

# 1 International League Against Epilepsy – the first period: 1909–1952

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For many years, time shrouded the detail of the origins of the International League Against Epilepsy (ILAE). Recent research, however, has revealed much about the inception and early development of the organisation. In fact the picture is now relatively complete, although certain details are still missing. For instance, we do not really understand the motivations of the League's founders or the financial basis of the organisation or the extent of the initial connection between the League and *Epilepsia*. Moreover, for important periods in the later history, significant source documentation has been lost. This is perhaps hardly surprising, but it makes it all the more important to collate what information exists, for knowledge of the history of any major organisation is vital for its health and wise future development. The purpose of this chapter is to piece together an account of the League through the years, to document what is known and to try and infer what is not.

The ILAE did not start in a vacuum. In the early 20th century, national associations of professionals interested in epilepsy were being formed in a number of different countries. Such epilepsy associations were known to have been set up in the United States, Brazil, Holland and Sweden, and were usually loosely linked to larger neurological or psychiatric associations which had been in existence for longer. Epilepsy seems to have led the way among the neurological subspecialties in this regard, and then as now, there was a notable impatience, a feeling that epilepsy itself deserved separate representation. In addition to these national associations, other international organisations existed in the fields of general medicine and in psychiatry. The psychiatric organisations in particular were well established and driven both by professional and medical social concerns. The American Psychiatric Association existed in rudimentary form as

early as 1845, and by 1909 every major European country had a national psychiatric society. Another important element was the opportunity afforded by the large international medical congresses for like-minded individuals to meet and discuss international cooperation. These congresses became a vehicle for such networking and a breeding ground for various initiatives, including the launch of the ILAE.

Epilepsy was then a much more stigmatised condition than now, linked in the minds of many with madness and associated with degeneration and in part with criminality. The iniquity of this reactionary attitude was recognised by many physicians, and the foundation of the League was in part a response to it. Chronic epilepsy was treated both by psychiatrists and neurologists – the two specialties were anyway closely aligned especially in Central and Eastern Europe – and especially by those working in asylums (known as alienist physicians). Indeed, the physicians involved in the early epilepsy organisations almost all had largely asylum-based practices.

It was in this context and setting that, for the first time, an international professional organisation was established in the field of epilepsy. It was known from the outset as the International League Against Epilepsy (or sometimes then as the *Ligue Internationale contre l'Épilepsie* or *Internationale Liga gegen Epilepsie*; or more recently simply as the ILAE).

## The International Institute for the Study of the Causes and Prevention of Insanity: the precedent for the ILAE

The ILAE had a precursor, the International Institute for the Study of the Causes and Prevention of Insanity



(or variations on this name).<sup>1</sup> Its aims, statutes and organisational structure were the prototype for the structure and aims of the ILAE, and key personnel involved in the planning of the institute (e.g. Augusto Tamburini and J. van Deventer) were also instrumental in establishing the ILAE. This institute was first proposed publicly at the 1906 International Congress on the Care and Treatment of the Insane in Milan, by Ludwig Frank, a neurologist from Zurich (see e.g. Tamburini 1906; Ferrari 1907). Tamburini was appointed president of a commission to establish the new institute and Frank its secretary-general. The idea had much momentum, and rapid developments were made in its first few years (Smith 1910; Shorvon *et al.* 2009). At the second meeting of the commission, at an international neurology and psychiatry congress in Amsterdam in September 1907, Louis Muskens took the floor to ask whether, in view of Frank's 'eloquent appeal' on behalf of mental diseases, it might not also be time to set up a similar international commission to study epilepsy. Thus was the embryonic idea of the League first delivered to a public audience (Bles 1907, 986–987).<sup>2</sup> The reaction of the meeting to Muskens' proposal is not recorded, but presumably it was favourable, for international developments in the field of epilepsy began thereafter.<sup>3</sup>

Ironically, despite intense activity initially and many meetings, the institute never actually got under way, and the initiative was destroyed by personal enmities and political machinations (as so often in medical affairs). The ILAE, however, a small offshoot of this grander organism, flowered into an organisation which was longer-lasting and altogether more imposing.

<sup>1</sup> For example, La Commission Internationale pour l'Etude des Maladies Mentales et leur Prophylaxie (and the equivalent in Italian; see Shorvon *et al.* 2009).

<sup>2</sup> Muskens's request did not come out of the blue. In his opening address, the congress president included epilepsy among the 'nervous disorders' that were the focus of the meeting. He also referred to the Dutch league against epilepsy, which Muskens had helped to found in 1902 (Marie and Ladame 1907).

<sup>3</sup> Including the creation of *Epilepsia* (see Chapter 7).

## ILAE: 1909–1914

### The founding of the League at the 16th International Medical Congress in Budapest

The League came into being in Budapest at the 16th International Medical Congress, held on 29 August–4 September 1909. It should be no surprise that Budapest was the chosen venue, for in this period it was a leading scientific centre and at the heart of affairs in Europe. It was a time of massive change – in the course of a few decades, imperial rule was followed by a republic, parliamentarianism by dictatorship, feudalism by industrial revolution and the imperial proclamation of war by a foreign army of occupation. Hungary was also a world centre of medicine, and particularly of psychiatry, with Ernő Moravcsik, a pioneer neuropsychiatrist, the leading figure. Sándor Ferenczi was also taking an increasingly prominent role in the International Psychoanalytic Association – he became president in 1918 when Budapest was the location of the 5th Congress of the International Psychoanalytical Association – and was Freud's closest friend on his secret 'Committee'. Rapid advances were also being made in other areas of medicine. In 1909, for instance, the discovery of salvarsan as a cure for syphilis was announced by Paul



Louis Jacob Joseph Muskens, a leading figure in the early ILAE, ca. 1909.

(*Opposite*) Portraits of 'epileptics' from Cesare Lombroso's *L'uomo criminale* (*Criminality*), 1887. (© BIUM Paris)

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Medal designed by Hungarian sculptor György Vastagh struck to commemorate the 1909 International Medical Congress in Budapest, and presented to all attendees at the conference, see pp. 217–219. (Source: Münz Zentrum Rheinland)

Ehrlich, the term ‘gene’ was coined by Wilhelm Johannsen, DNA and RNA were discovered by Phoebus Levene, and the secrets of radium were being uncovered by Marie Curie. Epilepsy, though, was rather in the doldrums, and possibly one reason for the formation of the ILAE was to bolster interest in the neglected condition. There was less research, fewer papers published on the condition and less academic interest than was the case even 20 years earlier, when the leading neurologists of the period were interested in the condition, and when epilepsy indeed was acknowledged as the Queen of Neurology.

The 16th International Medical Congress was a major affair (and all for the registration price of 25 crowns). Theodore Kocher (the 1909 winner of the Nobel Prize for Medicine and Physiology) was an honoured speaker, and future Nobel laureate Julius Wagner-Jauregg (Medicine and Physiology, 1927) lectured on the treatment of syphilis. Harvey Cushing gave a paper on the operation of partial hypophsectomy for the cure of acromegaly, and Paul Ranschburg spoke on psychoanalysis (a lecture about which Sándor Ferenczi complained to Freud).<sup>4</sup>

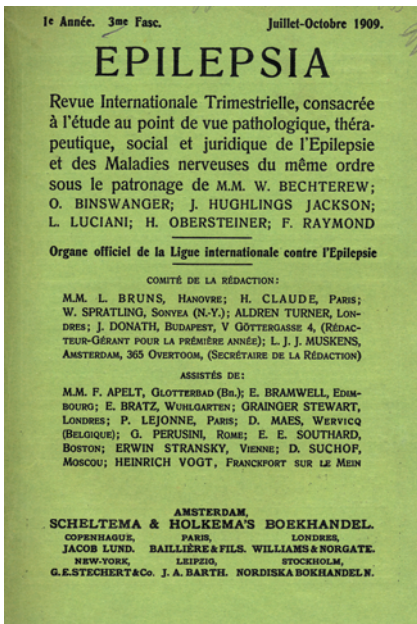
The main conference included separate sections on psychiatry and neuropathology, but only two major talks on epilepsy, both in the psychiatry section and both con-

cerned with institutional care.<sup>5</sup> In any event, at a meeting on 30 August, in the Salle Donau of the Hotel Bristol, Rue Maria Valeria, 46 persons met to discuss the founding of an international epilepsy society that would become the International League Against Epilepsy.<sup>6</sup> It is worth

<sup>4</sup> ‘Ranschburg said the stupidest things’ (quoted in Freud and Ferenczi 1993, 86). Ferenczi was also critical of Robert Sommer and Adolf Friedländer, two of the original members of the ILAE. Ranschburg presented his paper at the congress session where the formation of the League was announced.

<sup>5</sup> Otto Hebold, ‘Ueber Epileptikeranstalten’ (‘On Epilepsy Institutions’); and Auguste Marie, ‘Le Retour à la Terre et l’Assistance Curative des Epileptiques et Débiles Adultes’ (‘Rehabilitation and Treatment for Epileptics and Feeble-minded Adults’). J. van Deventer touched on epilepsy in his talk on care of the mentally ill. Muskens, who addressed the neuropathology section on the subject of segmental sensory examination, and chaired a session there, also included epilepsy in his considerations (de Torday 1910, 11:xxiv).

<sup>6</sup> The attendees of the first meeting of the League on 30 August 1909 were listed in *Epilepsia* as Anton, Balint, Bonebakker, Bourillon, Cabred, Catsarca, Deenik, van Deventer, Donáth, Dubief, Erpstein, Eijkman, Ferarri, Fischer, Frank, Frankl-Hochwart, Friedländer, Fuchs, Giese, Graves, Greidenberg, Hajos, Hebold, Hollós, v. Hovorka, Hudovernig, Juba, Kollarits, Ley, Macpherson, Marie, Medeiros, Meihuizen, Moreira, Obersteiner, Oppenheim, Pel, Roubinovitch, Rouley, Sachs, Sommer, Stichel, Szgetti, Tamburini and Wosinski. It seems to have been of the customs in those days to provide only patronymics in the pages of *Epilepsia*, but we presume – based on subsequent publications and lists (notably the first list of ILAE members in 1911 (Communication 1911) – that these persons are (and please note that in some cases this is uncertain supposition) G. Anton (Halle, Germany), R. Bálint (Budapest, Hungary), A. Bonebakker (Amsterdam, Holland), Edgar Bérillon (Paris, France), Domingo Cabred (Buenos Aires, Argentina), Michel Catsaras (Athens, Greece), A. Deenik (Loosduinen, Holland), J. van Deventer (Amsterdam, Holland), F. Dubief (Paris, France), Ladislaus Epstein (Nagyszeben, Hungary), P.H. Eijkman (The Hague, Holland), G.C. Ferrari (Bologna, Italy), F. Fisher (Pressburg, Hungary), L. Frank (Zurich, Switzerland), Lothar von Frankl-Hochwart (Vienna, Austria), A. Friedländer (Frankfurt, Germany), Alfred Fuchs (Vienna, Austria), Ernst Giese (St Petersburg, Russia), W.W. Graves (St Louis, United States), B. Greidenberg (Russia), L. Hajos (Budapest, Hungary), Otto Hebold (Wuhlgarten, Germany), Stefan Hollós (Budapest, Hungary), Oskar v. Hovorka (Vienna, Austria), Carl Hudovernig (Budapest, Hungary), A. Juba (Budapest, Hungary), Jenő Kollarits (Budapest, Hungary), Augustus Ley (Brussels, Belgium), John Macpherson (London, England), Auguste Marie (Paris, France), Mauricio Medeiros (Rio de Janeiro, Brazil), P.W. Meihuizen (The Hague, Holland), Juliano Moreira (Rio de Janeiro, Brazil), Heinrich Obersteiner (Vienna, Austria), H. Oppenheim (Berlin, Germany), P.K. Pel (Amsterdam, Holland), Pierre Rouby (Algeria), J. Roubinovitch (France), E. [Bernard?] Sachs (New York, United States), Robert Sommer (Giessen, Germany), A. Stichel (Graz, Germany), T. Szgetti (Hungary), Augusto Tamburini (Rome, Italy) and Stephan Wosinski (Balf, Hungary).



The cover of the July–October issue of *Epilepsia* announcing the association of the ILAE and the journal.

recording here the events in detail, as this meeting led successfully to the foundation of our ILAE.

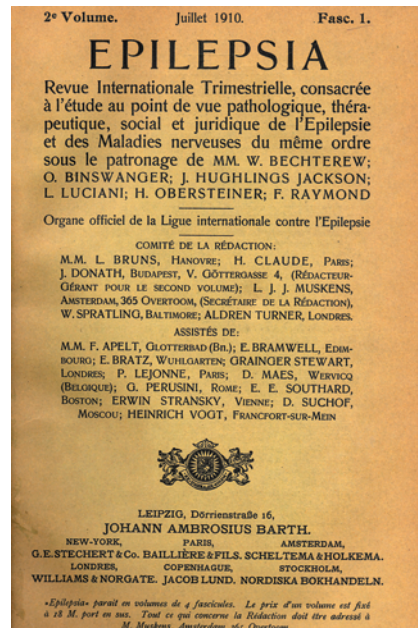
The main documentary information about these events comes from the pages of *Epilepsia*.<sup>7</sup> Both its inaugural issue of March 1909 and the second issue (June 1909) refer to the future meeting. In the first issue, the following notice (in English and in German) appeared:

On the occasion of the International Medical Congress to be held in Budapest August 29–September 4, neurologists, psychiatrists and all medical men, interested in epilepsy, are invited to a meeting, to consider the advisability of founding an International Association for the Study and Treatment of Epilepsy.

Gentlemen, who wish to take part in this meeting, are requested to send their names and address either to Prof Julius Donath<sup>8</sup> (Budapest, V. Bálvány-Gasse, 4)<sup>9</sup> or to any of the other editors of this periodical. Later on a communication will be sent giving the time and place of this meeting. (Nouvelles 1909, 123)

<sup>7</sup> The first issue of *Epilepsia* probably covered the quarter January–March 1909, although the issue is undated (see Chapter 7 for details).

