renamed Epilepsy International symposia and were held yearly. A merger was put to the chapters for vote in Kyoto in 1981 but failed to pass, after which the efforts to fuse the organisations ceased.



newsletter and fundraising activity of the International League Against Epilepsy and International Bureau for Epilepsy through a shared office and administrative staff'. Accordingly, *IBE Newsletter* was rechristened *Epilepsy International News* and carried the joint logos of the IBE and ILAE. A suitable letterhead was devised, with the spike-and-wave on the top left and the candle on the right. Epilepsy International was conceived as 'an agent' of the ILAE/IBE (a sort of umbrella organisation) but, if all went well, sometime in the near future it was the aspiration of some on the executives that the League and the Bureau would merge into a single entity, subject of course to the approval of the chapters.

ILAE 1977–1981 and the symposia in Amsterdam, Vancouver, Florence and Copenhagen

The 13th Congress of the ILAE and the 9th Symposium of the IBE, held from 9 to 12 September 1977, took place

at the RAI Congress Centre in Amsterdam, together with the 9th Congress of the IFSECN⁷⁸ and the 11th World Congress of Neurology. The working language of the congress was English, and Epilepsy International had a stand. Robert Naquet of Gif-sur-Yvette moderated a round table discussion on experimental models of epilepsy at which Juhn Wada discussed kindling and Brian Meldrum photosensitive epilepsy in *Papio papio* (a phenomenon Naquet himself had discovered in 1965). D.B. Tower, the IBE lecturer, spoke on epilepsy as a world problem. The efforts of the new scientific organising committee were evident not just in these and other auxiliary offerings, but in the rich selection of plenary and parallel sessions on themes ranging from cognition and epilepsy to the mechanism of action of antiepileptic drugs. On 12 September Dieter Janz and Harry Meinardi co-chaired

⁷⁸ The IFSECN meeting in Amsterdam was much more prominent than the ILAE meeting. Pete Engel, recalls going to Amsterdam and not even knowing an ILAE meeting was taking place.

a joint session of the League and the WFN on the pharmacotherapy of epilepsy and the pharmacokinetics of antiepileptic drugs.

The League's minutes from its meeting of 8 September 1977 at the Park Hotel are relatively perfunctory. A new slate of officers was proposed for presentation to the General Assembly at the conclusion of the executive session: president, Penry; secretary-general, Rubio Donnadiou; first vice-president, Dieter Janz; second vice-president, T. Wada (Japan); treasurer, Melin. Maurice Parsonage and Ted Reynolds reported on the Commission on Antiepileptic Drugs, and Jerome Merlis on the Commission on Classification and Terminology. At a second session on 11 September, the executive moved that there should be a clear policy on publication and distribution of symposia proceedings. The officers further agreed that the offices of the president and secretary-general of the ILAE should be supported financially to the amount of \$200 and \$500 (\$684 and \$1,710 in today's dollars), respectively. Janz proposed – presciently, as it turned out many years later – that 'it would be of great help to name commissions that could coordinate the different parts of the world as Europe, Latin America and Asia'.

Epilepsy International

In 1974 the League and the Bureau had optimistically assumed that Epilepsy International would become a reality by the time of the Amsterdam congress, and that programme planners should be made aware of it to recognise the merger. In fact, by the time 1977 rolled around, little progress had been made. Part of the problem was a conflict between the IBE and the ILAE over foreign travel which resulted in the IBE secretary-general and president (George Burden and Ellen Grass) both resigning. There were other knotty issues as well, relating to membership, constitutions and ownership of *Epilepsia*. Instead of pressing for a formal merger, the League and the Bureau agreed to delegate to Epilepsy International all activities except for commissions, membership and *Epilepsia*. The League and Bureau executive committees would constitute the board of directors of Epilepsy International. Their respective presidents and secretaries (and, later, treasurers) would form Epilepsy International's executive committee.⁷⁹ Beginning in 1978, all the European symposia and ILAE quadrennial congresses would be collapsed into a single yearly event: the

Epilepsy International Symposium. A new target date for the merger was agreed for 1981, in Kyoto.

Trying to sort out the trajectory of the new entity over the next period of time is a confusing, not to say exhausting, business. Three separate streams of activity (ILAE, IBE, Epilepsy International) ran in parallel, with the main focus of Epilepsy International being the newsletter and the now yearly international symposia. Following Amsterdam in 1977, the meetings occurred in quick succession: Vancouver 1978, Florence 1979 and Copenhagen 1980 (Table 3). These congresses were sizable, even though they occurred in off years and did not have the knock-on benefits of twin scheduling with the larger congresses such as the WFN. The concept of progressing science through small workshops – for example, the Neurotransmitters in Epilepsy workshop, still ongoing – was first approved during these years. However, the Epilepsy International symposia occasionally suffered from haphazard planning, and a theme common to all of them that emerges from the archives is rather poor science and the organisation's dire cash situation.

Technically, the main idea of Epilepsy International was to have one office to cut expenses (R. Porter, personal communication). Epilepsy International initially was run out of offices in London and Washington, DC. Eventually, the decision was made to locate the office in a 'neutral' country, and Grand Saconnex (near Geneva), Switzerland, was chosen. Despite some opposition owing to his speaking only English, American Richard Gibbs was hired as Epilepsy International's executive director in late 1977 and took up his post sometime in 1978. Almost immediately, however, things began to go wrong. Epilepsy International found that it could not actually afford the office in Geneva, and by the autumn of 1979 Gibbs returned to the United States to try to operate the organisation more inexpensively long-distance.⁸⁰ On 15 February 1980 he wrote to Harry Meinardi of his 'near complete frustration [over the previous 2 years] of trying to develop a

⁷⁹ Around 1978, the executive committee of Epilepsy International consisted of J. Kiffin Penry (chairman), Harry Meinardi, Francisco Rubio Donnadiou, Richard Grant and Richard Gibbs (executive director).

⁸⁰ In his 'Report of the Executive Director' of 1979, Gibbs noted that very little had been done to stimulate national or regional programmes: 'An unbelievable amount of time is spent with creditors'.

Table 3 International congresses of the ILAE, 1953–1991. The numbering of ILAE congresses reflects the League’s history, and for that reason is somewhat confusing. The League had its own meetings every 4 years until the IBE came into existence, after which the organisations began to meet together, at first informally and then, beginning in 1969, officially. Between 1978 and 1985, the ILAE and IBE held yearly symposia under the agency of Epilepsy International. When it failed, the organisations continued to manage congresses jointly, but only every 2 years, and under a different name (see pp. 216–17).

1953	ILAE Quadrennial Meeting	Lisbon
1957	ILAE Quadrennial Meeting	Brussels
1961	ILAE Quadrennial Meeting	Rome
1965	ILAE/IBE Meeting	Vienna
1969	11th ILAE/IBE Meeting	New York
1973	12th ILAE and IBE Congress	Barcelona
1976	IBE/ILAE International Symposium	Dublin
1977	ILAE 13th Congress/IBE 9th Symposium	Amsterdam
1978	10th Epilepsy International Symposium	Vancouver
1979	11th Epilepsy International Symposium	Florence
1980	12th Epilepsy International Symposium	Copenhagen
1981	13th Epilepsy International Symposium	Kyoto
1982	14th Epilepsy International Symposium	London
1983	15th Epilepsy International Symposium	Washington
1985	16th Epilepsy International Symposium	Hamburg
1987	17th Epilepsy International Epilepsy Congress	Jerusalem
1989	18th International Epilepsy Congress	New Delhi
1991	19th International Epilepsy Congress	Rio de Janeiro

programme with almost no money’. On 19 June, he wrote again to say that he had not been paid since July 1979. Gibbs’ did eventually receive his salary, and he was released from his contract. Joop Loeber took over his duties temporarily and then the operations of Epilepsy International were moved to Milan, where Patsy McCall-Castellano took over as executive director on a volunteer basis. Gibbs’ letter of June also went to ILAE treasurer Karl-Axel Melin, who on 30 June wrote to Meinardi, ‘What are the possible solutions? I am a bit afraid for ILAE money, as I foresee high expenses in connection with the Kyoto [1981 congress] adventure. Are any fund resources on their way in? ... Arthur Ward has claimed the advertisement money for *Epilepsia*, but I sit on all money just now, anxious that we cannot fulfil our obligations.’

ILAE chapter activity

Throughout this period, the ILAE continued to build its own membership. In September 1977, at its annual meeting, the ILAE Executive Committee recommended that Canada, Mexico and the Dominican Republic be proposed to the General Assembly as chapters. The officers also decided that each chapter should name a representative for the next 4 years, and that the person’s name should appear in *Epilepsia* to improve communications. Moreover, each chapter would be sent a president’s letter with a summary of the work of the League and the agenda of the Executive Committee. A year later, in Vancouver, now-president Penry presented a new directory of

chapters, and promised that a bulletin from the president would circulate. Secretary-general Rubio Donnadiu gave a summary of the chapters, which numbered 25: 14 in Europe and 9 in Latin America, plus chapters in Israel and Japan. Rubio Donnadiu was labouring on behalf of Venezuela, Ecuador and Costa Rica as well.