<sup>8</sup> In keeping with historical convention, in material directly quoted from early works, we have left the spelling as we found it, errors and all. Elsewhere, we have followed the spelling given by authoritative sources.



From 1910 onwards, *Epilepsia* was published by the firm of Johann Ambrosius Barth, in Leipzig.

This is the first published notice proposing the formation of the ILAE to the professional world. The second issue of *Epilepsia* announced (in French this time, which was the official language of the conference) that the meeting would be held at the Hotel Bristol. Plans had obviously been well laid, for it was also revealed that the

<sup>9</sup> Julius (Gyula) Donath was born in 1849 in Baja, Hungary. He attended the University of Vienna and received his doctorate at the University of Innsbruck. In the war of 1877–78 between Russia and Turkey, Donath acted as head surgeon on the side of Turkey. He was captivated enough by dancing dervishes to write an article on dance as culture worldwide for a Hungarian newspaper. In 1881 he worked in Berlin at Westphal's clinic for nervous diseases, as well as in the laboratory of Helmholtz, Du Boys-Reymond and Virchow. Returning to Budapest, he trained in electrotherapy and in 1893 obtained a consultant's post in the neurology outpatient department at the communal hospital of St Rochus, where he also established and directed the X-ray laboratory. Donath was editor for the Hungarian monthly medical journal *Klinikai Fuzetek* and for *Epilepsia*. In 1903 he was awarded the Craig Colony Prize by the state of New York. Apparently Donath, along with other Hungarian psychiatrists, was active in the post-First World War eugenics movement in Hungary and supportive of voluntary sterilisation for mental defectives. The movement does not seem to have gone far (Album 1909, 123; Siró 2003; P. Halász, personal communication).

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Hotel Bristol, Budapest, site of the founding meeting of the ILAE. The 1911 Baedeker's for Austria Hungary gave the hotel a star, indicating it to be 'well-managed, reasonable and adapted to modern requirements'. (Image courtesy Hungarian Museum of Trade and Tourism, Budapest)

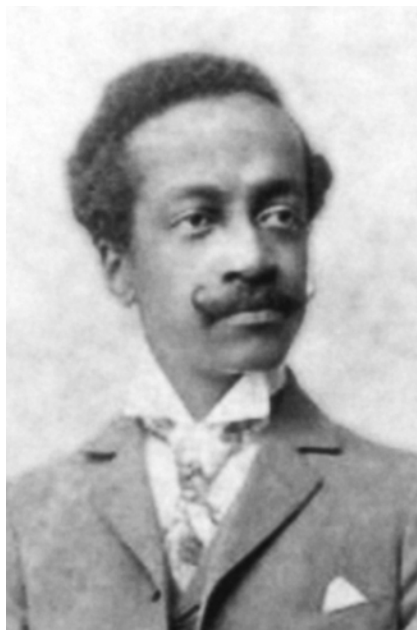
National Association for Epilepsy in the United States had nominated W.N. Bullard<sup>10</sup> to attend, the Dutch association J. van Deventer<sup>11</sup> and Brazil Juliano Moreira.<sup>12</sup> Indeed, archives show that at a meeting of the National Association for the Study of Epilepsy and the Care and

Treatment of Epileptics towards the end of 1908, James Frederick Munson, the association secretary-treasurer, reported that he had received a request from the Dutch league against epilepsy for help in setting up an 'international society to consider the problems of epilepsy' and

<sup>10</sup> William N. Bullard (1853–1931) was the US representative was invited to the meeting, but due to illness could not attend. He was a doyen of American epilepsy, professor of neuropathology at Harvard, previous president of the National Association for the Study of Epilepsy and the Care and Treatment of Epileptics in the United States (see p. 40), involved in the establishment of the colony at Monson, Massachusetts, an ardent eugenicist and author of an influential report titled 'Heredity in Epilepsy', which still makes interesting reading today (Bullard *et al.* 1911).

<sup>11</sup> At the time of the founding of the League, J. van Deventer was state inspector for insane asylums in The Netherlands, and a professor of psychiatry at the University of Amsterdam. He had previously directed the Wilhelmine Hospital in Amsterdam from 1879 to 1892. From 1892, he headed the Meerenberg insane asylum (Album 1909).

<sup>12</sup> Juliano Moreira (1875–1933) studied medicine in his native city of Bahia, Brazil, and later trained in Europe under Hitzig, Virchow and others. Returning to South America in 1896, he became professor of psychiatry at the University of Bahia and then superintendent of the government mental hospital in Rio de Janeiro. Under his audacious direction, the institution became a notable training ground for Latin American psychiatrists and neurologists. Moreira was a remarkable man, a broad-minded Afro-Brazilian who published widely and advocated for improved care of the mentally ill. He served as the ILAE's representative for Brazil, created several associations and brought into being a number of journals (Anon. 1933; Raimundo Oda *et al.* 2005).



Juliano Moreira (1875–1933), a dynamic Brazilian psychiatrist and early member of the ILAE. (Courtesy Fatima Vasconcellos)

had suggested 'Buda-Pest as a place for the first meeting, at the time of the International Medical Congress next fall' (Munson 1908, 145).

Accurate dating was, unfortunately, not a strength of the first editors of *Epilepsia*. In the following pages of the journal, various details of the League's first meeting are recorded, but variously reported as being on Monday 30 August 1909 at 6pm; Monday 30 September 1909 at noon and Monday 29 August at noon. In fact, only 30 August was a Monday, and it seems likely that this was the correct date. It is also the only date that would fit with the note in subsequent articles that the two follow-up meetings were held on the Wednesday and Thursday (1 and 2 September – although also wrongly dated in one *Epilepsia* report) and with the official transactions of the congress (de Torday 1910, 12:xxxvi).

Auguste Marie<sup>13</sup> from Paris was asked to act as chair for the first two meetings during that week, and to report the proceedings to the International Congress. Marie states that the initiative to hold the meeting came from himself, Donáth, Muskens<sup>14</sup> and van Deventer. What is

clear is that the agenda was carefully thought out, perhaps by this quadrumvirate, although Tamburini was almost certainly also involved. Several strands of evidence bear this thesis out. First, the report of Marie (see below) to the International Medical Congress, given within a few days of the meeting, was extremely detailed and precise and must have been the product of considerable preparation. Second, a committee of patronage established at the first meeting comprised leading neurologists many of whom were not there and who must have been approached beforehand.<sup>15</sup> Third, in Budapest Muskens and Donáth offered to put *Epilepsia* at the disposal of the newly formed league, at least until it had its own official

did not stand the test of time) and considered that convulsions were a mechanism to discharge poisonous substances. He used the conventional medicines of the time (mainly borax, bromides, phenobarbital) and mercuric iodide for syphilis. He also carried out limited surgical operations himself using techniques learned from Horsley. According to one biographical note, 'his colleagues had sometimes the impression that he trepanned the skull too often' (Lindeboom 1984). His physiological interest was concerned with the supravestibular system, and he wrote a monograph on this topic (*The Supra-vestibular System, in Animals and Humans, with Special Reference to Forced Movements*, Amsterdam, 1935). Although brought up in an environment where neurology and psychiatry were frequently merged, he believed in their separation and had a poor opinion of psychiatry, which he thought should focus on social issues while neurology was the 'organ speciality'. He had an abrasive personality by all accounts (and this is reflected in his writings). He found it difficult to relate to colleagues and was prone to value his own contribution highly and above that of others. Eling and Keyser (2003) comment that Muskens conducted his professional activity outside a university setting and was professionally isolated, not prone to compromise, and possessed of a lack of social feeling and a stubbornness that resulted in conflict. His undiplomatic approach caused the city council to terminate his docentship at the Municipal University of Amsterdam. His biographers comment also that his marriage was not a happy one, and one gets a picture of a talented man with few social graces whose life has elements of disappointment. As he wrote in the preface of his book on epilepsy, he was a disciple of the British and American schools of neurology, and was indeed more honoured abroad than at home. Maladroit though he was, Muskens was devoted to epilepsy: a careful perusal of the literature of the time, and even the rather thin store of archival materials that exists, makes it clear that it was in large part his unflagging activity that resulted in the ILAE's founding and that nudged it back to life again after the First World War.

<sup>15</sup> The committee of patronage of the ILAE, mentioned in Marie's first report, seems not to have further featured much in the ILAE history. It nevertheless comprised leading neurologists of its time. It was a coup to have involved such eminent personages, and no doubt the committee provided a very important imprimatur for the nascent League.

<sup>13</sup> Auguste Marie (1865–1934) was born in Voiron. He was a psychiatrist serving at the Colony of Dun-sur-Auron and at Villejuif, and at the time of his retirement was physician to the reception service at the Asile Sainte-Anne. He was a prolific author and wrote on all aspects of psychiatry, particularly syphilis and the use of malaria therapy to treat it. He also was interested in psychology, anthropology and sociology. He was active in the field of hospital administration and the provision of care for mental patients. He seems not to have written particularly on epilepsy, but his involvement in the ILAE undoubtedly derived from his interest in colonies and alienist medicine. He was honorary physician to the Hospitals of the Seine, corresponding member of the Medical Society of Hospitals, member of the Medical Society of Paris and commander of the Legion of Honour (Anon. 1935).

<sup>14</sup> Louis Jacob Joseph Muskens (1872–1937) has been the subject of an excellent historical monograph by Eling and Keyser (2003) from which many of these details are taken. Muskens was born in Nijmegen and studied medicine in Utrecht from 1889 to 1895, where he trained as a psychiatrist. He visited New York and then worked in London under Hughlings Jackson and Gowers and made the acquaintance of Sherrington. In 1902 he was appointed a specialist in nervous disorders and head of an outpatient clinic in Amsterdam. He conducted physiological research and published extensively on both experimental and clinical topics. Epilepsy was one of his major interests, and his *magnus opus* was *Epilepsy: Comparative Pathogenesis, Symptoms and Treatment* (1926, and published in English in 1928). He was most interested in what he called the myoclonic reflex, which he thought was of brainstem origin, and experimented with a number of different animal models of epilepsy. He developed an aetiological classification of epilepsy (which has

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journal. This offer no doubt needed the agreement of the other editors of the journal and the patrons. No journal ever was formed, and *Epilepsia* became at this meeting, and has remained so since, the official journal of the ILAE (a fact already recorded on the cover of the July–October 1909 issue). Finally, also, a notice announcing *Epilepsia* in a 28 February 1909 issue of one of the Hungarian medical magazines edited by Donáth stated explicitly that the purpose of the new journal was, among other things, to stimulate and promote an international association for the study of epilepsy and the care of epileptics (Donáth 1909).

Marie's report to the psychiatry section of the congress (a session interestingly chaired by Tamburini, with Maillard) is published at the beginning of the third issue of *Epilepsia* (Marie 1909), and is followed by minutes of the two subsequent meetings. As these are the only primary accounts of the origin of the ILAE, Marie's report is worth reproducing here in full:<sup>16</sup>

On the initiative of Messrs van Deventer, A. Marie, Donáth and Muskens, a plan for an International League Against Epilepsy was proposed to the members of International Congress at Budapest, which made available its national committee room for this constituent meeting.

The first general assembly took place at noon on Monday, 30 September [date wrong; see above], followed by two other meetings the following Wednesday and Thursday. Because I had the honour of being asked to preside over the first two meetings, and to communicate the results to the Congress, which has been kind enough to approve them, I believe it is incumbent on me to provide a brief account to the readers of *Epilepsia*.

Furthermore, the third meeting, chaired by Professor Tamburini<sup>17</sup> of Rome, ratified an initial set of rules, which I will summarise here.

The idea is to create an international action committee charged with centralizing all data related to the problem of epilepsy, its history, causes and various manifestations in different countries. The data would be consolidated, then checked and compared,



Gyula (Julius) Donáth (1849–1945), a leading figure in the early ILAE and the first Editor-in-Chief (réducteur-gérant) of *Epilepsia*, ca. 1909. (Courtesy Semmelweis Museum)

and a comprehensive inventory of regulations, laws, and private and public organisations could be created. Establishing what has already been done will make it easier to see what remains to be achieved; and on the basis of comparisons, we can come up with a programme.

Carrying out this data-gathering exercise will necessarily involve official contacts with public authorities. One can also imagine the need for a central clearinghouse arising before too long.

The plans and approaches of suitable institutions could be presented in special sessions during future conferences (for example, at Berlin in 1910). The comparative data could be

<sup>16</sup> Other, third-party accounts include the official proceedings of the Budapest congress itself (see de Torday 1910) and a report in the *Neurologisches Centralblatt* (see Schweiger 1909). Marie published a verbatim version of the *Epilepsia* account in *Revue Philanthropique* [‘Ligue Internationale Contre l’Epilepsie’, 1909–10, 26:64–66], in which, in addressing his audience, he quietly substituted ‘the readers of *Revue Philanthropique*’ for ‘the readers of *Epilepsia*’.

<sup>17</sup> Augusto Tamburini (1848–1919) was born in Ancona and qualified in medicine in Bologna in 1871. He was a renowned psychiatrist and researcher and was director of his institution in Reggio Emilia. Tamburini worked with Luciani on classic studies regarding cerebral localisation of function, which were contentious and important. He probably contributed to Luciani's theory of the cortical pathogenesis of epilepsy. He was among the first in Italy to study aphasia and was well known for his work *Sulla Genesi delle Allucinazioni* (1880). In 1905 he was appointed to the chair of psychiatry in Rome. From 1877 to 1919, he was editor-in-chief of the *Rivista Sperimentale di Freniatria*.



made the subject of comprehensive reports by an international commission that would divide up the work and would publish results, analyses and comparative tables. We can even envisage a permanent office, and for that, government support would eventually be indispensable.

We wish to set up something analogous to the International Office of Hygiene<sup>18</sup> or to the international psychological institute currently being created in Rome, under the patronage of the Italian government.<sup>19</sup> Indeed, why should these existing entities not extend a hand to their daughter organisation, the International League Against Epilepsy?

Obviously, such a vast and ambitious programme has the potential to engage the interest of philanthropists and intellectuals the world over.

Madness generally is governed by laws, national and international regulations, public and private aid organisations, in other words, it has codes and statutes. We would like to do the same thing for a class of unfortunates who up to now have been denied the benefits of society. Epilepsy may be a problem of heredity, or result from a variety of acute and chronic infections. Its associations span all the way from criminality to the limits of human genius. One hundred years after Pinel and his followers elevated prisoners to the dignity of patients, society must make for epileptics the same allowances and the same salutary efforts as it does for other disenfranchised persons. The League will devote itself to special projects on behalf of epileptics, and to finding a cure and means of prevention, as well as providing aid and social rehabilitation. Nor will the League neglect experimental research and comparative physiopathology, or laboratory work, which are essential for elucidating a series of problems as complex as those raised by the origin, evolution and nature of seizure disorders, with their attendant range of somatic and psychic complications.

<sup>18</sup> Also created in 1909, in Paris, the Office International d'Hygiène Publique was a forerunner of the World Health Organization.

<sup>19</sup> This is a reference to the precursor organisation to the ILAE (see above and Shorvon *et al.* 2009). In fact, at the founding meeting (although not mentioned in *Epilepsia*), Tamburini is reported to have said, 'Let me offer the Committee for the study of epilepsy the support of the Commission already established in Rome for the protection of epileptics and for the foundation of an epileptic colony. The International Committee that is presently being proposed will also have the support of the International Commission to Create an International Institute for the Study of the Causes and Prevention of Insanity, of which I have the honour to be president. The two committees must work together on these questions of such profound import to science and humanity' (de Torday 1910, 12:xliv).

I communicated the results of our initial efforts to Section XII before the general assembly and asked for its sanction and moral support:

I An International League was founded under the patronage of a committee consisting of Messrs Alt<sup>20</sup>, Hebold,<sup>21</sup> Friedländer,<sup>22</sup>

<sup>20</sup> Konrad Alt (1861–1922) is credited with inventing the modern asylum. He was born near Trier in Kirf, Germany. For a time he waffled between chemistry and medicine before taking a series of junior doctor posts that determined the direction of his career. Alt quickly built a reputation as a master diagnostician as evidenced by a treatise on electrodiagnosis and electrotherapy that he wrote with K.E.F. Schmidt in 1893. He practiced neurology for a year in Halle, where he established a clinic. He was then named director of the new (1894) Uchtsprunge asylum, which Alt proceeded to transform from a simple provincial epilepsy facility to a large-scale treatment and care institution for a range of sensory disorders. In 1911 he received royal honours for his service to psychiatry. Alt had very strong ideas about how institutions should be constructed. He also actively promoted the continuing education of physicians, both practical and basic, and he pioneered community care for the deinstitutionalised. He published frequently in German medical journals and was an editor for the *Psychiatrische Wochenschrift*. In 1897 he founded a journal on the care of the insane. He died in Magdeburg, at 61, following a bout of flu (Kolling 2004, 6–8).

<sup>21</sup> Otto Hebold (1856–?) was born in Bonn and studied at the university there. He began his medical career at the mental asylum in Brandenburg, and later served as a medical assistant at Andernach and Bonn, then as head physician at Soran. In 1893 he became director of the newly established Wuhlgarten institute for epileptics in Berlin (today the Wilhelm Griesinger Hospital), a 1,150-bed facility. At the 16th International Medical Congress in Budapest Hebold presented a talk on epilepsy institutions, distinguishing three major sorts. He singled out Wuhlgarten as an ideal model, for there, he said, 'any and all epileptic patients are accepted, and *only* epileptics' (Album 1909, 10; de Torday 1910, 12:137).

<sup>22</sup> Adolf Albrecht Friedländer (1870–1949) opened the Hohe Mark Clinic for the mentally ill and emotionally disturbed among the European nobility in 1904. When his clientele thinned in the aftermath of the First World War, Friedländer sold the clinic to the city of Frankfurt and entered private practice. He was born in Vienna and trained in psychiatry in Jena under Otto Binswanger and in Frankfurt under Emil Sioli. He qualified as a German physician in 1903, and completed his doctoral thesis while he was building Hohe Mark. He wrote widely, and was a sharp critic of psychoanalysis. Still, he visited Jung in 1909, and soon after Freud wrote to Sándor Ferenczi, 'I learned from Jung that Friedländer was with him, "sweet as sugar and wagging his tail"! He's a rotten character!' (Freud and Ferenczi 1993). In 1936, anti-Jewish sentiment drove him back to Austria (Austrian Academy of Sciences 2007, 363–364).

## 10 International League Against Epilepsy 1909–2009 A Centenary History

Bechterew,<sup>23</sup> Raymond,<sup>24</sup> Landouzy,<sup>25</sup> Sommer,<sup>26</sup> Weygandt<sup>27</sup> and Tamburini.

<sup>23</sup> Vladimir Bekhterev (1857–1927) was perhaps the most famous neurologist of his day. He made an enormous contribution to many fields of neurology, for example investigating the electrical activity of the brain and noting the role of the hippocampus in memory. In 1907, he founded the PsychoNeurological Institute, now the St Petersburg State Medical Academy, and he still has an institute named after him. In 1927, he was summoned to consult on Stalin. Bekhterev was said to have remarked that the dictator was a clear case of paranoia. He died a few days later, allegedly poisoned by a cake Stalin sent as a thank-you present for the consultation. Bekhterev's son, engineer and inventor, Pyotr Bekhterev, was executed during Stalin's purges, and his granddaughter, Natalya Bekhtereva, is a famous Russian neuroscientist and psychologist.

<sup>24</sup> Fulgence Raymond (1844–1910) trained first in veterinary medicine and achieved acclaim in this field. In 1870 he turned to medicine and became a student of Félix Alfred Vulpian. He graduated in 1876, and in 1894 was appointed as Charcot's successor to the chair of neurology at the Salpêtrière, in which position he contributed greatly to the fame of this institution. He made many neurological contributions, including studies of hemianaesthesia, central sensory pathways, medulla oblongata, cauda equine, spinal column and with Pierre Janet (1859–1947) on neuroses and psychosomatic states (*Névroses et idées fixes*). As with Landouzy, epilepsy was not his major interest, but again his presence would have greatly enhanced the League's committee of patronage. He died at La Planche d'Andillé.

<sup>25</sup> Louis Théophile Joseph Landouzy (1845–1917) was born into a medical family. He studied medicine in Reims and Paris, and worked for most of his career at the University of Paris. In 1884, he was the first to describe the infectious nature of herpesvirus. He was professor of therapy in 1893 and dean of medicine in 1901. He is most remembered for the eponymous Landouzy–Dejerine syndrome and the Landouzy–Grasset law, which states that in unihemispheric lesions a patient will turn his head contralaterally if there is spasticity, and to the side of the cerebral lesion if there is paralysis. However, his primary interest was in tuberculosis. He seems to have had no particular scientific interest in epilepsy, but his name would have enhanced the League's committee of patronage. Landouzy was the president of the French committee to the Budapest congress.

<sup>26</sup> Robert Sommer (1864–1937) matriculated at the University of Freiburg im Breisgau in 1883. He obtained a diploma in philosophy in Berlin in 1887, and another in medicine the following year. Noted for his unconventional thinking, Sommer founded and directed the psychiatric clinic at the University of Giessen. He also established the very first society for experimental psychology in the world, and is best known today for his descriptions of his eponymous 'sector' (Album 1909, 6).

<sup>27</sup> Wilhelm Weygandt (1870–1939) began his studies auspiciously with the philosopher-psychologist Wundt at Leipzig and learned psychiatry with Kraepelin (who had also studied with Wundt). He spent the bulk of his professional life at Hamburg, where he directed the University Psychiatric Clinic, and was professor of psychiatry at the University of Hamburg. In 1935, Weygandt and others produced a hefty textbook in German on nervous and mental diseases which on his death was described as 'an authoritative exposition of contemporary German psychiatry and neurology' (Anon. 1939).

2 This League has created a permanent office situated provisionally in Budapest, where Professor Moravcsik,<sup>28</sup> assisted by Mr Donáth, will set up a formal Hungarian national branch.

3 An international action committee<sup>29</sup> consisting of Messrs Tamburini, Hebold, Obersteiner,<sup>30</sup> A. Marie, van Deventer, Sachs<sup>31</sup> and Sommer will collaborate with the permanent bureau and with Dr Muskens, secretary-general charged with recruiting members and with collecting the first round of international data. This committee will form a constitutional commission and will develop a general plan of research.

4 The action committee will send questionnaires to the national committees, and distribute special reports proposing a plan of

<sup>28</sup> Ernő Emil Moravcsik (1858–1924) received his medical degree in 1884 from the University of Budapest, where he later was professor of psychiatry (1902–24) and rector (1918/19). He had a special interest in criminal forensic mental illness. A notable figure in Hungarian psychiatry, he carried out significant research in catatonia, dementia praecox, the psychogalvanic reflex and hysteria (Austrian Academy of Sciences 2007, 368).

<sup>29</sup> The committee was completely revised at the Berlin meeting to comprise Winterberg (Russia), Claus (Belgium), Veit and Friedländer (Germany), Ignaz Fischer (Hungary), van Deventer and Muskens (Holland), Obersteiner (Austria) and Ulrich (Switzerland). Only van Deventer and Muskens were members of the previous committee.

<sup>30</sup> Heinrich Obersteiner (1847–1922) was born in Vienna and received his doctorate from the University of Vienna in 1870. He continued there as professor of pathology and anatomy of the nervous system. He also directed a private mental asylum at Oberdöbling. In 1882 he founded the Neurological Institute in Vienna, making brain research its speciality, and inspired the creation of similar institutions in Europe and America. Obersteiner described concussion of the spinal cord and status epilepticus. With Emil Redlich, he established the zone where the central and peripheral nervous systems meet. Famous not least for the number of students he trained, Obersteiner also wrote a classic text on the anatomy of the nervous system (Album 1909, 25; Austrian Academy of Sciences 2007, 194).

<sup>31</sup> Bernard Sachs (1858–1944) obtained his BA from Harvard in 1878 and then studied medicine in Strasbourg, Vienna and Berlin, before spending a year in Paris and London. He worked with and met von Rechlinghausen, Freud, Charcot and Hughlings Jackson. He returned to New York in 1884, and in 1887 described a disease with which he is now eponymously linked (Tay–Sachs disease). He became a central figure in American neurology, and was president of the American Neurological Association between 1894 and 1932, president of the First International Congress of Neurology in Berne in 1931 and later president of the New York Academy of Medicine. Sachs published almost 200 articles and several books, including *The Normal Child* (1926), wherein he largely advocated that parents should be guided by common sense and not psychological theories. He had no particular interest in epilepsy. Interestingly, he opposed Lennox in the eugenics debate later in 1939.

action, which will be published before the Berlin Congress (on Psychiatry and Psychiatric Institutions). The second general assembly of the League Against Epilepsy will be held in 1910 in Berlin, during the aforementioned congress.

These represent our first steps. They should shortly yield appreciable results that the journal *Epilepsia* will report to its readers; for it has graciously been placed at the disposition of the League until such time as the latter is more fully organised.

<sup>32</sup> ‘The minutes of the first meeting: . . . Monday 29 August, 12 o’clock, in the Congress Building in Budapest . . . In his own name and that of Dr Muskens, Mr Donáth took the floor to say that it was time to do for the study and fight against epilepsy what was already being done for alcoholism, tuberculosis and cancer, where the international consolidation of power has already made significant strides. We aim to do the same by founding an International League Against Epilepsy. He invited Dr A. Marie, Paris, to take the chair, to general applause . . . The following people were present: Anton, Balint, Bonebakker, Bourrilon, Cabred, Catsarca, Deenik, van Deventer, Donáth, Dubief, Erpstein, Eykman, Ferarri, Fischer, Frank, Frankl-Hochwart, Friendländer, Fuchs, Giese, Braves, Greidenberg, Hajos, Hebold, Hollos, v. Hovorka, Hudovernig, Juba, Kollarits, Ley, Macpherson, Medeiros, Meihuizen, Moreira, Obersteiner, Oppenheim, Pel, Roubinovitch, Rouley, Sachs, Sommer, Stichel, Szigetti, Tamburini, Wosinski [see n. 4] . . . In keeping with the views of several speakers, Dr Marie suggested that in addition to an international committee, individual countries should choose national committees to work in the interests of the League at the local level. After some discussion, Messrs Donáth, Graves, Greidenberg, Hebold, Marie, Moravcsik, Moreira, Muskens, Obersteiner and Tamburini were chosen as provisional members of the international committee . . . Members of the national committee for Hungary are Messrs Donath, Hudovernig and Moravcsik, who may at their discretion invite additional colleagues to work with them. For Austria: v. Frankl-Hochwart, Fuchs, Halban, Obersteiner. For Holland: Bonebakker, Coert, van Deventer, Lykles, Muskens and Pel. For Germany: Bratz, Cramer, Friedländer, Hebold, Sommer, Vogt, Weygand. For France: Claude, Landouzy, Marie, Raymond. For England: Macpherson, Turner. For Italy: Ferrari, Tamburini, Perusini. For America: Everett Flood, Graves, Sachs, Spratling. For Algiers: Rouley. For Russia: Greidenberg, Minor, Suchof . . . It was further decided that next year the League will hold its annual meeting in Berlin, in association with the Congress on the Care of the Insane . . . At that venue, reports will be presented and further proposals discussed . . . Mr Halban related a regrettable experience in Austria regarding the planned formation of a national society and an institute for epileptics. In Vienna, one polyclinic alone sees 700 new cases of epilepsy annually. Sixty thousand crowns was raised but had to be returned. If an international league existed, the story would have turned out differently. He suggested that steps be taken to have the Congress request at its committee meeting that the problem of epilepsy be made the subject of special studies and aid . . . Messrs Donáth and Muskens said that, seeing as the League has no organ of its own, the new international journal *Epilepsia* is prepared to publish its proceedings free of charge. At the suggestion of Greidenberg, at the next meeting the secretary will submit a programme of work for the first year’ (Secretaire 1909, 232–233).