By 1979, Ecuador, India, Philippines and Venezuela were interested. The Brazilian chapter was thriving and even had a monthly journal titled *Liga Brasileira Contra Epilepsia*. Penry had visited the Philippines (where a chapter was under way) and Argentina (where one was being revived). The Democratic Republic of Germany had shown interest and would be sent guidelines. A question was raised about the problem of collecting dues from Eastern European countries. One option was to keep the funds in an ILAE account in the various countries, and use them later for the League’s regional or international congresses held in those regions. Colombia was forming a chapter, although it intended to represent only the central part of the country, around Bogotá, which violated the League’s stipulation that a chapter represent its entire country. The Uruguayan chapter had been re-organised. The Finnish chapter of the ILAE was organised as a professional section of the Finnish Epilepsy Association. The Israeli chapter invited the League to organise a future symposium with the support of the Israeli government. For the moment, China had declined to organise a chapter; and the Cuban chapter, although working since 1976 as a section of the Cuban Neurological Society, had

been unable to officially apply to the ILAE. During the 5th Pan-American Congress of Neurology in Caracas in October 1979,⁸¹ a decision was made to organise the First Epilepsy International Regional Symposium to be held in Merida, Yucatán, Mexico, in April 1981. The registration fee would be a symbolic \$25, with the rest to be covered by donations from the local Mexican government of Yucatán. ‘Epilepsia Pan-American’ took place as planned, with 200 delegates from North, Central and South America. A sequel was planned for Buenos Aires in October 1983. A list of officers had been published in 1978 but not updated since, as chapters frequently failed to give notice of changes among their officers, and consequently the League had no idea whom to contact.

Proposal for a revised clinical and electroencephalographic classification of epileptic seizures

The membership of the Commission on Classification and Terminology was reconstituted in 1979. Since its founding around 1963, the commission had endured through three administrations and was well into its fourth. Over the years it met repeatedly and staged workshops to ‘continue to update, amend and improve [Gastaut’s 1969] classification in the light of the capability afforded by the newer techniques to study seizures’ – a reference to video-EEG telemetry (Commission 1981, 489). A revised draft was to be circulated to the chapters for emendation with the goal of being presented and distributed at the League’s upcoming symposium in Kyoto in September 1981. Under the chairmanship of Fritz Dreifuss,⁸² the newer classification could be expected to present ‘no dramatic

changes and that these should be considered as evolution of concepts, for instance, the removal of speculation about localisation as a criteri[on] of classification of epileptic seizures and the removal of syndromes like [i]nfantile [s]pasms’. The commission held its last meeting on 8 September 1980, during the 12th Epilepsy International Symposium in Copenhagen. Although response to the draft proposal had included concerns about the timetable, as well as the definition of consciousness, responsiveness and so on, the commission decided the issues were not sufficient cause to delay publication, and it appeared in *Epilepsia* in 1981.

ILAE 1981–1985 and the symposia in Kyoto, London and Washington

The new Executive Committee was voted in at the General Assembly of the ILAE during the Kyoto meeting. It consisted of Mogens Dam, Denmark, president; Carlo

under the aegis of the NIH became a model for centres worldwide. His investigations of absence seizures greatly enhanced understanding of them. He served on the ILAE’s Commission on Classification and Terminology from 1977 until his death, and for most of that time was its chair. Dreifuss became secretary-general of the League in 1981 and its president in 1985. Under his astute leadership, the ILAE began to be more consequential as an international organisation, particularly through the growth of working commissions and the democratisation of the election process for the Executive Committee. At a time when the ILAE’s officers rarely met outside the yearly executive gathering, Dreifuss came up with the idea of a ‘management committee’ to keep things rolling in the interim. Dreifuss naturally formed strong friendships, and people liked being around him. Everyone has a Dreifuss story. Dreifuss was also known for his refreshing plain-spokenness and was a master of *le mot juste*, an attribute as rare as it was useful in navigating the political waters of the international epilepsy movement. In a letter to Harry Meinardi dated 21 July 1986, regarding the League’s dependency on the WFN, Dreifuss wrote, ‘We cannot continue to “suckle on the hind tit” and expect our share of nourishment’. In addition to his ILAE activities, Dreifuss was also president of the AES (1978) and served a number of functions in the Epilepsy Foundation of America (1978–1989). He received many awards for his contributions, including the ILAE’s Ambassador for Epilepsy award (1979), the William G. Lennox Award of the AES (1983) and the Ciba-Geigy/ILAE/IBE Epileptology Prize (1995). Despite his success, he considered himself primarily a clinician. He was deeply committed to his patients, and they adored him. As his student, one of us (S.D.S.) remembers well being driven by Dreifuss for hours to do long outreach clinics in the wilderness of the Blue Mountains. He died of lung cancer at the age of 71 (Porter 1998; Cereghino 2007).

⁸¹ This meeting was also to have included a special roundtable discussion that would enable interested professionals to meet with the secretary-general to learn more about how to form a chapter.

⁸² If Gastaut and Penry were among the League’s most dynamic leaders, Fritz Emanuel Dreifuss (1926–1997) must be its most beloved. And not only beloved, for he was also a superbly effective administrator, a master of witty and pointed remarks. He was become a brilliant ILAE president. Dreifuss was born in Dresden, Germany, and as a child escaped with his family first to South Africa then to New Zealand. He received his medical degree from the University of Otago, and carried out further studies at the National Hospital in London before moving to the University of Virginia in Charlottesville in 1959 where he indulged his growing interest in seizure disorders. In the 1960s he began working on epilepsy projects with the NIH, and when Kiffin Penry came on the scene, Dreifuss became his closest collaborator. The Comprehensive Epilepsy Program Dreifuss developed in Virginia

Arthur Ward (1916–1997) in his operating room; he was editor of *Epilepsia* from 1973 to 1985. Ward served as editor-in-chief of *Epilepsia* from 1973 to 1986, but held no other office in the League. He took over the journal following a very difficult period in its history. His tenure also coincided with the formation of Epilepsy International, and in the long debate over the merits of merging the ILAE and IBE, Ward had the wisdom to see that any such move could have a profound effect on *Epilepsia*.



Tassinari, Italy, vice-president; Masakazu Seino, Japan, vice-president; Fritz Dreifuss, United States, secretary-general; Francisco Rubio Donnadiou, treasurer; Arthur Ward,⁸³ United States, editor-in-chief, *Epilepsia*; Kiffin Penry, ILAE, past-president; Francesco Castellano, IBE, president; Richard Masland, IBE, secretary-general; and Patsy McCall-Castellano, Epilepsy International, executive director.

The 13th Epilepsy International Symposium in Kyoto was the first such congress to take place in Asia, and attracted around 900 participants. Repeating the now familiar quadrennial pattern, the 4-day event was held in conjunction with the 10th Congress of the IFSECN and the 12th World Congress of Neurology. The main themes of the scientific programme included classification, aetiology, antiepileptic drugs, epilepsy and behaviour, rehabilitation and cerebral lateralisation. Juhn Wada chaired a public seminar that featured Carlo Tassinari, Ernst Rodin and Henri Gastaut. The congress was especially significant because the League's General Assembly would be voting on the merger of the ILAE and IBE. 'It is our firm intention,' Meinardi wrote to Toyoji Wada of the Japan organising committee on 26 September 1980,

'i.e. of both the Executive Committee of the ILAE and of the Executive Committee of the IBE to merge during the Kyoto Conference and to dissolve the aforementioned organisations ... However, a decision will have to be taken by the membership of each of the organisations. Planning of meetings therefore will until the last moment be based upon a continuation of both IBE and ILAE. We do hope that in Kyoto these extra meetings can be cancelled, but we cannot decide now.'

The demise of Epilepsy International

In the lead-up to the congress, the plans for the merger had continued, financial and personnel difficulties notwithstanding. A Council⁸⁴ meeting in Copenhagen had taken place as scheduled on 9 September 1980, with representatives from Argentina, Austria, France, Germany, Italy, Japan, Mexico, Netherlands, Poland, Sweden, the United Kingdom and the United States. A summary of the meeting sent to all ILAE chapters in October 1980 laid out plainly the negotiations under way since 1974 between the ILAE and the IBE for the possibility of merging into Epilepsy International and listed the advantages of doing so. But although rumours had circulated for years about various apprehensions regarding this umbrella organisation, the executive had received nothing specific by way of feedback from the chapters. A set of minutes from a

⁸³ In June 1996 Margaret Lennox-Buchthal announced that she had no desire to continue as chief editor of *Epilepsia* any longer than necessary. Arthur Ward was mentioned as a replacement, but as the 1976 Executive Committee minutes are lost, the precise chronology of his selection is unknown. By September 1977, he was already installed.

⁸⁴ The concept of the Council first appeared in the 1973 version of the ILAE Constitution (Article IX).



Mogens Dam, ILAE president 1981–1985. (Courtesy Mogens Dam)

‘meeting of the officers of the [ILAE]’ from 19 September 1981 report that the proposed union ‘was not accepted by the majority’. A 1982 guest editorial in *Epilepsia* written by ILAE president Mogens Dam gives the official version: 28 votes against, 15 for and 4 abstentions – a rout. The Bureau had accepted the merger, but with some exceptions, the ILAE had not. ‘It is certainly my hope’, wrote Dam, ‘that this vote was a result of too little information available about the ideas behind Epilepsy International ... It is much more effective to have one organisation’ (Dam 1982, 240).⁸⁵ The editorial also laid out a series of objectives for upgrading and strengthening the organisation. It was decided to continue the use of

⁸⁵ Dam’s was not the only editorial on the subject in *Epilepsia*. In 1984, Maurice Parsonage asked and was granted the opportunity to present an opposing view. ‘I feel’, he wrote, ‘that we should scrutinise very carefully the claim that one organisation must of necessity be better than two.’ After reviewing the proposed functions of Epilepsy International and critiquing its bylaws and constitution in the context of the needs and goals of both the ILAE and the IBE, he concluded, ‘We in the United Kingdom have now had much experience in matters of this kind; it has often been far from agreeable ... It seems to me, therefore, to be preferable in the present climate of opinion, for our two organisations to maintain their independent control of their affairs’ (Parsonage 1984, 405, 407).

Epilepsy International as an ‘agent’ for the ILAE and IBE for another 4 years and to dissolve the organisation at the next General Assembly in Hamburg in 1985. The reason for this prolongation is not entirely clear, although it may well have been a combination of blind hope and the practical fact that several future meetings had already been scheduled under the name of Epilepsy International. One immediate consequence of the vote, however, was to scale back the yearly symposia to a joint ILAE/IBE international congress every 2 years. During in-between years, regional meetings would be encouraged (Table 3). Committee activity was increasing, and workshops were being organised that provided invited scientists with a forum for dealing with specific problems of epilepsy.

The new Executive Committee assembled for its first formal meeting at the Grosvenor House Hotel, London, in August 1982 in connection with the 14th Epilepsy International Symposium. The symposium itself was not a scientific or financial success, nor much enjoyed. When the conference organiser failed to pay the headquarters’ hotel bill, the hotel threatened to sue Epilepsy International. According to a memorandum dated 31 May 1983 from Francesco Castellano to the Epilepsy International board of directors, the symposium incurred a loss of 47,600 Swiss francs. At the Executive Committee meeting, Dam reviewed his activities concerning the role of Epilepsy International and his attempt at communicating about it to the chapters via his editorial in *Epilepsia*. One of the main problems was that without a single organisation acting for all, it would be difficult to raise the funds needed to carry out the organisation’s aims. In Kyoto, the Dutch league had called for an extraordinary meeting of the General Assembly to deal with the issue of the merger, but that was against the constitution. Instead, it was decided to call a meeting of the Council.⁸⁶ A request for funds for the Epilepsy International 1983 meeting budget was denied owing to the state of the organisation’s financial affairs.

The Executive Committee meeting had been preceded by a meeting of Epilepsy International, and the officers discussed the merger in great detail. Dam recommended that chapters not in favour of a merger be asked to state their reservations and be given more time to deliberate before the revisions to bylaws were drawn up and the entire matter brought before the General Assembly in

⁸⁶ This meeting took place on 17 August 1982, 2 days after the Executive Committee meeting.



Roger Porter, ILAE secretary-general 1989–1993, and Fritz Dreifuss secretary-general 1981–1985, and president 1985–1989.

1985. Kiffin Penry reminded his colleagues that he had worked 'since 1974 towards bringing the two organisations together in order to avoid an undue number of meetings, an undue diffusion of funds and to allow ... an integrated mobilisation of resources'. Carlo Tassinari, on the other hand, felt that the 'ILAE was ... being directed by EI [Epilepsy International] and by EI regulations for which ILAE had never voted and that EI was running away with the direction of the organisation rather than acting as its agent'. A year later, on the occasion of the 15th Epilepsy International Symposium in Washington, DC, when yet another Executive Committee meeting followed a full-day meeting of Epilepsy International, Dam stated that it was quite clear that the majority wanted to keep the ILAE and IBE separate and that Epilepsy International should form a bridge between the two (in which case it would have to have an office with a paid full-time executive). Fritz Dreifuss countered that the all-day meeting exemplified the futility of the present effort: the meetings of the organisations were repeating each other, and Epilepsy International was consuming more and more time.

At least the Washington symposium was a much more felicitous event than the prior year's affair in London,

its scientific quality was high and it made money (a relief after the London debacle). The meeting may well have owed its success to the fact that it was co-sponsored by the AES and the Epilepsy Foundation of America, which gave the ILAE not only a shared programme but also access to the larger groups' audiences. The themes chosen by the League for the symposium were hormones and pregnancy in epilepsy; the role of the government in epilepsy; surgical aspects; neurotransmitters and peptides; and antiepileptic drug binding. A point of pride for the organisers was that the meeting generated an approximately \$50,000 surplus, to be divided equally between the now cash-strapped League and Bureau.

Because no symposium was scheduled for 1984, the 1983 Executive Committee closed with no certain idea of where the next meeting would be and concerns about the cost of getting 14 people together. In the event, the group convened at the Homestead, a resort in Hot Springs, Virginia, on 20 October 1984. The second item on the agenda was the report of the president Dam, who did not mince words on the subject of Epilepsy International: 'The concept of [the] merger is *dead*,' he said. 'We are now the spectators of death throes.' What remained was to breathe new life into the Bureau and the League – especially the League. The Bureau wished to continue as Epilepsy International, but as the ILAE held half the copyright to the name, that would be impossible. Dam wanted to 'keep good relations with the Bureau'. During the Epilepsy International era, he said, 'we have shared a lot ... It has been my feeling and that of many others that the Bureau activities have always taken higher priority than our activities.' Considering proposals made by the IBE the preceding day, the ILAE agreed that collaborative ventures between the two organisations in the post-Epilepsy International era would include fundraising (but limited to activities approved jointly); appointing ambassadors; congresses, symposia and meetings; workshops (but each body could still have its own workshops); and the Commission on Developing Countries. On 20 October, the executive discussed the proposed points of collaboration and basically agreed to all of them. Pure League functions would be *Epilepsia*, existing commissions (except for the Commission on Developing Countries) and new commissions. *Epilepsy International News* would be retitled to avoid confusion now that Epilepsy International was finished, but in the meanwhile would be kept 'until all existing agreements expire or come to renewal and then

new contracts will be dealt with under International Epilepsy News'. In the end, and for all the effort that had gone into creating it, Epilepsy International was surprisingly easy to dismantle.

In retrospect, it is easy to see that the idea of joining the IBE and ILAE was ill-conceived. It was predicated mainly on the opportunity it provided for fundraising, but never managed to raise anything like the required sums. In other ways, it was doomed from the onset, for the nature of the two organisations – both their mission and their constituencies – was so different. The advocacy of a few key individuals gave the initiative a certain momentum, but support from the majority was never more than lukewarm, and the vote of the chapters reflected this disquiet. It was a bruising episode in ILAE history, consuming much time and effort which might have been better employed. When the idea was finally buried, the League advanced rather quickly over the next decade. It was probably the first time, too, in ILAE history that the chapters really engaged democratically in strategic decision making. Of course, as the leadership found out, you can take a horse to water, but you cannot make it drink.

ILAE 1985–1989 and the congresses in Hamburg and Jerusalem

The next biennial congress of the ILAE, held from 6 to 9 September 1985, was titled 'Epilepsy International' in name only. (The label persisted through the 1987 congress in Jerusalem, and thereafter reverted to 'International Epilepsy Congress'.) The 3-day event attracted just over 1,000 participants, the first ILAE meeting to do so.⁸⁷ The themes of the conference were self-help groups; the effectiveness of antiepileptic drugs; the natural history of epilepsy; neuropathology; biorhythmicity and epilepsy; and electrogenesis. At the League's General Assembly on 9 September, the Executive Committee changed hands. Dreifuss was made president; Dam became past-president; Masakazu Seino and Pierre Loiseau (France) were vice-presidents; and Harry Meinardi, who had been president of the IBE from 1977 to 1981, was made secretary-general.

⁸⁷ There was, as had become the pattern, for the last time a joint session with the WFN meeting. As a sign of the dominance of the WFN then, the invites were sent out by the WFN and not the ILAE, even to active ILAE figures (as Engel recalls).

Arthur Ward remained editor-in-chief of *Epilepsia* until 1986, when he was replaced by James Cereghino. Joop N. Loeber of the Netherlands and Richard Masland of the United States represented the IBE ex officio.

The proceedings of Epilepsy International meetings had been published in annual volumes as *Advances in Epileptology* by Raven Press and in some way are now the only visible remains of this episode in the ILAE's history.⁸⁸ The volumes provide a good impression of the focus of epilepsy research during this period and the state of knowledge; they are thus useful in a historical sense. However, the general standard of papers was generally low, and questions were raised continuously about the scientific value of the volumes. Were they worth the effort (which was significant) and the cost of putting them together? The answer was obviously 'no', and with the last volume of *Advances in Epileptology*, covering the 1987 Epilepsy International Symposium in Jerusalem, the series was terminated. Later abstracts of the congresses were provided as supplements to *Epilepsia*.

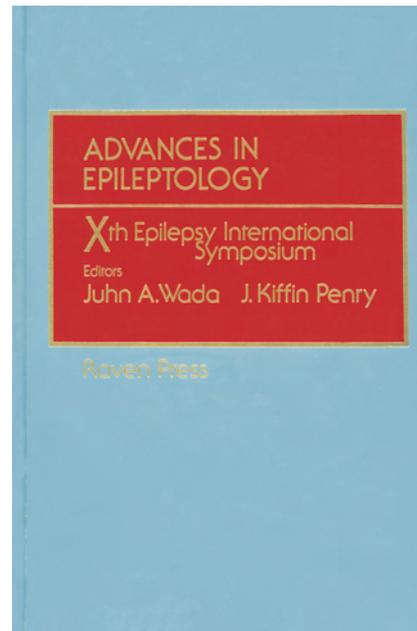
The Hamburg meeting marked another milestone for the League, for there the General Assembly approved a change to the constitution that dramatically revised the procedure for nominating and electing the officers of the Executive Committee. According to the then current (1973) constitution, officers were proposed by a Nominating Committee appointed by the Executive Committee. After approval by the Executive Committee, this slate was presented to the General Assembly for election. Other candidates could be presented by chapters through their chapter vice-presidents (how often that happened is not clear, but as far as we can tell, probably never). The Nominating Committee had itself been an innovation. The 1953 constitution stated only that 'a list of candidates for office shall be submitted by the Executive Committee.' In the spring of 1985, the Nominating Committee in the

⁸⁸ There were in all seven volumes published (by Raven Press) covering the 10th–16th Epilepsy International Symposia; the longest 700 pages in length. Some volumes comprise extended abstracts, others longer papers and some a mixture. Even though the abstracts were mostly selected, the standard of science in general was low, and important scientific progress was reported anyway in the conventional scientific literature. The benefit of these volumes therefore was largely to document what was discussed at the symposia; this is obviously of rather limited value and the decision of the ILAE executive to abandon the volumes was the recognition of this. The volumes, now haunting the shelves of neurology libraries, gather dust and are seldom consulted.

persons of J. Kiffin Penry (chair) and Masakazu Seino⁸⁹ proposed a new election process – based on the model of the federated EEG societies – which for the first time would solicit nominations from chapters for the positions of president and officers. A slate of candidates would then be drawn up, based on the nominations (those receiving the most nominations making it onto the slate). The election would be conducted in two stages, with the president being decided first, followed by election of the vice-presidents, treasurer and secretary-general ‘en bloc’. This newly elected committee would then be submitted for ratification by the General Assembly.⁹⁰ The new system was much more democratic, and perhaps reflected the growing maturity of the ILAE.