The minutes of the founding meeting on 30 August<sup>32</sup> and the third meeting on 2 September<sup>33</sup> follow a few pages later in *Epilepsia*. These are largely in accord with Marie’s report (although dated wrongly). Donáth opened the first meeting, and mentioned that there were members of national committees from Hungary, Austria, Russia and Germany present. It was also agreed to hold the next meeting at the International Congress on the Care of the Insane in Berlin. The third meeting was chaired by Tamburini. The workplan was itemised. All countries were to prepare statistics on a wide range of topics: the numbers of new non-institutionalised and chronic institutionalised cases; the number of existing hospitals and colonies, and their admission rates (for new and chronic cases); and the number of patients treated both as inpatients and outpatients in the various private and public hospitals and sanatoriums over the past 5 years. Governments should be requested to collect official statistics on epileptics in their country. The military, too,

<sup>33</sup> ‘[Second] meeting of the Liga on 2 September 1909. Chair, Prof Tamburini . . . After discussion on the part of Messrs Fuchs, Halban, Hebold, Szigetti and Sommer over the work plan submitted by Messrs Donáth and Muskens, the following measures were formulated: . . . Proposal of the secretary regarding the plan of work for the first year of the International League Against Epilepsy . . . First, each country must provide statistics on epileptics that distinguish two groups: . . . New, non-institutionalized cases . . . Chronic, institutionalized cases . . . How many hospitals and colonies exist? How many new cases are accepted each year? Among the accepted cases, how many are chronic cases, and how many show signs of mental disorder? . . . Further: . . . How many epileptics have been treated in the various private and public hospitals and sanatoriums over the past 5 years? How many are currently being treated in polyclinics, that is, on an outpatient basis? . . . Governments should be requested to collect official statistics on epileptics in their country, as has been done in England, Germany and Hungary with cancer. The military, too, should be asked to give the number of epileptic recruits . . . Also, individual countries will be asked to provide an overview of aid for epileptics, as well as the number of epileptics determined by the most recent census . . . In carrying out their investigations, governments should be advised of the high degree of criminality among epileptics . . . Eykman suggested that, for the time being, *Epilepsia* serve as the official organ of the League, so long as the League has no organ of its own . . . Amid applause, the chair, A. Tamburini, suggested to those present that at the conference next year in Berlin, an entire day be devoted to the subject of epilepsy, to wit, not only the discussion of reports but also its pathogenesis and other scientific questions. Ideally, the reports should be submitted for publication to the journal *Epilepsia* at the beginning of next year, to ensure a fruitful discussion . . . The Secretaries’ (Secretaire 1909, 233–234).

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Auguste Marie (1865–1934), noted French alienist, who chaired the League's first official meeting in Budapest. (© BIUM Paris)

should be asked to give the number of epileptic recruits. Individual countries might provide an overview of aid for epileptics, as well as the number of those affected determined by the most recent census. In carrying out their investigations, governments would be advised of the high degree of criminality among epileptics.

The formal proposal by Eijkman<sup>34</sup> that *Epilepsia* become the official organ of the League (at least for the time being) was approved. Tamburini suggested that a whole day be dedicated to epilepsy at the Berlin conference for the

<sup>34</sup> Pieter Hendrik Eijkman (1862–1914) studied in Amsterdam and began his career as a physician in Zaandijk. From 1894 to 1904 he was medical director of the psychiatric hospital at Scheveningue. Thereafter, he returned to his practice. Eijkman was an ardent internationalist, and campaigned tirelessly to establish a scientific world capital near The Hague which was the linchpin of his overarching dream of creating a new social and intellectual order. Although he managed to attract the interest of prominent figures such as Harvey Cushing and Andrew Carnegie, Eijkman's plans eventually came to nought. His ideas about coordinating international efforts in medicine are spelled out in *L'Internationalisme Médical* (F. Van Rossen, Amsterdam, 1910). Eijkman's brother Christiaan shared the 1929 Nobel Prize for Physiology and Medicine (*Album* 1909; Somsen 2006).

presentation of the national reports and also a discussion of pathology and any other scientific questions. Reports were to be prepared early in the year, so that they could be published in time for the conference.

These documents are important, for they reveal the stated motives for setting up the League and lay out its initial organisation and work programme. The central aim of the new League, as recorded in these pages, was to alleviate the plight of epilepsy and to act for patients with epilepsy who were a disenfranchised group ('denied the benefits of society'), rather than a concern with any professional or scientific issues. The primary method for achieving this aim was to collect and centralise statistical data related to 'the problems of epilepsy, its history, causes and various manifestations in different countries'. It was recognised that only with these data in place could future action be rationally planned. In fact, collecting statistics remained at the centre of League activity for the next several decades (many were published in *Epilepsia*). It is noteworthy that the League's vision at this stage seems primarily bureaucratic, and unconcerned with professional issues, but aimed at bringing about change by lobbying government, much like the current ILAE focus via the Global Campaign.

It is also interesting to observe that the perspective of the League, in those days, was very much based in asylum practice. Indeed, asylums were generally considered to be the appropriate setting for the treatment (and custodial care) of patients with chronic epilepsy and for research. The leading figures of the organisation were alienists, and the League was primarily concerned with the institutionalised patient. These patients invariably had chronic and severe epilepsy, and a division was made between 'insane' and 'sane epileptics', the former group comprising mainly those with learning disabilities but also those with affective and psychotic disorders. There was also considerable interest in the criminality and inheritance of 'insane' epileptics, and the provision of their institutional care. It was generally agreed that asylum places were lacking for patients with epilepsy of all types, and that asylums had to be able to distinguish the handling of sane epileptics from that of patients with psychiatric disorders or dementia.

Marie's presentation contains a statement of purpose which would be appropriate as a vision statement of the current League (Table 1). Although the focus of activity at that stage was primarily bureaucratic, science and medical research were not excluded. This was indeed a

**Table 1** Marie's statement of purpose: the original 'mission statement' of the League.

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The League will devote itself to special projects on behalf of epileptics, and to finding a cure and means of prevention, as well as providing aid and social rehabilitation. Nor will the League neglect experimental research and comparative physiopathology, or laboratory work, which is essential for elucidating a series of problems as complex as those raised by the origin, evolution and nature of seizure disorders, with their attendant range of somatic and psychic complications.

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bold and ambitious scheme, as Marie commented, and the reader of these documents will be struck by their clarity and efficiency (not always the case in the League's subsequent history).

The International League was founded as a primarily international organisation with individual members (Table 2). However, from the beginning the members were strongly encouraged to form national committees, but none of the national committees were separate legal entities as some are today. The members would belong both to the national committees and the international body, although the primary membership was of the central (international) organisation. Membership was conferred at the annual meetings of the ILAE, for a standard membership rate.<sup>35</sup> Nowadays, there is an inherent ambiguity in to the extent to which the ILAE is a federation of chapters or an individual membership organisation, but in the early years no such ambiguity existed; membership was of individuals grouped into chapters. This is a fundamental issue which should be addressed again now as the ILAE enters its second century.

It was recognised at the first meeting that a key element was a vehicle for publishing the findings of ILAE research (and particularly statistical research). On 2 September *Epilepsia*, which had been in existence only for a matter of months, was formally adopted for this purpose as the official organ of the League (Secretäre 1909, 234). This was a wise decision, for without a medium of communication it is difficult to see how the League could have flourished.

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<sup>35</sup> Nowadays, the national chapters are the members of the ILAE and individuals pay dues to their national chapters, in amounts that vary from country to country. The national chapter pays a subsidy to the central organisation, which depends on the national membership fee and the number of members.

**Table 2** International associations and the creation of the ILAE.

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|------|---|
| 1898 | National Association for the Study of Epilepsy and the Care and Treatment of Epileptics is founded in New York by William Pryor Letchworth; L.J.J. Muskens is a corresponding member  |
| 1902 | A Dutch league against epilepsy is founded in The Hague by Muskens, P.K. Pel and J. van Deventer  |
| 1906 | The International Commission for the Study of the Causes and Prevention of Insanity (the International Commission) is established in Milan at the behest of Swiss psychiatrist Ludwig Frank; its ultimate aim is to create an institute   |
| 1907 | The Office International de l'Hygiene Public is ordained by the Treaty of Rome; a forerunner of the World Health Organization, it will have its office in Paris (1909)  |
|      | The International Commission meets for the second time, at an international congress in Amsterdam, and draws up a set of statutes; during the congress, Muskens proposes a similar effort with a focus on epilepsy  |
| 1908 | Third meeting of the International Commission, Vienna; statutes approved  |
|      | National Association for the Study of Epilepsy and the Care and Treatment of Epileptics receives a letter from the Dutch league asking for help in setting up an international association for the study of epilepsy  |
| 1909 | September: The International League Against Epilepsy (ILAE) is formed during the International Medical Congress in Budapest; the International Commission, in the person of Tamburini, pledges its support to the ILAE and says they should work together; in reporting the event in <i>Epilepsia</i> , Marie (who was also active in the International Commission) refers to the ILAE as a 'daughter' organisation of the Commission |
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### The second meeting of the League: Berlin, 4 October 1910

As proposed at the Budapest meeting, the second meeting of the League took place in Berlin, on the occasion of the 4th International Congress on the Care and Treatment of the Insane.<sup>36</sup> The programme was announced in *Epilepsia* (Programme 1910) and followed closely the work plan proposed the previous year:

1 The current status of the International League (Tamburini [Rome], president; Donáth [Budapest], first secretary)

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<sup>36</sup> The congress is described on p. 219.

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2 Short reports of the national committees of the League: number of epileptics in different countries, institutions etc. (reports to be published in *Epilepsia*)

3 Paper entitled: 'Criminality Among Epileptics' (Veith, Wuhlgarten)

4 Paper entitled: 'Physiopathological Research in Epilepsy' (Muskens, Amsterdam)

5 Choice of a permanent office

6 Work plan for the national committees for the year 1911

It was noted also that the provisional central office of the League was now established in Budapest, with Moravcsik as president.

The secretary's report published in *Epilepsia* provides details of the business carried out at this meeting. Eleven members were present,<sup>37</sup> and members were

<sup>37</sup> 'Second annual meeting of the International League Against Epilepsy: 4 October 1910, 5 o'clock in the afternoon, in the Parliament Building, Prinz Albrecht Strasse in Berlin ... Chair: Prof A. Tamburini (Rome) ... Present: Prof Friedländer (Hohe Mark in Taunus), Dr Veit (Wuhlgarten), Dr Urstein (Warsaw-Berlin), Dr Hirschfeld (Berlin), Dr Leubuscher (Hoppegarten), Dr J. van Deventer (Amsterdam), Prof Borchardt (Berlin), Prof Binswanger (Jena), Dr Ulrich (Zurich), Dr Ignaz Fischer (Budapest), Dr Muskens (Amsterdam). ... Mr I. Fischer took the floor: ... Gentlemen: ... In the name of Prof Moravcsik, who regrets his absence owing to university obligations that could not be postponed, as well as Prof Donáth, who – as senior consultant of the municipal hospital – had to remain at his post in the face of an impending cholera threat and also could not be here, I would like to take the floor as second secretary of the temporary central office and greet you all warmly ... During the 16th International Congress at Budapest, at the instigation of Prof Donáth and Dr Muskens, a decision was made to create an International League Against Epilepsy to research and fight against epilepsy, as has already been done against alcoholism, tuberculosis and cancer. This proposal was accepted with enthusiasm, and the International League was born ... At the suggestion of Mr A. Marie, it was further decided that in addition to an international committee, national committees should be organised at the country level to work locally in the League's interests ... At the same time, it was proposed that the League would have its annual meeting the next year in Berlin, in association with the Congress on the Care and Treatment of the Insane ... In compliance with this proposal, here we are, and according to the present agreement, the permanent office of the Epilepsy League will remain in contact with the Bureau of the International Medical Congresses, which has its permanent seat in The Hague ... This meeting will report statistics on people with epilepsy in individual countries, according to the work plan submitted last year ... Regarding next year's work plan, I suggest that the following people meet Wednesday afternoon at 3 o'clock in Room 7: Winterberg (Russia), Claus (Belgium), Veit and Friedländer (Germany), Fischer (Hungary), van Deventer and Muskens (Holland), Obersteiner (Austria), Ulrich (Switzerland). This committee

nominated to form the national committees in 15 countries. Donáth had been unable to attend as a cholera epidemic was threatening Budapest. Ignaz Fischer, sent by the Hungarian branch in his place, suggested that the ILAE office should liaise with the permanent bureau of the international medical congresses, which was in

meeting will also discuss the financial implications of any decisions made. The results will be reported in the following meeting on Friday ... The suggestions of the Budapest committee are accepted with enthusiasm ... Next, the secretary will read aloud the brief content of the reports of the national committees received thus far. Insofar as these (from Russia and Hungary) have not yet been published in the League's organ, they will appear in the next issue of *Epilepsia* ... Mr J. van Deventer believes it would be desirable to present the numbers of epileptics in a standardised format. He suggests that Messrs Friedländer and Vogt prepare a schema within three weeks and send it to the secretary, so that a copy could be forwarded to the secretaries of the national committees. The motion passes ... Mr Dr Claus (Antwerp) emphasises that not only should chronic cases of epilepsy be counted but also new cases, whose treatment represents an important social problem that should be considered. Dr Claus and Dr Meeus have secured a contract by the Belgian government to investigate which measures different countries have taken in this regard. The Belgian legislature has asked for statistical data regarding the frequency of psychic disorders due to epilepsy, information on the rearing of epileptic children and so on. The Belgian government is also specifically interested in discovering the extent of criminal behaviour in consequence of epilepsy ... As regards the publisher of the provisional organ of the League, *Epilepsia*, Mr Ulrich notes happily that, so long as the League numbers at least 100 members, Johann Ambrosius Barth is ready to enter into a regular contract with the League. Mr Ulrich suggests that the yearly contribution be set at 10 marks. Every member of the League would then receive a complimentary copy of the journal; the League would pay Barth the sum of 9 marks for each member ... Several people have expressed the wish to have preliminary constitution of the League drawn up fairly quickly. To distribute the work, the chair and Dr J. van Deventer suggest that Prof Ferrari (Modena) and Dr J. Claus (Antwerp) as vice-secretary of the League should serve alongside the chair ... The national committees will be formed by the following people: ... Algeria: Prof Bouley. Belgium: Dr Claus and Dr Meeus. Brazil: Prof Moreira. Germany: Prof Alt, Prof Binswanger, Dr Bratz, Prof Cramer, Prof Friedländer, Dr Hebold, Prof Sommer, Prof Vogt, Dr Weygandt, Prof Ziehen. England: Dr Macpherson, Dr Turner, Dr Wilson. France: Prof Claude, Prof Déjérine, Prof Landouzy, Dr A. Marie. Holland: Dr Bonebakker, Dr Coert, Dr J. van Deventer, Dr Lykles, Dr Muskens, Prof Pel, Dr Deenik. Italy: Prof Ferrari, Dr Perusini, Prof Tamburini. Austria: Prof Frankl-Hochwart, Dr Fuchs, Dr Halban, Prof Obersteiner. Poland: Urstein. Russia: Prof Bechterew, Prof Breidenberg, Prof Minor, Dr Imhof. Switzerland: Dr Ulrich. Turkey: Rashid Taschin Bey. Hungary: Prof Donáth, Dr Fischer, Dr Hudovernig, Prof Moravcsik. As regards the United States, the chair will accommodate the preference of the president of the "American Association". Finally, Dr Veit will present a lecture on the criminality of epileptics, which will appear in the journal *Epilepsia* ... The Secretary.'