The 1985 General Assembly did vote to amend Article VIII(2) of the ILAE Constitution governing elections (see Appendix 5) to enable the two-stage election process, and it was thus approved for use first in the 1989 election. In April 1986, Dreifuss appointed a new Nominating Committee, comprising Seino, Carlo Tassinari, Penry and Ingver Løyning. At the executive in Basel in March 1988, Seino reported ‘extensively’ that four candidates (Joseph Roger, Francisco Rubio Donnadiou, Juhn Wada and Harry Meinardi) had been put forward [for the presidency] and that ‘voting [was] now in progress.’ On 5 July of that year, Seino sent a letter to all chapter delegates announcing that, according to the results of the ‘presidential election by mail voting’, Meinardi had been officially elected as president of the League for the period 1989–1993.⁹¹ In May 1989, Seino further reported that the election of the four other officers was still in progress (19 chapters had voted with 6 abstaining).

For all its benefits, the modern process was not without problems. In particular, once the president was decided, it was not completely obvious how to assign the other positions on the executive on the basis of the votes received. In an undated report recommending its slate of officers for the 1993 General Assembly in Oslo, the Nominating



Advances in Epileptology, a series of proceedings of the Epilepsy International Symposia (10th to the 16th symposia) which ceased publication after 1987.

Committee (comprising Fritz Dreifuss, chair, Seino and Mogens Dam) proposed, by way of clarification for the ‘future’, an addition to the constitution and bylaws ‘to indicate that “The person obtaining the highest number of votes will be assigned the position of secretary-general and the other positions in order of votes will be assigned as treasurer, first vice-president and second vice-president in that order.”’ No such change seems to have been put into the constitution or bylaws. Rather, in the 1997 constitution, Article VIII(2) carries the following new clause: ‘The Nominating Committee will, with the advice and consent of the president-elect, appoint the secretary-general, the treasurer and two vice-presidents from the newly elected slate which must be approved by the General Assembly.’ The process as conceived in 1985 is still fundamentally in effect. But no one has ever argued that it is simple, and the system was open to manipulation by the officers. Since then, there have been a series of further revisions including, in 2005, the so-called Danish amendment (see Chapter 3 and Table 4), and more revisions have been proposed for approval by the General Assembly in Budapest in 2009 (see Appendix 5).

⁸⁹ The committee also included Yngve Løyning and Pierre Loiseau.

⁹⁰ The editor-in-chief of *Epilepsia* is not elected, but appointed by the president.

⁹¹ The tally of votes was Meinardi (22), Roger (18), Wada (12) and Rubio Donnadiou (2). Twenty-eight ballots were received from individual chapters, ‘of which 24 were found to be valid and had reached our office in time’. One chapter abstained. The number of chapters at the time was approximately 30.

Table 4 ILAE election procedures as spelled out over time in the ILAE Constitution and bylaws.

		<i>Constitution/bylaws (C/BL)</i>					
<i>Article</i>	<i>1909</i>	<i>1939</i>	<i>1953</i>	<i>1973</i>	<i>1985</i>	<i>1997</i>	<i>2005</i>
	<i>C2</i>	<i>CIII</i>	<i>CVI</i>	<i>CVIII(2), X(6)</i>	<i>CVIII(2)</i>	<i>CVIII(2), B-LII</i>	<i>CVIII, B-LI</i>
Who?	Pres, v-p, sec, 2 asst-secs, treas	Pres, v-p, treas, gen sec, ed <i>Epilepsia</i>	Pres, pres-elect, 2 v-p's, sec-gen, treas, ed <i>Epilepsia</i>	Pres, 1st v-p, 2nd v-p, treas, sec-gen*	Pres, 1st v-p, 2nd v-p, treas, sec-gen [†]	Pres, 2 v-ps, ‡ treas, sec-gen	Pres, v-ps, § treas, sec-gen
Where?	At a general meeting***	At 'international meetings'	General Assembly	General Assembly	Mail ballot to be ratified at the General Assembly	Mail ballot to be ratified at the General Assembly	Mail, e-mail, fax ballot to be ratified at the General Assembly
How?	By majority	Nominating Committee to be appointed by the president 'after consultation with other officers'	By majority of votes cast by the national branches through their chapter vice-presidents, based on a list of candidates submitted by the Executive Committee (on recommendation of the Nominating Committee)	On submission of a proposed slate by the Executive Committee (on recommendation of the Nominating Committee) and any other nominations submitted by chapter delegates (chapter vice-presidents) (by majority implied)	Two-stage procedure ^{††} : (i) Chapters nominate one candidate for president, and Nominating Committee chooses three ^{‡‡} candidates by a plurality of votes; slate submitted to each chapter for a vote. Each Chapter has 1-4 votes. (2) Each chapter asked to submit four names en bloc as candidates for 1st v-p, 2nd v-p, treas and sec-gen; Nominating Committee then submits to each chapter a slate of 12 candidates based on a plurality for voting. Each Chapter has 1-4 votes	Same as 1985, but specifies that 'the Nominating Committee will, with the advice and consent of the president-elect, appoint the secretary-general, the treasurer and two vice-presidents from the newly elected slate which must be approved [by majority at] the General Assembly'	Four-stage procedure: (i) Elections Commission submits to the Chapters a list of candidates for president and asks each Chapter to vote for one of them ^{§§} ; more than 50% carries. If no candidate receives 50% or more, a second round run off is held. (ii) Chapters requested to submit a slate of four candidates for the remaining officer positions (iii) Elections Commission chooses a slate of not more than 12 candidates on the basis of weighted multiple nominations from the chapter lists (iv) Slate submitted to each chapter for voting. Each Chapter has 1-6 votes

* The 1973 constitution did away with the post of president-elect. Beginning in 1973, the post of editor-in-chief of *Epilepsia* was changed to be appointed by the Executive Committee, subject to ratification by the Council (a body consisting of the Executive Committee and the chapter vice-presidents that had the power to make certain decisions between meetings of the General Assembly).

† According to the 1985 constitution, the editor-in-chief of *Epilepsia* was now to be appointed by an editorial advisory board consisting of the Executive Committee.

‡ The 1997 constitution removed the ranking of the vice-presidents.

§ With the 2005 constitution, the number of vice-presidents was no longer limited to two. Moreover, the so-called Danish amendment specifies that under-representation in (a) of any 'fully operational region' in a newly elected Executive Committee can be remedied by having the chapters of that region elect an additional vice-president.

** Vote 'secret', publication only on signature of the president or the vice-president, and the secretary.

†† Actually, looked at closely, this 'two-stage' process subdivides in a way quite similar to that of the four-stage process which took effect in 2005.

§§ In the preceding term the constitution was amended so that the president had to have been a previous member of the Executive Committee. In addition, no member could serve more than 16 years. The effect was to limit the presidential candidates to only those who had been on the executive for 8 years or less, as the president had to serve for a further 4 years as past-president.

By 1993 this number had changed to four. The League's constitution has been continuously tinkered since at least 1985, and possibly before.

At the spring meeting Penry also suggested that the chapters be asked to consider changing the constitution to state that the General Assembly should meet every 2 years and that the requirement that the meeting coincide with the WFN – traditional since 1935 and enshrined in the 1953 constitution – be dropped. These two proposals were agreed by the executive, but seem not to have made it onto the agenda in 1985, for neither appears as a change to the constitution that year. Both, however, were implemented in the revised constitution of 1997. The desire to decouple the League's meetings from those of the WFN was probably for practical reasons rather than reflecting any more fundamental disagreements. The conferences of each organisation were getting longer, and few participants would have the stamina or time to attend both. Another drawback was that the arrangement dictated the venue for the international congresses, which was further complicated by the decision to hold the congresses jointly with the IBE. The schism does, however, also have a more symbolic resonance – indicating the increasing separation of epileptology from neurology and the growing influence of ILAE itself. The wisdom of the previous arrangement had already been queried at the General Assembly in Amsterdam in 1977. Moreover, during the planning for the ILAE Congress in Hamburg in 1985, the WFN pre-empted the ILAE in choosing the best site for the headquarters hotel. The nearest alternative was a 10-minute walk away, prompting renewed complaints by members of the executive.

One downside of splitting the meetings was that the traditional joint symposium, held between the ILAE and WFN, would no longer occur. This carried the dual likelihood that epilepsy would be downgraded on the WFN programme and the influence of the ILAE on the WFN would diminish (and indeed, both adverse consequences occurred). The executive also considered recommending to the WFN that a local epileptologist be represented on the programme committee of the WFN. In spring 1986 the executive moved to make ILAE president Fritz Dreifuss the League's representative to the WFN. On 21 July 1986 Dreifuss wrote to Harry Meinardi laying out the WFN's negotiating terms for the 1989 congress in New Delhi. For example, the WFN wished to hire someone to solicit exhibitors to the congress as a package deal (Neurosurgery, WFN and ILAE), and Dreifuss was adamant that the accounting be kept separate. Moreover, the WFN had offered the Indian organisers a \$50,000 interest-free loan, something the ILAE was not in a

position to do. In the aftermath of the New Delhi congress, on 19 November 1990, Dreifuss wrote to Meinardi again, 'On looking through the Committee structure it is ridiculous that a major organisation such as the ILAE is not represented fully. I hope that there will be some way of redressing this inequity.' Ultimately, the League did become a full member of the research group of the WFN, and Roger Porter agreed to serve as representative. On 3 December 1990, Meinardi wrote to Ted Reynolds, 'There has been some discussion with respect to severing the link between the ILAE congresses and the congresses of WFN ... Consensus was reached that a good compromise would be to ask your commission [on education] to offer WFN support in case they plan to arrange for educational sessions on epilepsy in the context of their congress.' Reynolds must have asked Porter about possible competition with ILAE congresses, for on 7 January 1991 Porter wrote him, 'It seems unnecessarily defensive for us to be protecting our congress turf when our object is to educate everyone – including physicians – about epilepsy. I suggest that you move directly ahead to assist with epilepsy programs at the WCN [World Congress of Neurology].'

The 17th Epilepsy International Congress in Jerusalem was a standalone event that took place from 6 to 11 September 1987. As in Hamburg, delegates topped the 1,000 mark. Participants remember it for the diarrhoea epidemic that was sweeping Israel at the time, for the tear gas demonstration and the soldiers on the buses, and for the out-of-the-ordinary scientific programme. In addition to sessions on the biochemistry, drug treatment and diagnosis of epilepsy, the scientific programme also dealt with themes of employment and of sleep, and finally of religion, law and epilepsy (including a speaker from the Vatican). The congress was also the first such meeting to offer four industry-sponsored symposia, on the subjects of childhood epilepsy (Ciba-Geigy), Vigabatrin (Merrel Dow), antiepileptic drug research (Warner Lambert/Parke-Davis) and the management of resistant epilepsy (Hoechst & Roussel Uclaf). This development was as much a byproduct of new drugs coming on the market as it was of Harry Meinardi's negotiations over several years as the League's fundraising commissar.

National chapters

In the previous administration, Mogens Dam had tried and failed to establish a chapter in the Soviet Union. Ecuador, Indonesia, Yugoslavia and Guatemala were all

welcomed as new members in Hamburg. Guatemala had caused some confusion by sending separate applications both to the League and to the Bureau. At the League's 1985 Executive Committee meeting in Rheinfelden, Switzerland, Francesco Castellano had brought up the question whether a single chapter might have joint membership in the ILAE and IBE. The specific example was Australia. Robert Gourley, the head of a lay organisation in Australia, wished to represent the Australian epilepsy movement with dual membership in both the IBE and ILAE rather than countenancing development of a professional chapter of the League. However, because the constitution quite specifically states that a League chapter represents the professional segment of the epilepsy movement, Gourley was advised to allow the formation of such a chapter.⁹²

At a subsequent executive meeting, the question arose how representative the Swedish chapter really was of the profession in Sweden. Each chapter was required to have an annual meeting to avoid control by a small cadre, as happened in 1973 in Argentina and Belgium.⁹³ Some Swedish neurologists appeared to be unaware that a Swedish chapter existed, yet payment had been received for 20 members of a Swedish chapter.⁹⁴ In 1987, Australia and Algeria (the first African chapter) were granted provisional membership, pending full approval at the 1989 General Assembly in India. Venezuela's application was nearing completion. An individual membership had also been submitted from Tanzania, which at the time represented the country's only possibility to join the ILAE. Potential chapters included Bulgaria, Costa Rica, Honduras, Hungary, Kuwait, Panama, Peru, Taiwan and Turkey. There was some confusion about who to approach in Pakistan. One League member had contacts with Servipharma, and it was suggested that he act as an intermediate. The Brazilian league had expressed the

desire to be informed of activities more frequently. At the 1988 Executive Committee meeting in Basle, Switzerland, ILAE president Fritz Dreifuss announced jubilantly that there would be nine chapters to be voted on at the time of the 1989 congress. Applications from Cuba, Hungary, Morocco, Panama, Peru, Sweden, Venezuela and Zaire were all in accordance with the constitution and bylaws of the League. There were in total 39 chapters in 1989. Indeed, the growth of the ILAE was remarkable, although the existence of some of the smaller chapters was fragile where there were few members and where the organisation depended heavily on single individuals. A case in point was the Moroccan league. The Polish chapter asked for a waiver of the registration fees to the New Delhi Congress. So as not to set a precedent, the executive declined.

ILAE commissions are expanded⁹⁵

In 1986, Dreifuss had established a Commission on Education. In giving the new body its mandate, he had specifically asked the commission to organise a workshop in India as requested by K.S. Mani⁹⁶ on behalf of the Indian Neurological Society and authorised it to raise the necessary money. The commission was also tasked with producing a film and a book on epileptic seizures, and to liaise with the Commission on Terminology and Classification in this effort. A film produced by the Commission on Antiepileptic Drugs was to be distributed and used through the Commission on Education. Moreover, the chairmen of the ILAE's Commission on Education and its counterpart on the IBE were to interchange the minutes of their meetings.

⁹⁵ For a long time, the League used the terms 'committee' and 'commission' fairly loosely. In 1986, the executive moved to drop the word 'committees' in favour of 'commissions', as it was too difficult to distinguish between the two. Despite the resolve, 'committee' did persist.

⁹⁶ K.S. Mani (1928–2001) was born in Madurai, Tamil Nadu, India, and trained in medicine at Madras Medical College and in neurology at Queen Square. In 1957 he moved to Bangalore where he started the department of neurology at the All India Institute of Mental Health. Roughly 15 years later he co-founded the Indian Epilepsy Association, and he was instrumental in bringing the 18th International Epilepsy Congress to New Delhi in 1989. Colleagues remember Mani not least for his elegant turn of English, his passion for and commitment to epilepsy, his asceticism and the huge public meetings he organised for patients and relatives (meetings sometimes attended by over 1,000 people). During these meetings, he famously mimicked various kinds of seizures with extraordinary verisimilitude.

⁹² The 1985 minutes also state that Ellen Grass, who had been 'very generous to the Australia epilepsy movement specifically wanted the ILAE to be the transmitting agency for her funds in order to foster the professional segment of the epilepsy movement'.

⁹³ Although this has always been the position of the executive, it is not actually part of the constitution or bylaws.

⁹⁴ The secretary-general was asked to write to Karl-Axel Melin in Sweden to find out the status and precise nature of the Swedish chapter, as its executive committee appeared to be partly professional and partly lay. By September 1987, the League had received word announcing organisation of a Swedish branch of the League.

Dreifuss also re-appointed the Commission on Classification and Terminology to ‘develop a classification of the epilepsies, get it approved by the active chapters of the ILAE and other pertinent national societies, develop a current dictionary of the epilepsies and promote its use throughout the world’ (Commission 1985, 268). The commission intended its ‘Proposal for Classification of Epilepsies and Epileptic Syndromes’ as a complement to the classification of epileptic seizures revised in 1981. The authors of the 1981 classification had taken the radical and controversial step of ignoring pathophysiology and anatomy because they believed that there was insufficient evidence to do otherwise. Those who were doing invasive recording (among them Pete Engel) strongly disagreed. A most contentious decision was to ignore anatomy in defining seizure semiology, and this produced complaints from those involved in cerebral localisation for surgery who depend on seizure semiology, and in recent times attempts to launch alternative classifications (for instance by Hans Lüders [e.g. Lüders *et al.* 1993, 1998]) who was a member of the Commission in 2006 but who disagreed with its report). Another decision which proved problematic was to base the dichotomous classification of simple vs. complex partial seizures on the presence or absence of impaired consciousness.

The new proposal was published in *Epilepsia* in June 1985. At the meeting of the Executive Committee in Hamburg later that year, Dreifuss announced that the preliminary reaction to the classification proposal⁹⁷ had been mixed. The main complaint was that it was too complicated. Few people seemed to realise that the proposal for classification of the epilepsies and of epileptic seizures were two entirely different proposals and two entirely different documents. The executive was mixed on whether to bring the classification to a vote. J. Kiffin Penry was strongly in favour. His own survey showed that most of the people who were opposed to the classification did not understand it very well, and some had not even read it in any detail. Carlo Tassinari wondered whether it would help to produce a simplified version for general consumption. Dreifuss mentioned that Natalio Fejerman of Argentina had been doing work relating the classification of epileptic seizures and the epilepsies in a single table. In the end, the classification was provision-

ally approved, and was expected to be finally accepted in New Delhi in 1989.

Penry had suggested that a new glossary be developed by the next Commission on Antiepileptic Drugs with careful definition of terms. As of September 1987, the Commission on Antiepileptic Drugs was still looking for funds to finalise production of a glossary that would be a compendium of the international names of the various antiepileptic drugs. The process had been complicated by incompatibilities between the electronic source texts and the printer’s equipment. An additional project, the guidelines on clinical evaluation, was also stalled. Pharmaceutical manufacturers had expressed concern that the present draft appeared to exclude marketing of drugs not shown to be superior to existing drugs on clinical evaluation. The Executive Committee was willing to keep the concern in mind, but generally agreed that protecting the patient also meant reducing me-too pharmaceuticals (‘unless it would be me-too but cheaper’). By 1988, money had finally been raised to solve the technical glitch that had delayed publication of the glossary, and the document was expected to become available before the end of 1989. About \$20,000 was available to finance the production and distribution of the glossary as a supplement to *Epilepsia*. In spring 1991, the Executive Committee agreed to order 2,000 extra copies of the antiepileptic drugs glossary at a rate of slightly more than \$3,000 per thousand. They would be distributed by the IBE and ILAE from Holland. The ILAE would pay for 1,000 copies.