Prussian House of Deputies in Berlin: the location of the second meeting of the ILAE. (Source: Wikimedia Commons)

The Hague.<sup>38</sup> This proposal resulted in the inclusion of members of this bureau as non-voting members on the League's committee. It was also decided that the International Action Committee should consider the financial aspects of the ILAE and devise a plan of work for the following year. Ulrich informed the meeting that the firm Johann Ambrosius Barth of Leipzig would publish *Epilepsia* if at least 100 members joined the League. The annual dues were to be set at 10 marks (roughly £37 today)<sup>39</sup> which was to include 9 marks for the publisher. This proposal was obviously approved, as the second volume of *Epilepsia* was indeed put out by Barth, which continued to publish the rest of the first series. Van Deventer suggested that a uniform questionnaire be devised to be applied in different countries to assess the frequency of epilepsy,

work that was devolved to Friedländer and Vogt. This questionnaire was published in the second volume of the journal (Friedländer and Vogt 1910/11) but, as was reported many years later (Schou 1940, 252), it was too detailed and resulted in responses only from Great Britain, America and Switzerland. A more successful attempt at an international survey was conducted in 1935 (see below).

Muskens's paper, announced on the programme, probably was never given, and Muskens later makes no mention of it. However, the paper Veit presented on criminality amongst epileptics ('Über Kriminalität der Epileptiker') was subsequently published in *Epilepsia* (Veit 1910/11).

The national committee's statistical reports presented from Great Britain, Holland and Sweden were also published in the journal (Rapports des comités 1911, 274–289, 398–400). W. Aldren Turner presented the British report, and these figures probably constitute the best published at that time from anywhere in the world. He culled them from five official sources.<sup>40</sup> He followed

<sup>38</sup> The permanent office in The Hague is a curious story of its own (see n. 34). Intended by Eijkman as an 'organisation of organisations' to be built on the North Sea, it never materialized, although much effort was expended in its planning (Somsen 2006).

<sup>39</sup> In this chapter, we have converted original currencies into current values using the British retail price index (RPI) converted into 2007 sterling values as the primary measure until 1945, and then after 1945 the American Consumer Price Index (CPI) converted into 2007 dollar values. These measures are chosen as being the most representative. Exchange rates also have varied considerably over the years. For convenience, we have converted other European currencies into sterling before 1945 and then converted the figure into current sterling values. The data are taken from tables published on [www.measuringworth.com](http://www.measuringworth.com), where an explanation of the measures is also given. The £37 figure is a bit of an approximation, as conversion rates for German marks are available only beginning with 1913.

<sup>40</sup> Turner's statistics are an impressive collection. His five sources were reports from: (1) the Commissioners of Lunacy of England and Wales, which give the number of epileptics in asylums and registered houses and homes in England and Wales; (2) the Asylums Committee of the London County Council, which gives the total number of epileptics under care in the administrative County of London; (3) the statistics from the National Hospital for the Paralysed and Epileptic (Queen Square); (4) the reports of eight 'Epileptic Colonies' – Chalfont Colony, Maghall Colony, David Lewis Colony, Ewell, Lingfield Homes and Schools, Monghull Colony, Meath Home and St Luke's Home; and (5) statistics of the Registrar General for England and Wales giving the number of deaths from epilepsy.

the lines proposed at the Budapest meeting, breaking down his figures into acute (no reliable statistics) and chronic cases, and inquiry into mental status, but noted that no figures were available for the general prevalence of the condition in the population and that his numbers were heavily biased. It is interesting to note, *inter alia*, from his figures that epilepsy accounted for 3,689/15,234 (24%) of new outpatients at the National Hospital over a 5-year period; that there were 2,367 patients with epilepsy in the London homes, asylums and the eight colonies; and that epilepsy accounted for 856–1,154 deaths per million persons in seven successive quinquennia between 1871 and 1901 in England and Wales.

It was the habit of the ILAE to publish its membership lists in these early days (a practice that ceased in 1939,<sup>41</sup> and in our opinion should now be revived), and in 1911, there were 96 members from 19 different countries.

### The third meeting of the ILAE: Zurich, 6 and 7 September 1912

The next meeting of the League took place on 6 and 7 September 1912, during the International Congress for Psychology and Psychotherapy in Zurich, and concurrently with the Association for Swiss Psychiatrists and Neurologists. The programme for the meeting was published in *Epilepsia* and also in the *Neurologisches Centralblatt*. For the first time, science and business components were kept separate, and the scientific day had an excellent and interesting programme (NB: the items on the scientific agenda in square brackets represent differences between the announcement in *Epilepsia* and an announcement published in the 16 August 1912 issue of *Neurologisches Centralblatt* (1071–1072; third-party reports of the lectures are given in the 16 November 1912 issue of the *Centralblatt*<sup>42</sup>):

#### A Association meeting (Chairs: Tamburini, von Monakow)

- 1 Fixing the time and place of the next meeting
- 2 Committee appointments
- 3 Debate on the constitution (*Epilepsia*, vol. II, issue 4, p. 320, and vol. III, issue 3)



Alfred Ulrich (1869–1944), who hosted the League's third meeting in Zurich, in 1912. (Source: Neujahrsblatt der Hüllfgesellschaft in Zürich)

- 4 Relationship between the League and the national committees
- 5 Financial situation of the League and its organ
- 6 Work plan for the coming year

#### B Scientific meeting (Chairs: Forel, Donáth) [see p. 219]

The proceedings were published in detail in *Epilepsia*, including minutes of two separate administrative meetings (*Secretäre* 1912, 1–86). They are also summarised, in English, in a brief history of the League that Muskens wrote many years later (Muskens 1938). The opening session commenced at 9:30am on 6 September at the Swiss epilepsy asylum in Zurich. With Weeks in the chair, Donáth greeted the attendees and read a telegram from Tamburini apologising for his absence and regretting that events constrained him to resign from the presidency. The presidency would pass to Weeks. Muskens read the report of the secretariat, which was approved. A subsequent business meeting, chaired by Donáth, took place on the morning of 7 September at the schoolhouse in Hirschengraben. America was provisionally chosen as the next meeting location, and Weeks was to head the local organising committee. Veit suggested an intermediate

<sup>41</sup> The exception to this was the membership list of the American chapter, the only chapter active after 1939, which was published up to 1940.

<sup>42</sup> Muskens himself wrote up a brief summary of the meeting for the *Correspondenz-Blatt für Schweizer Aerzte* (Muskens 1912).



David Weeks (centre front, 1884–1929), first American president of the ILAE, was an avid sportsman during his medical school years. (Courtesy Collections of the University of Pennsylvania Archives)



meeting on European ground (London), which was approved. Donáth then proposed that the national committees each be given a mandate to enable them to obtain the material and moral support they would require especially in gathering statistics.

A discussion followed among Claude, Ladame, Veit and Muskens regarding the desire of the American Association for the Study of Epilepsy and the Care and Treatment of Epileptics to ally with the International 'Liga'. The application was accepted, subject only to the relevant statutes (see below) being translated into German and French to avoid misunderstanding on the part of non-English-speaking members. Donáth suggested that for future meetings, talks should be registered 3 months in advance. Ulrich reported that Kocher had taken on the presidency of the Swiss Liga, with Forel and Monakow as vice-presidents.

The final business meeting occurred on 7 September. Present were Anfimow, Bratz, Claude, Donáth, Muskens, Ulrich and Weeks. Muskens opened the discussion with a question about how cases of epilepsy were to be tallied. Donáth tabled a draft of a standardised questionnaire that physicians could use. A report by Muskens followed on the financial situation of the secretariat and the national committees (no details appear in the journal). Donáth said that to approach governments for assistance, the Liga would have to have something positive to show. A discussion ensued about the amount of income to be paid by

the national committees to the International Committee. Claude suggested 1/10 to general approval.

Bratz suggested that the Liga seek to affiliate with another, larger international psychiatric society and its congress, for example the International Congress for the Care of the Insane. Muskens reported on the relationship of the Liga and the publisher of *Epilepsia*; Anfimow provided an update on Russia. Ulrich suggested, to approbation, that membership in the Liga be opened to the supporting public. (The issue of criteria for membership in the League is one which would come up time and time again over the years.) Finally, Musken's reports ends with a review of the new title page of *Epilepsia*.

The proceedings include the report of the secretaries, which is largely a recap of statistical reports published in the second and third years of the journal. The document concludes by considering how to guarantee the usefulness of the Liga's large-scale investigation into epilepsy. It might, the secretaries wrote, be best to distinguish three broad groups of genuine epilepsy: toxicity-induced exogenous and endogenous cases; focalised epilepsy; and 'cases that have no toxic nor anatomic basis but that arise with some regularity like a natural phenomenon, even in otherwise healthy families. It is precisely this last group that have the tendency to inheritance and segregation. It would thus be of the utmost importance to cull these varieties and, in so doing, to advance eugenics in a powerful way' (Secretäre 1912, 86).

## 18 International League Against Epilepsy 1909–2009 A Centenary History

The draft ‘Object’ of the ILAE (the statutes) was prepared by William Shanahan (United States) ‘assisted by’ M. Urstein (Germany) and published in *Epilepsia* (Shanahan and Urstein 1912, 316).<sup>43</sup> This document formally enshrines, for the first time, the administrative structure of the ILAE. Shanahan and Urstein proposed the following:

### (a) International Committee and its general meetings

The International Committee was the equivalent of the current Executive Committee. The committee was to comprise a president, a vice-president, two assistant secretaries and a treasurer. These officers were to be elected at the ILAE general meetings, and appointments made by a simple majority. The members should serve for a three-year term. Only members of a national committee could stand for these posts. It was proposed that the International Committee should meet immediately before each regular meeting of the League. Three members made a quorum, and only those present were eligible to vote. The International Committee should present a report at each regular meeting of the League, and at these general meetings, 12 members were required to form the quorum.

In addition, it was proposed that the general secretary and assistant secretary of the Permanent Commission for the International Medical Congresses should be non-voting members of the International Committee of the League, presumably to allow coordination of the ILAE meetings within the programmes of the International Medical Congresses.

### (b) National committees

These committees were the equivalent of the current boards of the national chapters. It was proposed that national committees should be appointed ‘in all civilised countries’. No guidance was given about the membership or election of these committees. And indeed, in the subsequent development of the League different structures have evolved in different countries – although not all were loosely based on the formula of the International Committee.

<sup>43</sup> In an article titled ‘A Short History of the First Period of Activity of the International League Against Epilepsy’, Muskens attributes the work on the statutes to Shanahan and himself, in spite of the fact that they were published under the authorship of Shanahan and Urstein. Muskens mentions that Donáth’s statement that it was time to set up an International League was made on his (Muskens’) own behalf (Muskens 1938, 321). A later version of the statutes in English, not published in *Epilepsia*, carries the names of Muskens (as secretary-general) and David F. Weeks, who was elected president of the ILAE at the Zurich meeting. The statutes were apparently sent as an attachment to a circular letter to the membership dated 1 December 1912 (Weeks and Muskens 1912).

### (c) Members

Membership of the ILAE was open to ‘any person who is interested either scientifically or practically in the work of the Liga’. It was proposed that those who wished to join should inform the secretary of their national committee, and membership was to be approved by the national committees. Annual dues for each member were proposed to be 5 US dollars, 20 British shillings or the corresponding amount in other currencies – paid in advance [£79 today]. All members would receive a copy of *Epilepsia* (the first volume of which would be issued in January 1913 – this is the first time the month of publication of an issue of *Epilepsia* has been clearly stated).

It was also proposed that the ILAE could elect honorary members, whose names were submitted by the respective national committees to the International Committee, and membership was to be granted if four out of the five members of the International Committee approved.

### (d) Regular meetings of the League

These are equivalent to today’s International Epilepsy Congresses. At the beginning of each regular meeting, the president was to appoint three members to receive invitations regarding the place of the next meeting. As soon as this was decided, the president should appoint a programme committee of at least three members. The chairman of this committee would be a member of the national committee of the country in which the next meeting was to be held. Persons wishing to present papers or other matter would submit the titles to the secretary of the national committee at least three months before the regular meeting, who would then submit these to the programme committee at least two months before the meeting. At that time there was no requirement for the national chapters to hold meetings.

These objects were then formulated into a draft constitution<sup>44</sup> which was presented at the Zurich meeting for ratification (Communication 1911, 326–327) and provisionally approved, as mentioned above. This was a skilful and well-constructed administrative plan, and indeed its framework served as the basis for the League structure for most of its first 100 years – albeit with almost continual tinkering. As mentioned above, membership in those days was primarily of the ILAE, not the national chapters.