At the Executive Committee meeting at Hot Springs, in 1984, Penry had suggested reviving the old Long-Range Planning Committee, which had been set up in 1976 when Epilepsy International was being formed. The commission was confirmed in April 1985, and had its first meeting at an Academy of Neurology meeting. At the 1986 executive, the committee recommended that news of international activities be sent to the chapters every 3 months. Further, communication between the members themselves should be improved. Minutes of all commissions should be available to members on request, and the annual reports of the commissions would be distributed to all chapters – a precursor of the current ILAE Annual Report. The Long-Range Planning Committee had asked the president to appoint a further commission to improve interaction between basic scientists and clinicians in neglected areas of epileptology. But the executive suggested that such activity was actually

⁹⁷ Actually, to the circulation of the preliminary report rather than the final report.

part of the task of the Long-Range Planning Committee itself, perhaps through organising specific workshops. A proposal to establish a fundraising commission was unanimously accepted. At this same meeting, the Commission on Epilepsy, Pregnancy and the Child, which was formed in 1983, was renamed the Commission on Epilepsy, Genetics, Pregnancy and the Child.⁹⁸ A Commission on Surgical Therapy was tasked with reviewing and evaluating the forms of the treatment and resources necessary to undertake effective surgical intervention. Finally, an additional article was added to the bylaws stating that the president, treasurer and the secretary-general would act as Management Committee in between meetings of the Executive Committee (with actions subject to ratification by the Executive Committee). Following its initial burst of activity, however, the Long-Range Planning Committee ran out of wind. Between 1987 and 1988, little happened. The extent of the lull was such that, at the Executive Committee meeting in Basle, Switzerland, in March 1988, Dreifuss decided ‘to expand the [committee] with Drs Heinemann and Noebels to strengthen the scientific component of this activity’.⁹⁹

At the 1987 executive in Liestal, discussion turned to workshops. Harry Meinardi volunteered that workshops were originally organised by members of ILAE chapters, but had proved successful and could help the ILAE to reach its goals. For example, the Commission on Epilepsy, Pregnancy and the Child had grown out of a workshop on pregnancy and antiepileptic drugs. Workshops (some conceived under Epilepsy International) had subsequently been held on tolerance, chronic toxicity and metabolism of antiepileptic drugs; neurotransmitters and epilepsy; education and epilepsy; and memory and antiepileptic drugs. Now, Meinardi proposed general guidelines for conducting workshops. These were read and discussed, and a corrected version would be circulated among the Executive Committee before sending them to the chairpersons of all commissions. A question (unanswered) was raised about

the accountability of workshops: the ILAE could not be responsible for their financial handling, although surpluses could be used to subsidise new workshops. The amended workshop guidelines were approved in September 1987, and were now ready to be sent to the chapters.¹⁰⁰ The executive also discussed how workshops might compensate the lack of attention to the basic sciences that was a frequent criticism of the ILAE/IBE congresses.

ILAE 1989–1993 and the congresses in New Delhi and Rio de Janeiro

The new Executive Committee ushered in at the General Assembly in New Delhi comprised Harry Meinardi (president), Fred Dreifuss (past-president), Paulo R.M. de Bittencourt (vice-president, Brazil), Ted Reynolds (vice-president, UK), Roger J. Porter (secretary-general, United States), Masakazu Seino (treasurer), Bill McLinn (ex officio, IBE, United States), Hanneke de Boer (ex officio, IBE, Netherlands) and James J. Cereghino (editor-in-chief, *Epilepsia*).

The 18th International Epilepsy Congress in New Delhi was the first to run fully under the post-Epilepsy International banner. It also represented the first meeting the ILAE had mounted independent of the World Congress of Neurology since 1935. The choice of India, as a less affluent country, was deliberate. The congress was significant for another reason: for the first time, the congresses were starting to raise significant sums of money by letting exhibition space to industries wishing to flag their products. The event was to have marked the 80th anniversary of the founding of the ILAE, but for some reason, plans petered out. Margaret Lennox declined a request to edit a historical issue of *Epilepsia*, and the written commemoration was reduced to a fairly bland editorial composed by outgoing president Dreifuss.¹⁰¹ In his final presidential address, Dreifuss cited the achievements of the past 4 years, in particular, a greater number of commissions, reflecting

⁹⁸ Ultimately ‘pregnancy’ would be dropped and incorporated into the drug commissions (Andermann 2006).

⁹⁹ The Long-Range Planning Commission was not the only laggard. The Commission on Neurosurgery also had little to show, and Dreifuss proposed to ask Herbert Silfvenius of Sweden and Heinz-Gregor Wieser of Switzerland to take over the leadership of the commission. Their charge would be to prepare a review of the types of neurosurgery performed worldwide, and to analyse its impact as well as the need for neurological centres.

¹⁰⁰ The secretary-general was also asked to develop guidelines for commission chairpersons, chapter secretariats and fundraising.

¹⁰¹ Indeed, a number of events were planned for 1989. In addition to the *Epilepsia* supplement, the chapters would be asked to provide an overview of their own history. The League would cooperate with the Bureau in supporting a proposal by Arthur Sonnen to have an audiovisual competition during the congress in New Delhi. The League capped its own budget for the project at \$4,000.

the League's greater reach of activities. A new commission on basic sciences in epilepsy would try to bridge the gap between basic scientists and clinical scientists. The break-up of Epilepsy International had been for the best, although he did not word it in precisely those terms. Finally, regional concerns were becoming more of an issue, and local meetings to address these were beginning to take place between the biennial meetings of the League.

The last meeting of the 'old executive' took place on 16 October 1989. The Cyprus league was denied membership as a chapter owing to an insufficient number of professional members active in the field of epilepsy. Note was made that a chapter constitution is only in agreement with the ILAE constitution if the officers rotate and have a period during which they are not re-eligible. The finances of *Epilepsia* were pronounced to be in the black for the first time ever. The Commission on Antiepileptic Drugs' glossary was 'really nearly ready' for publication as a supplement to *Epilepsia* but funds for the project had been severely depleted, and another \$20,000 might be needed (this was a source of annoyance to the executive as the costs had spiralled). The Commission on Classification and Terminology had published a revised proposal for a classification of the epilepsies, and in the new administration would move on to updating the classification of seizures and producing a new dictionary to update Gastaut's. Moreover, the chairman of the Nominating Committee should be a person who cannot be elected or re-elected. A commission was to be nominated and charged with describing and registering the tasks and function of the Nominating Committee. Other commission activities were discussed.

In welcoming his Executive Committee on 21 October, newly appointed ILAE president Harry Meinardi noted that too little time was available at the congress for business meetings and that future congresses should remedy the situation. He asked the Long-Range Planning Commission to address several issues, specifically, a comprehensive membership list, increased registration fees for non-chapter members (not considered favourably) and the possibility of publishing congress abstracts in *Epilepsia*. A commission on commissions was going to be needed to set guidelines for creating and decommissioning ILAE commissions. Richard Masland would be editing *International Epilepsy News* for the next 2 years, after which a new layout would be considered. The IBE would take the lead, but the ILAE was expected to make a

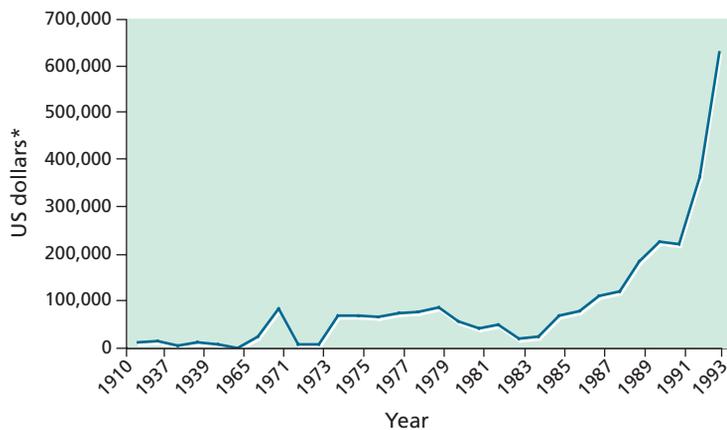
contribution. In the interest of a better relationship with WHO, Dreifuss had appointed Pierre Jallon, president of the French League, to be the liaison for the ILAE. Several important countries, such as India, Russia and China, still had no chapters. The new secretary-general, Roger Porter, would begin contact with these countries.

The 19th International Epilepsy Congress, held 14–19 October 1991, in Rio suffered from the ambivalence of the League and the IBE over whether to even hold it there. Its reputation for crime, a cholera epidemic and Brazil's jittery financial markets were major disincentives. As it turned out, 1,300 delegates made the trip – a perfectly respectable number – and even the drug companies showed up to stage four satellite symposia. Seven themes were chosen for the congress, of which the structural biology of the epilepsies, genetics in epilepsy, and tropical diseases and epilepsy represented new topics. The Executive Committee met on 12 October, but had little to report since the spring. Roger Porter, secretary-general, suggested that the League had evolved to the point where a permanent secretary and office might be needed. First vice-president Paulo de Bittencourt led a discussion on issues of fundraising and policy on epilepsy vis-à-vis regional meetings and organisations, although the minutes provide no details. James Cereghino announced that Rio would be the first time abstracts of a major ILAE congress were published in *Epilepsia*. Bulgaria was provisionally approved as a full member of the League.¹⁰²

Financing the ILAE, 1953–1992

Trying to trace the League's fiscal history through the minutes of the Executive Committee is an inexact science. The picture one gets is no more than fragmentary, and consequently hard to make sense of. Amounts discussed at the executive's meetings do not necessarily coincide with those officially reported by the treasurer. The treasurer's statements themselves for the period 1953–1993 do not help much. They are cursory at best, and the categories and periods covered change from year to year. For some years (notably 1973, 1982 and 1983) there are no reports at all. Banks tended to be wherever the

¹⁰² It was previously approved in 1969, but like many other chapters, went through a long period of inactivity, and its status as a functioning chapter in these years is uncertain.



The financial growth of the ILAE, 1909–1992. *In 2007 US dollar equivalent figures.

treasurer was situated, and currency changed from pounds to florins to dollars to kroners and back to dollars again. By the 1990s, the League had money stashed all over the globe and no systematic way of accounting for it. What is certain is that, for a long time, the ILAE had little cash and spent little. Until the early 1970s, it survived largely on loans from the Dutch branch, and both its activities and expenses were minimal. The balance as of August 1953, for example, was \$563.73 (\$34,988 in today's dollars). The finances of the next two decades are reported erratically in *Epilepsia*. Archival records do not appear until the early 1970s, and the amounts are small. By 1974, however, as both the tally of chapters and the number of subscriptions to *Epilepsia* grew, the League began to accumulate enough to put in an interest-bearing account.¹⁰³ The ILAE's objective at this point was to operate its general administrative expenses and annual Executive Committee meetings on a central core of funds obtained from chapter membership dues. Of course, given the League's international nature, collecting dues was hardly straightforward.¹⁰⁴

¹⁰³ For reasons that are not quite clear, the treasury from 1965 to 1973 was in Phoenix, but from 1970 to 1973, the amounts were reported in florins. Secretary-general Otto Magnus had established an account at Wassenaar for the convenience of the European chapters. At this point, however, the treasurer and secretary-general were not getting along, and how they negotiated transfers of funds between them is not documented.

¹⁰⁴ The new constitution adopted in Barcelona made clear that chapter dues would have to be established. At the 1974 Executive Committee meeting, Penry proposed that each chapter pay \$3 per individual member to the ILAE annually; individual members would pay \$10. The dues would apply to professional members only.

Some chapters were very reluctant to pay the League any dues and there was a suspicion (for many years) that others deliberately under-reported membership numbers to reduce the payment. There was also a view held by individual chapters that they received little benefit in return for the payments they made to the ILAE executive. These issues persist to this day.

Moreover, figuring a way to budget the available monies for the League's activities required more administrative capabilities than the organisation had at the time. The ILAE did manage to file articles of incorporation in Washington, DC, in 1975, a first step in gaining tax-exempt status from the US International Revenue Service.

In Vancouver, in 1978, with the balance at 158,368 Swedish krona (\$88,239 in 2007 dollars), then treasurer Karl-Axel Melin called the financial situation of the ILAE 'rather healthy'. The largest consistent expense was the Executive Committee meetings. The income from *Epilepsia* did not cover its costs (and never had), and the executive was generally agreed that the funds to cover the cost of producing the journal should come 'first from advertising; second from Raven Press [the new publisher of the journal]; and third from member dues'. By now as well Epilepsy International had come into being. Initially conceived largely as a mechanism to make the ILAE and IBE more efficient, it never managed to even to cover its costs. This state of affairs culminated, in 1982, in the debacle of the Epilepsy International Symposium in London. The League and the Bureau considered taking the conference organiser to court, but concluded it would be too expensive with a doubtful return if won. The hotel gracefully wrote off the unpaid bill as 'not retrievable'

(H. Meinardi, personal communication). A worst-case outcome could have bankrupted the League. Luckily, that did not happen, and several years later, Epilepsy International had ceased to be.

For the period 20 September 1983 to 19 October 1984, the League had income of \$6,773 (\$14,100 in 2007 dollars) and expenses of \$7,236. That left a balance of \$11,558 with a loss of \$463 for the year. The deterioration compared to the situation in 1978 is striking, but is left unmentioned in the executive's minutes. Treasurer Francisco Rubio Donnadiu reported that he had not received any 1984 dues from the chapters, despite a letter mailed in June. Moreover, several countries, for example Argentina, Brazil and Uruguay, could not send money out. Another complexity involved money paid directly to the League's bank account in Houston: names were not always correct and so on. (The issue was of some concern, as chapters had to be in good standing to be able to vote.) Secretary-general Fritz Dreifuss was asked to send letters to each chapter to pay its 1985 dues or risk jeopardising its vote at the meeting of the General Assembly. Such concerns notwithstanding, in 1984 the League's income had surpassed \$40,000 (\$79,825 in today's dollars) for the first time, and would be required to file a tax return with the Internal Revenue Service.¹⁰⁵ The balance in the ILAE account at the end of 1985 was \$41,349.

As of September 1985, 11 chapters had paid their dues and 5 chapters were in the process of paying. Funds from Raven Press for *Epilepsia* were \$4,400 for 1984 and \$2,200 for the first three-quarters of 1985. The journal also had a \$30,000 reserve (in a separate account in Washington, DC) largely derived from advertisements and supplements. At the first meeting of the new Executive Committee on 12 April 1986 in Montpelerin, Switzerland, the officers agreed to send to the treasurer's office all royalties derived from publications on behalf of the League. Future contracts were to be reviewed by the secretary-general before they were concluded. Commissions and committees would be accountable to the treasurer for monies raised or spent in their name. The secretariat was authorised to spend up to \$1,000. Monies associated with *Epilepsia* were to go to the journal's office, which

would be responsible for accounting for the money to the treasurer. Individual commissions would be required to raise the funds for the budget of their commission. Harry Meinardi was appointed commissar for general-purpose fundraising (in addition to his fundraising tasks for an upcoming congress in Jerusalem).

The ILAE also instituted a policy of approving a commission's budget before committing itself to any expenditure of funds on the commission's behalf. The increasing complexity of the organisation was beginning to give rise to questions of accountability. The ILAE had never been submitted to an official audit. The treasurer's statements overlapped. Joop Loeber, present ex officio for the IBE, suggested that the treasurer make a full annual report. Dreifuss proposed that all 'independent' commission treasurers report to the League treasurer twice a year to enable the ILAE to function as a single organisation. In September 1987, at its meeting in Jerusalem, the Executive Committee for the first time considered the use of its reserve capital. The proposal (which was accepted) was to use the money first as a buffer for operating expenses for the 2-year period between congresses. Second, it would be used as seed money for a congress in its initial phase when no other sources of income were available. Additional income could be derived from soliciting the publication of workshop and symposium proceedings as supplements to *Epilepsia*.

In March 1988, ILAE president Dreifuss told his Executive Committee that the League had progressed from 'a saltatory to a more continuous activity'. But he was worried about the financial situation for the future. AIDS had by now made its appearance, and money would need to be diverted to find drugs to fight it. Within the pharmaceutical industry, moves to generic drugs and tightened regulatory standards would increase the cost of new drug development. Finally, a proliferation of epileptology journals risked diluting the value of an 'all things to all men' publication such as *Epilepsia*. On the bright side, his were the concerns of 'a vibrant and viable organisation', signalling 'growth and activity'. The IBE decided that any group or country that wished to organise a meeting under the aegis of the IBE and/or ILAE would in future have to pay a fee of 5% of the budget (i.e. maximally 10% of their budget) to the two organisations to be permitted to carry the name of ILAE and IBE. By the end of the 1988 executive, the ILAE had made a similar decision. In 1989, this requirement was

¹⁰⁵ During 1983, after having let its incorporated status lapse, the ILAE was re-incorporated in the District of Columbia and obtained full tax-exempt status from the Internal Revenue Service.

refined to apply only to congresses or symposia with paying participants. Workshops initiated by the ILAE with a limited number of non-paying participants would not be required to pay a fixed amount. It is not clear that this particular idea was actually instituted, and it certainly does not apply now.

In May 1990, the ILAE was in good financial condition, by virtue perhaps largely of the better governance which Dreifuss especially had worked towards. Indeed, on 8 October, the balance of the League's account, after expenses, was \$142,929 (\$226,742 by today's reckoning). The executive had decided to provide the secretary-general with secretarial and logistical support to the extent of \$10,000 for 1990/91, and to charge the management committee with investigating staffing and financial management services for the League. The executive moved to begin collecting the financial records of all the ILAE accounts – including from *Epilepsia* and the commissions – each year by 15 March to facilitate filing of taxes. Hereafter, the treasurer would report to the Executive Committee annually on the entire funds of the ILAE. Each international congress would have a separate account in Holland for its own affairs. The executive also moved to authorise the organisers of the 19th International Epilepsy Congress, in Rio de Janeiro, to raise funds for the production of a supplement to *Epilepsia*, plus 1,200 copies of the supplement, which would contain all the abstracts. In 1991, the Commissions on Neurobiology, Education, Neurosurgery and Tropical Diseases were each awarded \$4,000 for their activities based on having 'appropriately applied' for the monies. When the Executive Committee next met, in Rio, the secretary-general noted wryly that the grants had sparked a certain level of interest and would be re-offered the following year. The ILAE's budget for 1991–92 was \$131,500.

In Basle, in 1992, discussion turned again to the League's surplus monies and how they could most wisely be spent. The ILAE needed a floor of dollars to protect its integrity, and especially that of *Epilepsia*, but beyond that, it needed a long-term strategic plan for expending funds. For the coming year, the committee moved to create a reserve of \$125,000 for the operations of the journal, and \$150,000 for the ILAE general budget. For the first time, *Epilepsia* was to have a full-time professional secretary or editorial assistant, at an approximate cost of \$40,000. Eight commissions had applied for \$4,000 grants, and all were awarded. The Commission on Drivers Licensing and the

Commission on Developing Countries, both joint with the IBE and ILAE, received \$2,000 each. The outgoing treasurer would provide the necessary documents to the new treasurer. The executive agreed to leave the ILAE's funds in the United States for the present time.

With the beginning of the 1990s, the League was tightening up its governance and administration. This was necessary not least because of its rapidly growing size and complexity, its generally able leadership, the fact that *Epilepsia* and the congresses were beginning to bring in more money and that it was no longer distracted by the spectre of Epilepsy International. This set the scene for the coming years, in which great strides were made.