The League’s membership had risen to 106 members. The League was now also beginning to attract affiliation of some national societies which were already in existence.

<sup>44</sup> For the full text of the constitution, see Appendix 2.

The rise of eugenics: a baby being examined for a better babies contest in the United States, ca 1910. The first 'Scientific Baby Contest' was held in 1908, where measures of contestants' physical and intellectual development were taken. In 1914, the American Model Eugenic Sterilization Law was proposed to authorise sterilisation of the 'socially inadequate' (those in institutions or dependent on care provided at public expense) and encompassed the 'feebleminded, insane, criminalistic, epileptic, inebriate, diseased, blind, deaf, deformed; and dependent' as well as 'orphans, ne'er-do-wells, tramps, the homeless and paupers. (Image courtesy Mrs Frank de Garmo Papers, 1900–1985, MS-1879, University of Tennessee, Knoxville, Special Collections Library)



In the United States, William Shanahan, who drew up these statutes, was then president of the American National Association for the Study of Epilepsy and the Care and Treatment of Epileptics,<sup>45</sup> which had been set up in 1898. On June 1912, in his presidential address, he suggested that the national association become a component part of this organisation. He expressed the hope that the association would be properly represented at the Zurich meeting and noted that 'concerted effort in all parts of the civilised world should result in a material gain in the

amount of research work in the epilepsies' (Shanahan 1913, 119–130). This was the first American chapter officially to join the League.

#### **The fourth meeting of the League: London, 13 August 1913**

The next meeting of the ILAE was held in London on 13 August 1913 at the Royal Society of Medicine, which then as now was located at 1 Wimpole Street. The meeting was held at the time of the formidable 17th

<sup>45</sup> The National Association for the Study of Epilepsy and the Care and Treatment of Epileptics was founded in 1898 in the United States (Anon. 1898), where it had an active role in the development of epilepsy services. Its early presidents included William Bullard, William Spratling (who ceded the position when he went to take the chair of neurology at Johns Hopkins in Baltimore) and William T. Shanahan. Spratling and Shanahan were energetic and effective leaders, and the association had large and scientifically important programmes. This society, like the ILAE, was based firmly in institutional practice. (Spratling was instrumental in establishing Craig Colony in 1894 and was the first medical superintendent there.) In 1901, Spratling was the secretary of the association, and it is interesting to note that William Osler was the second vice-president. In 1925, the association was subsumed into the Section for Convulsive Disorders of the American Psychiatric Association, whose history is well documented in a paper by Kirby Collier (1945).

The reasons for the union are not entirely clear. Lennox had his own rather uncharitable view that it was forced on the American association because of its profligacy (Lennox 1939b, 174–176). It had 103 active members and 157 associate members in 1907, with

dues which, if collected, would have amounted to nearly £200. However, Lennox maintained, the branch died, not on account of the war but because all the dues went to publishing expensive annual proceedings and because research was insufficient to maintain hope and interest amongst its members. A much more positive view of the union was taken by the then-president of the national association, who stated that it would recognise that epilepsy had many psychiatric aspects and that the power of the American Psychiatric Association (which was established in 1845 and had by 1945 over 3,000 members) could be applied more beneficially to the problems of epilepsy if there was a union than by the organisations independently. This was the first fully formed 'section' of the American Psychiatric Association, and it continued to meet until 1945 at least (Kirby Collier 1945). In the 1940s, joint meetings of the section and the American Branch of the ILAE were set up, owing much to Lennox according to Kirby Collier.

The members of the American National Committee of the ILAE in the early days were all luminaries of the National Association for the Study of Epilepsy and the Care and Treatment of Epileptics, and included famous names in American epileptology such as Shanahan, W.F. Drewry, E.T. Flood and L. Pierce Clark.



Royal Society of Medicine building, site of the 4th ILAE meeting in August 1913. The building was opened in May 1912 by King George V and Queen Mary. The society was formed in 1805, with the aim of promoting ‘conversation on professional subjects, for the reception of communications and for the formation of a library’. The library housed in this building is now one of the best medical libraries in the world. (By kind permission of The Royal Society of Medicine)

International Medical Congress, but largely independent of the main event (see p. 220). It is interesting to note that the meeting was formally noted to be the ‘First meeting of the National Committees of the ILAE’ and National Committees from Brazil, England, Holland, Germany, Hungary, Norway and Switzerland were represented. The meeting seems to have been confined to 10 persons<sup>46</sup> (i.e. less than the quorum suggested in the objects). The programme of the meeting was published in *Epilepsia* (Programme 1913, 350):

- 1 Presidential address
- 2 Relation of the National Committees to the League (e.g. annual contribution)
- 3 Reports of the various National Committees
- 4 Discussion on the desirability of establishing separate institutions for fresh cases, or of segregating such cases in institutions for confirmed cases
- 5 Central bureau for the study of epilepsy under the charge of the National Committees
- 6 Paper by Dr McDougall: ‘Schools for Epileptics and the Education of Epileptic Children’

<sup>46</sup> According to the list of names published in *Epilepsia*, although it is possible that there were other un-named attendees.

7 Paper by Dr Collins: ‘Statistics from Family Histories of Epileptics’

8 Paper by Dr Anton: ‘Operative Beeinflussungen von Entwicklungstörungen des Gehirns, Insb. der Epilepsie’<sup>47</sup>

9 Paper by Aldren Turner: ‘Relative Frequency of Epilepsy in England’

Visits were arranged to the London County Council epileptic colony at Epsom on 13 August, and to the David Lewis Colony at Alderley Edge near Manchester on Thursday 14 August.

The papers by McDougall, Collins, Anton and Turner were published in *Epilepsia*, as was the presidential address by Aldren Turner. The emphasis of this meeting was the provision of asylum care for patients with epilepsy and epilepsy statistics. In his address, Turner discussed the evolution of care in Great Britain. He emphasised the interplay between state and private provision, the separation of children and adults, and the philanthropic origins of the institutions. Collins addressed the question of heredity, a major theme of neurological research of the period, and it is reported that eugenics was a main topic of

<sup>47</sup> [Trans.] Surgical effects of developmental brain disorders, especially epilepsy.



William Aldren Turner (1864–1945), prominent British epileptologist, a leading figure in the early ILAE and founding editor of *Epilepsia*. (Courtesy Institute of Neurology, National Hospital for Neurology and Neurosurgery, Queen Square, London)

the International Medical Congress (Bynum *et al.* 2006, 227).<sup>48</sup> Turner then updated the conference on epilepsy statistics from England using the same format as in his paper in 1909. The subject of eugenics was broached in *Epilepsia* in 1912, in the report of Weeks' presentation in Zurich, and in a paper directly following the report by H.M. Carey (1912).

<sup>48</sup> Eugenics was a topic in which several ILAE members were involved. The most notorious was Edwin Katzen-Ellenbogen, a eugenicist who wrote New Jersey's sterilisation law for epileptics in 1911 while working for 2 years as a psychopathologist at the Skillman Village for Epileptics in New Jersey. The law was revoked by the US Supreme Court in 1913. New Jersey was the fifth state to have a sterilisation law for epileptics, and the first to revoke the law. Katzen-Ellenbogen published several papers in the first series of *Epilepsia*. He was a fraudster who may never have had a medical degree and left the United States in 1915. In the 1940s he ended up at the Buchenwald concentration camp, where he was a notorious collaborator with the SS, perhaps directly implicated in lethal injections of thousands. He was convicted of war crimes and given a life sentence, but it was reduced to 12 years because of an alleged heart condition (M. Nevins, personal communication).

**Table 3** International congresses of the ILAE, 1909–1949.

1909	Budapest
1910	Berlin
1912	Zurich
1913	London
1935	Lingfield
1939	Copenhagen
1946	New York
1949	Paris

NB. In 1931, according to Muskens, discussions were held in Berne on the occasion of the 1st International Neurology Congress in an attempt to revive the League (see p. 24). Muskens took part in two discussions, and gave a paper titled 'Affection of the Central-Tegmental Tract and the Symptoms of Falling Forward and Backward; Their Relation with the Tracts and Centres, that are Involved in Paralysis of Upward and Downward Associate Movements of the Eyeballs' (Proceedings 1931). In addition to Muskens' name, a perusal of the list of speakers turns up a few other early members of the League, as well as a young Macdonald Critchley.

The proceedings of the meeting were also published in *Epilepsia* (Proceedings 1913, 351–354). A membership and *Epilepsia* subscription charge was agreed for the ILAE. In that period, two classes of members were to be admitted – one with full privileges with a subscription to *Epilepsia* for 25 francs (£75 in today's currency); and the second of 4 francs (£12) to be designated associate members.

#### **Proposed fifth meeting of the ILAE: 5–7 September 1914, Berne**

At the London meeting, it was agreed to hold the next ILAE meeting in Berne, Switzerland, on 5–12 September 1914, on the occasion of the International Congress of Neurology, Psychiatry and Psychology, and the Meeting of the Society for German Neurologists and the Swiss Neurological Society (Table 3).

The programme was announced in the summer of 1914 in *Epilepsia* and was to include, on 7 September, lectures by Kocher on the 'Surgical Treatment of Epilepsy' and Dr Robert Ammann from Aarau on 'Electricity from the Air and Epilepsy' and 'Introduction to the Discussion Concerning the Census of People with Epilepsy'. These presentations were to be followed by lectures from the Central Office for Epilepsy Research by Drs Bouche of Brussels, Muskens, Turner (on 'Epileg [sic] and Tumor

Cerebri') and A. Macicsza of Crakow on 'Brown-Séguard's Epilepsy in Guinea Pigs' (Nouvelles 1914, 222).

The meeting was to take place in Kocher's surgical clinic in Berne. A discussion was also planned on the frequency of epilepsy in the population of different countries (this eventually took place in 1939), and the rules and regulations of the ILAE were to be approved. Statistical information from England, Hungary, Germany, Holland, Sweden and Denmark was to be presented (Muskens 1937, 14).

The meeting was never held. On 28 June 1914, Franz Ferdinand, crown prince of the Austro-Hungarian Empire, was assassinated in Serbia, and Europe was plunged into the First World War. During the famously beautiful summer of 1914 no one believed the war would last long, and in *Epilepsia* a brief optimistic note was published: 'Because of the European war, the meeting of the International League Against Epilepsy has been adjourned until the summer of 1915' (Nouvelles 1915, 282). The expectation that the adjournment would be brief was, sadly, wildly optimistic.

#### ILAE 1909–1914: Summary

Such was the history of the ILAE during the period 1909–1914. It had made a good start. There was a clear administrative structure, over 100 members and national committees in at least 17 countries (Algeria, Austria, Belgium, Brazil, Germany, England, France, Holland, Hungary, Italy, Norway, Poland, Russia, Sweden, Switzerland, Turkey and the United States). It had a distinguished committee of patronage, a defined work plan, a well-written constitution and statutes, and clear objectives. It was integrated with the permanent commission for the International Medical Congresses, and had held annual meetings in four different countries. It had a high-quality journal, itself with a distinguished committee of patronage and editorial board.

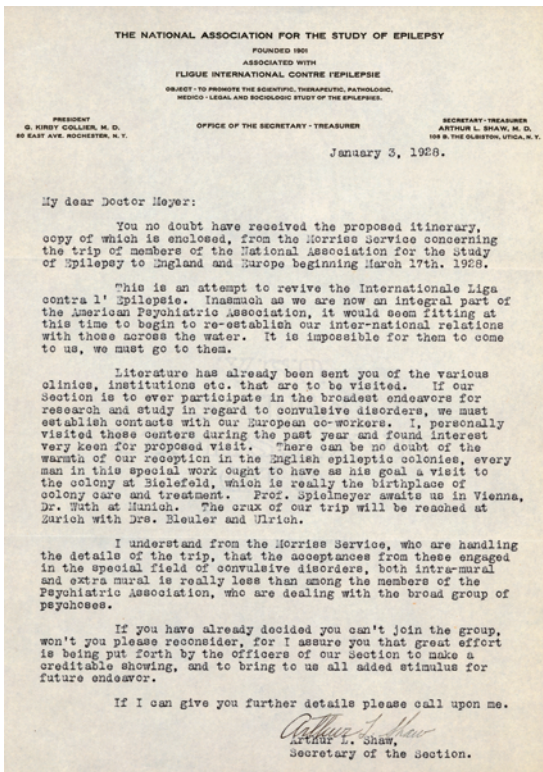
At that time, though, the League was very small, and in most senses a 'club' (and hence would have been unrecognisable to current eyes). With some exceptions, its meetings lasted a single day and may have had an audience of as few as 10 persons. The meetings were initially not primarily scientific, but rather administrative, although in Zurich, scientific meetings were broken out separately. The main scientific medium of the ILAE then was *Epilepsia* and not its own conferences. The members of the League were largely Europeans (and most from central Europe –

55 of the 106 members in 1911) with, in that same year, five American and three Brazilian members. It was run largely by alienist doctors, and its focus was very much on the activities of epilepsy institutions. All this was achieved by the voluntary work of a small group of neurologists and psychiatrists. It surely was a model of what could be built by international cooperation, and in this sense achieved more than the larger and more ambitious Institute for the Study of the Causes and Prevention of Insanity, on which it was based. Yet all was interrupted by the First World War, which itself changed the world order forever.

The war, of course, was not over by the summer of 1915, and the Berne meeting evaporated. Indeed, the prolonged hostilities resulted in the termination of all League activities, and the League ceased completely to exist. National associations for epilepsy (without any international connections) were formed in the subsequent period in several countries, but during most of this time there was no appetite for international cooperation or any international organisation. *Epilepsia* ceased to exist in early 1915, after 'financial and other difficulties' (Muskens 1937, 14). What opportunity was lost for epilepsy by the cessation of the League is difficult to know.

In the spring of 1928, a group of American epileptologists and psychiatrists set sail for Liverpool on the SS *Caronia* accompanied by Kirby Collier and Arthur L. Shaw, president and secretary, respectively, of the National Association for the Study of Epilepsy.<sup>49</sup> In a letter of invitation to Adolf Meyer, dated 3 January 1928, Shaw wrote, 'This is an attempt to revive the Internationale Liga contra l'Epilepsie.' During the month-long trip the group would visit all the major European epilepsy centres and meet with ILAE members Muskens, Ulrich, Claude and Wuth, among others. Also promised were a 'glimpse of life on the Rhine', 'a day and a half in the capital city of the oldest republican government in Europe [Zurich]' and a Saturday afternoon on the Parisian boulevards (Shaw 1928). How the trip went is lost to history; it was reported before but not after the fact, and the League stayed dormant. For the time being, all efforts at a new start appeared stymied.

<sup>49</sup> The association's letterhead carries the wording 'associated with l'Ligue [sic] Internationale Contre l'Epilepsie: object – to promote the scientific, therapeutic, pathologic, medico-legal and sociologic study of the epilepsies' (see, for example, Shaw 1928).



American epileptologists tried in vain to revive the ILAE as an international organisation following the First World War. (Reprinted with permission from the Adolf Meyer Papers housed in the Alan Mason Chesney Archives of the Johns Hopkins Medical Institutions)

### ILAE: 1935–1939

The second series of *Epilepsia* began publication in February 1937, and the first issue contains a number of papers concerning the restitution of the ILAE. These again remain the only published source of information about the events of that time. The new editor, Hans Iacob (H.I.) Schou from Denmark, titled his opening editorial 'Reorganisation of the International League Against Epilepsy'. Schou informed the readers that at the time of the International Neurological Congress in London,<sup>50</sup>

<sup>50</sup> The 2nd International Neurological Congress, held from 29 July to 2 August 1935, was remarkable not only because splendid weather prevailed for the duration but also because the morning session of the first day was devoted to a symposium on 'epilepsies', considering the aetiology, pathogenesis, physicochemical factors and treatment of the disease. Nor was that the end, for another 40 papers on the

a meeting of those particularly interested in epilepsy was held on 31 July 1935, at Lingfield Colony. The superintendent of the colony at the time was J. Tylor Fox,<sup>51</sup> who was to remain an active member of the League's governing body until his death in 1948. Thirty-two doctors representing 14 countries were present, and at lunch that day at the nearby Dormans Park Hotel, they decided to relaunch the ILAE. 'After discussion', Schou wrote:

subject featured among 250 other 'short' talks on neurology presented in the afternoons. The *Lancet* and the *British Medical Journal* provided generous coverage. Lennox showed definitively that generalised cerebral anaemia was not the cause of spontaneous seizures, and transfixed the audience with a display of EEGs from patients. In one of two talks that he gave, Muskens pronounced epilepsy the 'Cinderella among diseases' in terms of institutional care. Wilder Penfield (transformed in a *New York Times* dispatch to 'Wilded Winfield') presented the results of 75 surgeries on the skulls of epileptics. The congress sat in the large hall of University College on Gower Street. Sir Charles Sherrington was initially to have presided, but ill health prevented him, and Gordon Holmes assumed the role. Otfried Foerster gave the Hughlings Jackson centenary lecture (each delegate also received a medal in commemoration of Jackson). Ivan Petrovich Pavlov, then 86, travelled all the way from Leningrad to London to read a paper on canine temperaments to a packed audience, and afterwards had to fight off autograph seekers. Egaz Moniz, also in attendance, later claimed to have conceived the idea of lobotomy at the 1935 congress. The social programme included receptions at Lancaster House and at the Royal Society of Medicine, and an official banquet at the Grosvenor Hotel. In its report of 10 August, the *British Medical Journal* noted that the congress was distinctive for being 'predominantly German-speaking, but except in the business sessions there was no demand for interpretation, and apparently everybody understood everybody else. Even humour ... gl[ot] across.'

<sup>51</sup> J. Tylor Fox (1884–1948) was superintendent of the Lingfield Epileptic Colony from 1916 to 1946. He came from an old Quaker family, many of whom were doctors, and his father was a member of the Royal College of Physicians. He qualified in medicine from Cambridge and the London Hospital in 1910. In 1916 he went out to Russia with the Friends' War Relief Expedition and on his return took up his work in epilepsy. The Lingfield Colony was founded by the Christian Social Service Union initially as a home for unemployed epileptics, and Fox greatly increased its scope and in particular formed a school for 250 children, the largest of its kind. He was a reticent person who wrote little, but was deeply caring and committed. His obituaries mention his compassion and 'his great tolerance to the frailties of human nature', his many friends and his devotion to his clinical and social work on behalf of epilepsy. He worked indefatigably to alleviate the problems of education and employment, and was world-renowned for this aspect of his work. He was president of the British branch of the League, chairman of the Epilepsy Committee of the Association for Mental Health and also chairman of the Lebanon hospital in Beirut at the time of his death (Obituary 1949; Williams 1949).



Dormans Park Hotel Lingfield in 1936 (photographed by Francis Frith). It was during lunch at this hotel, on 31 July 1936, that the 32 doctors present resolved to relaunch the ILAE and where it was decided to propose the appointment of William Lennox as the new president. The formal proposal was made and accepted on 2 August at the 2nd International Neurology Congress. (Courtesy [www.theweald.org](http://www.theweald.org))

It was unanimously decided that the International League Against Epilepsy should be revived ... At the adjourned meeting on August 2nd, with Prof A. Ley of Brussels in the Chair, the following officers were elected:

President: William G. Lennox, Boston, USA

Vice president: L.J.J. Muskens, Amsterdam, Holland [although by October 1936, Wilfred Harris, London, UK, seems to have replaced Muskens, who died in 1937; and then Stauder from Munich in 1938 or 1939]

Secretary: H.I. Schou, Dianalund, Denmark

Treasurer: Tylor Fox, Lingfield, Surrey, England

All persons interested in improving the condition of epileptics are invited to join the League. Membership, which includes subscription to the periodical, is the equivalent of 5 shillings a year or 15 shillings for the four-year period. (Schou 1937, 9)

At the Lingfield meeting, it was also decided to revive *Epilepsia*, this time not primarily as a scientific journal but more as 'an organ for our league' as Schou put it. It was planned to publish the periodical annually, and the first issue appeared in February 1937.

It is interesting to note that only one of the officers of the reconstituted League was an officer in the organisation from 1909 to 1914, Muskens, although the chairman of the meeting on 2 August, Augustus Ley,<sup>52</sup> was also a founding member of the League in 1909. Muskens was previously secretary, and he wrote that in the post-war years he had taken repeated steps with his American colleagues to restart the international campaign against

epilepsy (Muskens 1937, 14–22). This was in vain, until in 1931, at the International Neurological Congress in Berne, representatives from six or seven countries met, although nothing seems to have developed from this meeting.<sup>53</sup> The first fruitful discussions took place at the 1935 London congress (The 2nd International Neurology Congress, and the centenary of Hughlings Jackson, for whom a medal was struck; Reynolds 2005).

<sup>52</sup> Auguste Ley (1873–1956) studied medicine in Brussels.

He spent 9 years in Anvers working as a doctor and organising teaching for backward children. Indeed, he pioneered the study and care of abnormal children. He also was one of the first to use and to advocate lumbar puncture, in the face of considerable opposition. He similarly circumvented scepticism concerning malarial treatment for paresis by taking one of his patients to Holland and returning with a stock for supplying asylums in Belgium and France. He laboured for better pay for psychiatrists, and he established examinations for asylum heads. He was active in both the temperance and international mental health movements. An article on the centenary of his birth called him 'an indefatigable agent of progress' (*Album* 1909, 45; Alexander 1973).

<sup>53</sup> Further correspondence from Meyer to Collier dated 1 July 1929 describes Muskens as badgering Ulrich 'to arrange an international meeting of those interested in epilepsy together with the 1931 Neurological Congress in Berne. Ulrich has not any great confidence in this scheme and would not like to work with Muskens' but fragmentary undated notes among Meyer's papers assert that 'the prime mover in the reorganisation is Dr Muskens.





William G. Lennox (1884–1960), a dominant figure in the ILAE after its rebirth in 1935.



Lennox's famous Seizure Unit at Children's Hospital, Boston.

A medal struck to commemorate the centenary of John Hughlings Jackson on the occasion of the second International Neurological Congress held in 1935 at University College London on 29 July to 2 August 1935. The congress coincided with the centenary of the birth of John Hughlings Jackson, and was held in Jackson's honour. S.A. Kinnier Wilson, the celebrated Queen Square neurologist and himself one of Jackson's students, was secretary-general of the congress, and it was he who arranged for all congress delegates to receive a copy of the medal. (Reproduced from *Journal of Neurology, Neurosurgery and Psychiatry*, E.H. Reynolds, 76, 858–859, 2005 with permission from BMJ Publishing Group Ltd)



The appointment of William G. Lennox<sup>54</sup> as president was highly significant, for Lennox became the dominant figure in the League for the next 15 years at least. It was he who maintained the organisation through the disruption of the Second World War, and he who very much directed the agenda of the League during those years. Lennox later wrote that, at the Lingfield meeting, Muskens urged that the presidency of the newly formed

ILAE should be an American uninvolved with the politics of Europe, which had proved so disastrous. Lennox wrote that he was in Lingfield as ‘an innocent bystander’ in place of [Stanley] Cobb, who had been unable to attend at short notice (Lennox 1952b; Goodkin 2007). Nevertheless, the bystander was clearly ‘the right man in the right place’, and his presidency was to prove of great importance to the League.

<sup>54</sup> William Gordon Lennox (1884–1960) was probably the leading figure in American epileptology from the 1930s until his death, and he has been the subject of a number of laudatory notices and articles (Cobb 1961; Lombroso 1988; Millichap 1990). He was born into a wealthy family in Colorado Springs and attended Colorado College. He had hoped to attend Boston University Divinity School, but when he was rejected because of a weakness in Latin and Greek, he turned to medicine and entered Harvard Medical School. He then spent 4 years as a medical missionary in China at Union Medical College. He became interested in epilepsy for personal reasons. It has been variably stated that his daughter, Margaret (the future editor of *Epilepsia*), had epilepsy and that an 8-year-old daughter of a friend was afflicted with the condition. Certainly, there was epilepsy in his family and his book of 1960 reports petit mal seizures in his niece, with her EEG. He returned to the United States and began a long career at Harvard Medical School in 1922. There he collaborated and published over 240 papers, including landmark works on the newly developing technique of EEG with Stanley Cobb and Erna and Frederic Gibbs. Lennox was the elected president of the International League Against Epilepsy from 1935 to 1946, and was the official editor of *Epilepsia* from 1945 to 1950 (although de facto editor from 1939). He wrote, with Margaret Lennox, a standard work, *Epilepsy and Related Disorders* (Lennox and Lennox 1960), which was completed days before his death. His writing has a curious flowery alliterativeness, perhaps reflecting his interest in Chinese language, which he had learnt while abroad. His contribution to epilepsy was largely in the fields of EEG, therapy and descriptive semiology. He described absence status and wrote extensively on absence epilepsy and on twin studies and other aspects of epilepsy genetics. Lennox–Gastaut syndrome was described in part by Lennox and named after him. His contribution to the ILAE was immense, and among his achievements were the maintenance of the organisation and its journal through the war years, his involvement with the layperson’s league and its close association with and financial support of the ILAE. He was also chief of the seizure division at the Children’s Medical Center in Boston, and from this unit were published many papers. Experimentation and investigation were the mainstay of his practice, and Millichap provides a vivid picture of the unit: ‘Almost all his patients would form part of a study: a trial of a new drug, an electroencephalographic study of twins or relatives, biochemical and blood flow studies, and the investigation of psychological factors. All aspects of epilepsy were studied, and a team of secretaries were at hand to aid with the many publications produced in his Seizure Unit. In 1951 Lennox won the Lasker Award for his efforts’ (Millichap 1990). The ‘Seizure Unit’ became the most famous epilepsy unit of its time, and trained many students – all of whom were devoted to and admired Lennox. The directorship of

the unit passed to one of these students, Cesare Lombroso, after Lennox’s death.

Although Lennox was a tireless campaigner for the alleviation of the social problems of epilepsy, he was also involved with the eugenics movement, as indeed were many of the early members of the ILAE. This appears paradoxical from the perspective of today, but Lennox himself clearly saw no contradiction. In 1938, he gave a notorious lecture to the Harvard Phi Beta Kappa, recommending both sterilisation and euthanasia for ‘the congenitally mindless and for the incurable sick who wish to die’. He was an economic hawk, and one stated reason for his eugenic view was that the mentally handicapped were an unacceptable drain on societal resources. Perhaps another was his desire to remove the stigma from epilepsy and to emphasise the normality of most sufferers (including his own daughter). He wrote up the lecture in the same year, in which he stated, ‘The principle of limiting certain races through limitation of off-spring might be applied inter-nationally as well as intra-nationally. Germany, in time, might have solved her Jewish problem this way’ (Lennox 1938). Other aspects of Lennox’s medical eugenics are covered in a recent article by Offen (2003), and make uncomfortable reading. In 1943, Lennox joined the advisory council of the Euthanasia Society of America (later known as Partnership for Caring). In 1950, he wrote an article titled ‘The Moral Issue’, calling for the mercy killing of ‘children with undeveloped or misformed brains’ as a way of opening up space in ‘our hopelessly clogged institutions.’ He was, in fact, a leading figure in the eugenics and euthanasia movements in the United States: from the early 1930s, and for at least 20 years, Lennox was instrumental in bringing what was then a minority interest to the forefront. This aspect of his life was previously rather overlooked but has attracted considerable recent commentary. Interestingly, eugenics does not feature prominently in his 1960 textbook (with Margaret Lennox), and he may have tempered his views by then. Part of the impulse to eugenics was economic; throughout his life Lennox was interested in the subject and right wing in his thinking about it, a strong advocate of competition and ‘survival of the fittest’ and an enemy of social welfare.