References

- Aarli, J.A. (2007) World Federation of Neurology, 1957–2007. *Journal of the Neurological Sciences* 258:1–3.
- Andermann, F. (1987) Francis Lothian McNaughton. *Epilepsia* 28:198–200.
- Andermann, E. (2006) Interview conducted by G. Weiss, digital recording, San Diego, CA, 4 December.
- Announcement (1959/60) *Epilepsia* 1:232.
- Announcements (1964) *Epilepsia* 5:376–378.
- Announcements (1967) *Epilepsia* 8:71–72.
- Anon. (1970) Clinical and electrographical classification of epileptic seizures. *Epilepsia* 11(1):112–112.
- Anon. (1982) Report of the Third Commission on Antiepileptic Drugs of ILAE, 1978–1981. *Epilepsia* 23:225–228.
- Anon. (1989) Guidelines for clinical evaluation of antiepileptic drugs. Commission on Antiepileptic Drugs of the International League Against Epilepsy. *Epilepsia* 30:304–308.
- Appeal (1961) *Epilepsia* 2:100.
- Beaumanoir, A. and J. Roger (2007) *Une histoire de l'épileptologie francophone*. John Libbey Eurotext: Paris.
- Blume, W.T., H.O. Lüders, E. Mizrahi, C. Tassinari, W. van Emde Boas, and J. Engel, Jr. (2001) ILAE Commission Report: Glossary of descriptive terminology for ictal semiology. *Epilepsia* 42:1212–1218.
- Cereghino, J. (1994) David D. Daly, M.D., 1919–1991. *Epilepsia* 35:244–245.
- Cereghino, J. (2007) Interview conducted by G. Weiss, digital recording, Philadelphia, PA, 3 December.
- Commission on Antiepileptic Drugs of the International League Against Epilepsy (1991) Workshop on antiepileptic drug trials in children. *Epilepsia* 32:284–285.
- Commission on Antiepileptic Drugs of the International League Against Epilepsy (1993) Guidelines for therapeutic monitoring on antiepileptic drugs. *Epilepsia* 34:585–587.
- Commission on Antiepileptic Drugs of the International League Against Epilepsy (1994) Guidelines for antiepileptic drug trials in children. *Epilepsia* 35:94–100.

- Commission on Classification and Terminology of the International League Against Epilepsy (1969) Clinical and electroencephalographical classification of epileptic seizures. *Epilepsia* 10 (Suppl.):S2–13.
- Commission on Classification and Terminology of the International League Against Epilepsy (1985) Proposal for classification of epilepsies and epileptic syndromes. *Epilepsia* 26:268–278.
- Commission on Classification and Terminology of the International League Against Epilepsy (1981) Proposal for revised clinical and electroencephalographic classification of epileptic seizures. *Epilepsia* 22:489–501.
- Commission on Classification and Terminology of the International League Against Epilepsy (1989) Proposal for revised classification of epilepsies and epileptic syndromes. *Epilepsia* 30:389–399.
- Constitution for International League Against Epilepsy (1940) *Epilepsia* 1:248.
- Constitution, International League Against Epilepsy (1953) *Epilepsia* 2:112–114.
- Dam, M. (1982) Message from the president of the International League Against Epilepsy. *Epilepsia* 23:239–241.
- Dravet, C., and J. Roger (1996) Henri Gastaut, 1915–1995. *Epilepsia* 37:410–415.
- Dreifuss, F.E. (1986) Report on the International League Against Epilepsy. *Epilepsia* 27:1–2.
- Dreifuss, F.E. (1989) On the occasion of the 80th anniversary of the founding of the ILAE. *Epilepsia* 30:387–388.
- Dreifuss, F.E. (1996) J. Kiffin Penry, 1929–1996. *Epilepsia* 37:1023–1024.
- Gastaut, H. (1954) *Epilepsia* 3:110.
- Gastaut, H. (1969a) Clinical and electroencephalographic classification of epileptic seizures. *Epilepsia* 10 (Suppl.):S2–13.
- Gastaut, H. (1969b) Classification of the epilepsies. *Epilepsia* 10 (Suppl.):S14–21.
- Gastaut, H. (1970) Clinical and electroencephalographical classification of epileptic seizures. *Epilepsia* 11:102–113. [NB: A reprint of 1969a]
- Gastaut, H., W.F. Caveness, H. Landolt, A.M. Lorentz de Haas, F.L. McNaughton, O. Magnus, J.K. Merlis, D.A. Pond, J. Radermecker, and W. Storm van Leeuwen (1964) A proposed International Classification of Epileptic Seizures. *Epilepsia* 5:297–306, 297.
- General Assembly of the International League Against Epilepsy (1965) *Epilepsia* 6:348–350.
- General Assembly of the International League Against Epilepsy (1970) *Epilepsia* 11:95–100.
- Glaser, G.H. (1982) Obituary: Jerome K. Merlis. *Epilepsia* 23:563–564.
- Hess, R. (1971) Hans Heinrich Landolt (1917–1971). *Epilepsia* 12:295–297.
- Jasper, H.H. (1964) Some physiological mechanisms involved in epileptic automatism. *Epilepsia* 5:1–20.
- Kelner, K.L. (1996) Honoring J. Kiffin Penry, M.D.: Summary of a symposium held at Wake Forest University, September 16–18, 1994. *Epilepsia* 37:287–305.
- Ledeboer, B. Ch. (1953) Report of the quadrennial meeting: Lisbon, Portugal, September 7–12, 1953. *Epilepsia* 2:56–57.
- Ledeboer, B. Ch. (1954) Report of the secretary-general. *Epilepsia* 2:111–112.
- Lennox, M.A. (1982) Professor Gastaut's contribution to the International League Against Epilepsy. *Electroencephalography and Clinical Neurophysiology* 35 (Suppl.):9–12.
- Lennox, W.G., and M. Lennox (1960) *Epilepsy and Related Disorders*, 2 vols. Little, Brown.
- Lüders, H., J. Acharya, C. Baumgartner, S. Benbadis, A. Bleasel, R. Burgess, D.S. Dinner, A. Ebner, N. Foldvary, E. Geller, H. Hamer, H. Holthausen, P. Kotagal, H. Morris, H.J. Meencke, S. Noachtar, F. Rosenow, A. Sakamoto, B.J. Steinhoff, I. Tuxhorn, and E. Wyllie, (1998) Semiological seizure classification. *Epilepsia* 39:1006–1013.
- Lüders, H.O., R. Burgess, and S. Noachtar (1993) Expanding the international classification of seizures to provide localization information. *Neurology* 43:1650–1655.
- Magnus, O. (1967) To the memory of A. M. Lorentz de Haas. *Epilepsia* 8:219–222.
- Masland, R.L. (1959) Classification of the epilepsies. *Epilepsia* 1:512–520.
- McNaughton, F.L. (1971) The International League Against Epilepsy. P165 Francis Lothian McNaughton Fonds. Osler Library of the History of Medicine, McGill University, Montreal, Quebec, Canada.
- Meinardi, H. (1999) *International League Against Epilepsy and Its Journal Epilepsia, 1909–1999*. ILAE: Hilversum.
- Meinardi, H. (2001) K.S. Mani, M.D., 1928–2001. *Epilepsia* 42:963–964.
- Meinardi, H. (2002) Epileptology. In *History of Neurology in the Netherlands*, ed. J.A.M. Frederiks, G.W. Bruyn and P. Bing. Boom: Amsterdam, chapter 13.
- Meinardi, H. (2007) Interview conducted by G. Weiss, digital recording, The Hague, 23 May.
- Merlis J.K. (1970) Proposal for an International Classification of the Epilepsies. *Epilepsia* 11:114–119.
- Naquet, R. (1996a) In memoriam Henri Gastaut. *Electroencephalography and Clinical Neurophysiology* 98:231–235.
- Naquet, R. (1996b) Hommage à Henri Gastaut (1915–1995). *Neurophysiologie Clinique* 26:170–176.
- Naquet, R. (1997) Entretien avec J.-F. Picard, 21 January. <http://jfpicard.free.fr/Naquet.html> [accessed 24 August 2008].
- Niedermeyer, E. (1995) A. Earl Walker: Neurosurgeon, neuroscientist and epileptologist. *Epilepsia* 36:516–521.
- Ninth Meeting of the International League Against Epilepsy (1961) *Epilepsia* 2:101.
- Notes and news (1937) *Lancet* 3 (April):823.
- Parsonage, M. (1984) Guest editorial. *Epilepsia* 25:405–407.
- Pedley, T. (2007) Present at the beginning: Ellen Grass and the evolution of modern concepts regarding EEG and epilepsy. *American Journal of Electroneurodiagnostic Technology* 47:241–256.
- Penry, J.K. (1974) Report of the Commission on Antiepileptic Drugs of the International League Against Epilepsy. *Epilepsia* 15:143–146.
- Pippenger, C.E., J.K. Penry, and H. Kutt (1978) *Antiepileptic Drugs: Quantitative Analysis and Interpretation*. Raven Press: New York.
- Porter, R.J. (1998) Fritz E. Dreifuss, 1926–1997. *Epilepsia* 39:556–599.

- Reports from the Branches (1953) *Epilepsia* 2:108–110.
- Reports from the Branches (1955) *Epilepsia* 4:110–114.
- Reynolds, E.H. (1975) Chronic antiepileptic toxicity: a review. *Epilepsia* 16:319–352.
- Shorvon, S. (2006) An episode in the history of temporal lobe epilepsy: the quadrennial meeting of the ILAE in 1953. *Epilepsia* 47(8):1288–1291.
- Tomson, T. (1996) Karl Axel Melin. *Epilepsia* 37:589.
- Third and Fourth Commissions on Antiepileptic Drugs of the International League Against Epilepsy (1985) Availability and distribution of antiepileptic drugs in developing countries. *Epilepsia* 6:117–121.
- Trufant, S.A. (1996) Arthur Earl Walker, 1907–1995. *Annals of Neurology* 39:275.
- van Bogaert, L., and J. Radermecker, Eds. (1959) *International Congress of Electro-Encephalography and Clinical Neurophysiology. 8th Meeting of the International League Against Epilepsy*. Pergamon: London.
- Wada, J.A. (n.d.) A brief history of the Canadian League Against Epilepsy (CLAE). http://www.canadianepilepsy.org/imports/pdf/CLAE_history.pdf [accessed 25 August 2008].
- Walker, E.A. (1955) The president's report. *Epilepsia* 4:109.
- Walker, E.A., and H.A. van Alphen (2005) In *Fifty Years of the World Federation of Neurological Societies (1955–2006)*, ed. H.A. van Alphen, De Zaak Haes: Amstelveen.
- Williams, D. (1953) Report of the treasurer. *Epilepsia* 2:105.
- Zottoli, S. (2001) The origins of the Grass Foundation. *Biological Bulletin* 201:218–226.