His personal life is less well documented. He was rather stern and notoriously prone to periods of silence. His students retained fond memories of him. Lombroso has written that he was not interested in academic pursuit and that he was not made full professor at Harvard because of this (and envy of his fame), although his eugenics activities may also have been a factor. He retained an admiration for Chinese culture dating from his early experiences. He retired from Harvard in 1958 at the age of 74 years and died 2 years later from a stroke which occurred while he was speaking at a dinner at the Harvard Club in his honour.

From the beginning of his leadership of the ILAE, Lennox assumed an active role and wrote regularly in *Epilepsia*. In his first article Lennox provided the following *raison d'être* for the new ILAE, which should 'forward the fight against epilepsy' in the following ways:

1. By collecting and presenting detailed information concerning the extent of epilepsy and the institutional care available for epileptics in the various countries of the world.
2. By encouraging investigation and by facilitating the spread of new knowledge gained among both physicians and the public.
3. By personal acquaintance of those most interested in the problem through visitation and through attendance at the International gathering every four years. (Lennox 1937a, 7)

This vision was similar to that of the ILAE founders in 1909, and like Marie, Lennox presented his own version of a work plan for the League.<sup>55</sup> The emphasis on institutions and asylums (colonies) in the earlier League though is now less prominent, and Lennox, who was not an alienist, was keener himself on research, publishing literature reviews and disseminating clinical information.

It was proposed that the League would meet every 4 years in place of the earlier regular annual meetings; and the next congress would take place in 1939 in Copenhagen. It was also agreed that *Epilepsia* should appear every year instead of four times a year, and in a changed form (Schou 1937, 12).<sup>56</sup> This 'second series' of *Epilepsia*, now owned by the League, was edited by Schou 'in collaboration with Tylor Fox, Lennox and Muskens'. Neither *Epilepsia* nor the League any longer had a *comité de patronage*.

Other changes were also evident in the first period of the revived ILAE. Perhaps the most important was the much greater contribution to the activities of the ILAE from the Anglophone world. Reflecting this, the pages of *Epilepsia* were now largely in English, with few contributions from continental Europe generally, but especially from Germany and the Central European countries –

thus had the world changed generally after the First World War.

The League in its newly revived form consisted of only three chapters: the American, British and Scandinavian branches. Membership lists were published in *Epilepsia* and show the radically changed form of the League in this second period. By the end of 1936 there were 248 members: 86 members in America; 102 in Britain; 31 from Scandinavia (Sweden, 11; Norway, 5; Denmark, 14; Finland, 1); and also 29 members from countries without chapters.<sup>57</sup> The three chapters each published their annual reports and national statistics, and the American and British branches also published their constitutions.

Lennox reported that American members of the International League (including those in Canada) had organised themselves into an 'American Branch of the League' (see below) that met for convenience during the annual meeting of the American Medical Association.<sup>58</sup> Lennox also mentioned that the former National Association had become affiliated with the American Psychiatric

<sup>57</sup> These members were from countries in three areas: Europe – Austria 1, Belgium 1, Czechoslovakia 1, France 1, Germany 2, Holland 2, Italy 3, Poland 1, Romania 1, Spain 3, Switzerland 2, USSR 2. Countries in the British Empire – Australia 1, Egypt 2, India 1, Palestine 1, South Africa 1. South America – Brazil 2. Thus, members from Anglophone countries accounted for 195/248 members, and this replaced the representation from Central and Eastern Europe which was predominant in the earlier period.

<sup>58</sup> The programmes of early meetings of the ILAE's American chapter were published in *Epilepsia*. The second meeting, on 7 June 1937 at Temple University (Fay 1938), for example, demonstrates the vitality of the group. (The first meeting, in Kansas City, in 1936, was not recorded officially, although a letter by Lennox describing it exists: see below.) Fifty-four members were present. Dr Temple Fay was now president. The programme included a demonstration by W. Edward Chamberlain of a glass model of the physio-dynamics and hydraulics of CSF; papers by Michael Scott on his plan of an ideal epileptic institution, by Temple Fay on the treatment of convulsive patients, by Dr Pigot on the structural inadequacy of the base of skull, and problems of institutional care and supervision, and by Ernest Spiegel on the cortical relationships of the 'delta' rhythm and a demonstration of his new methods for producing convulsions in rabbits by an electrical current passed through the eyeballs – and the effects of antiepileptic drugs on this (this was the immediate precursor of the method subsequently adopted by Merritt and Putnam for the discovery of phenytoin). The programme also offered a visit to the Skillman Colony for epileptics, where 'many interesting types of convulsive state were demonstrated'. The 6 June 1938 American branch meeting was held in San Francisco at a joint meeting with the Section on Convulsive Disorders of the American Psychiatric Association (McQuarrie 1939, 224–226).

<sup>55</sup> Lennox wrote about the activity of the League (Lennox 1937a, 8). 'Immediate measures which can be taken: ... 1. Printing annually of a news sheet such as this [*Epilepsia*], containing general information of value to all those interested in epilepsy ... 2. Dissemination of scientific information by means of an exchange of reprints and also by the preparation and publication of a review of the recent literature on epilepsy throughout the world ... 3. The securing of grants and gifts for more intensive research and for more adequate care of epileptics.'

<sup>56</sup> See Chapter 7.

## 28 International League Against Epilepsy 1909–2009 A Centenary History

Association to become the Convulsive Section of the Association, and the American Branch of the League planned to hold joint sessions with this section. Another break with the past was Lennox's comment that members of the Convulsive Section were more concerned with institutional care, whereas the American branch was composed mainly of those interested in research and treatment of extramural patients. One wonders if this departure from the former national association reflects a political schism or simply the evolving focus away from psychiatry and institutional care. The constitution of the American League was also published in *Epilepsia* (Constitution 1937, 33–34). Finally, Lennox contributed a paper on the institutional care of epilepsy in the United States, and details of the number of cases dealt with in institutions and hospitals, and outpatients and their costs. He contrasted the large, publicly supported colonies in the United States with the colonies in Britain and Europe, which were usually governed by philanthropic, often religious, private organisations. As he wrote 'I, myself, believe that while the class of "hopeless" epileptics can probably be given custodial care most cheaply in a large public institution, remedial treatment of incipient cases should be made available in small, well staffed, highly-motivated institutions, such as exist at Lingfield in England, and Filadelfia in Demark' (Lennox 1937b, 39).

<sup>59</sup> Details of the first two meetings of the British Branch were also published in *Epilepsia*. The first meeting was held on 16 October 1936 in the Medical Society of London (10am–4pm), and 35 members were present. The following officers were appointed: president, Wilfred Harris; secretary, Macdonald Critchley; treasurer, Tylor Fox; hon. member of council, W. Aldren Turner; other members of council, Douglas Turner, G.W.B. James and Edwin Bramwell. The constitution was approved. The subscription rate was increased from 2 shillings and 6 pence (£5.84 in today's currency) to 5 shillings (£11.67), with a 5-year subscription of £1 (£46.70). Seven scientific papers were read: Douglas McAlpine on two cases of traumatic epilepsy treated by surgery; Gwenvron Griffiths on periodicity in epilepsy; Norwood East on epilepsy and crime; Frank Schneider on epilepsy in delinquent defectives; W. Russell Brain on further observations on the inheritance of epilepsy; Mayer-Gross on recent German investigations into the heredity of epilepsy; and Helen Murray on treatment of epilepsy with prominal. The second meeting of the British branch took place on 22 October 1937, with 32 members present. The officers were re-elected. Membership numbered 100. Six papers were read: F.R. Ferguson on the value of medicinal treatment in epilepsy; Dennis Brinton on bromides in epilepsy; Miller Page on prominal in epilepsy; T.A. Munro on myoclonus epilepsy associated with deaf mutism in five brothers and sisters; Grey Turner on the electroencephalogram in epilepsy; and Miller Page (again) on relief of epileptic attacks following pneumonia and blood-letting.

The British branch was reinstated in 1936, with Wilfred Harris as president and Macdonald Critchley as secretary; the first meeting was held 16 October 1936 at the Medical Society of London.<sup>59</sup> The constitution of the branch was published in *Epilepsia* (Constitution 1937, 43–44). An excellent paper was also published by Tylor Fox on institutional care for epilepsy in Britain.

The Scandinavian branch was formed on 5 September 1936, initially with 20 members and then 31. No scientific meeting seems to have been held, but Schou presented a well-documented paper on the institutional care of epileptics (Lennox 1952a). He deplored the fact that there were too few hospitals for patients and that epileptics still had to be treated at hospitals for the insane and feeble-minded. He also made a plea for more *real hospitals* (in distinction to institutions offering custodial facilities only). Improvements in the treatment of epilepsy, he concluded, had five elements: (i) earlier diagnosis, (ii) phenobarbital therapy, (iii) dehydration diet and borax, (iv) better treatment of complications (bad teeth, constipation, exanthema) and (v) better diagnosis of organic cerebral disease and its treatment by surgery. He noted that the sterilisation of non-symptomatic epileptics, compulsory then in Germany, was voluntary in Denmark and Sweden after petitioning the ministry of justice.

By 1938, branches were reported to have been formed in Holland<sup>60</sup> and in Czechoslovakia (7 members).

The first issue of the second series of *Epilepsia* ends with an article by Schou in which he reports that a proposal was made during the Lingfield meeting to send out a questionnaire to each of the countries represented by the League to ascertain information about the institutions for epileptics in each country. The questionnaire was designed to be simpler than that of Friedländer and Vogt sent out in 1910, which generated few replies. Questions were asked about institution and support; the number, sex, age and types of patients; the number of medical and nursing staff and other employees; future plans; and financial information such as charges, annual expenditure and sources of support. The results from Britain, the United States and Scandinavia were published in

<sup>60</sup> In Holland, a Nederlandse Vereeniging van de ILAE had existed since 1909 next to other organisations involved in epilepsy. Following the Lingfield meeting all these organisations met (23 October 1936) to form a Federation of Associations and Persons engaged in the Fight Against Epilepsy which then became the official member of ILAE.



H.I. Schou (1886–1952), an important figure linking the pre-First World War and the post-Second World War ILAE. (Courtesy Danish Epilepsy Centre, Filadelfia)

the first issue of *Epilepsia*, and from Germany, Holland, Belgium, Czechoslovakia, Romania, India, South Africa and Australia in the second issue. Schou summarised his findings in a paper presented to the 1939 congress and published in *Epilepsia* (Schou 1940). This was an excellent record of the state of outpatient and institutional care around the world. He found that the best treatment of epileptic patients was in Holland, England, Germany, Switzerland and Scandinavia. He recommended a system of care that distinguished fresh and acute cases, chronic cases and insane epileptics. His ideas were not far from those of today, and set a rigorous standard for the age. His final remarks, echoing Lennox, were a plea for the establishment of a laymen's league.

In the April 1939 issue of *Epilepsia*, Lennox published a paper titled 'The Future of the International League Against Epilepsy' which provides some interesting historical detail and insights into Lennox's vision. He urged that branches be set up in as many countries as possible, 'for the ability of an organism to reach its destination depends on its legs and on its powers of coordination. In our organisation, the branches in various countries are the limbs, and the officers and *Epilepsia* provide for coordination'. Size is

no bar – and he cited the example of Czechoslovakia. He lamented the lack of interest in France, Germany and Italy. He then turned his attention to *Epilepsia* – 'All are agreed that the first and foremost enterprise [of the League] is the publication of *Epilepsia*.' Funds were not sufficient to meet the cost of the journal, and he urged either that dues should be increased or that money be secured from donations from relatives or from a laymen's society. He ended his paper with a curious message: 'The International League Against Epilepsy is an unselfish effort to assist an unfortunate group of the population. It is a patriot effort to do away with the economic losses which epilepsy causes. The officers of the League are determined to do their part in keeping the organisation alive and growing no matter what may come. The world is desperately in need of people who will work together for the good of mankind. Therefore, in addition to scientific and humanitarian aspects our League plays a part in maintaining the stability of civilisation' (Lennox 1939b, 176).

Unfortunately, this sentiment was overoptimistic, as within 6 months the world was again engulfed in war.

The 3rd International Congress of Neurology took place in August 1939 in Copenhagen, and a sectional meeting of the congress, on Thursday 24 August, was held by the ILAE. The League now had four chapters: United States (129 members), Britain (105 members), Holland (49 members) and Czechoslovakia (11 members). At the meeting were about 50 persons from the congress and 'several members of the League'. The constitution of the ILAE was proposed and approved. Then the officers were appointed, for up to then only a provisional board had been in place 'for the commencing period'. It was agreed to appoint the current provisional board, which included as president, Lennox; vice-president, K.H. Stauder (Germany); treasurer, Tylor Fox (England); and secretary, Schou. Exactly when Stauder was appointed to the board in place of Muskens, and then Wilfred Harris, is unclear (presumably 1938 or 1939), and it seems a remarkable choice as Germany had no chapter and also as the countries were about to lock horns in war. The first treasurer's report was presented, which showed income of £105<sup>61</sup> and

<sup>61</sup> The figures on this page calculated in today's equivalents work out as follows: £105 (£4,474), £44.1.7 (£94), 4s (£8), £1 (£43), \$293 (£2,815), £105.32.6 (£4,679), £30.12.2 (£1,343), £5.8.9 (£239), £70.11.5 (£3,097), £50.6.8 (£2,209) and £4.3.5 (£183).



The famous mural in the Montreal Neurological Institute (MNI), entitled 'The Advance of Neurology'. The Institute was founded in 1934 by Wilder Penfield, partly with a \$1.2 million grant from the Rockefeller Foundation.

The mural was painted by Mary Filer, a nurse at the institute, who appears in the picture both as the nurse with her back to the viewer and also as the patient herself. Folklore has it that she was painted uncovered in the original and that Penfield insisted on repainting in more decorous attire. The picture also contains a rather random sample of historical figures and Montreal luminaries. Amongst the former are the bare-chested Hippocrates, Jean-Martin Charcot, Claude Bernard, Wilhelm Erb, Constantin von Monakow, Ivan Pavlov, Alois Alzheimer, Silas Weir Mitchell, William Osler, Franz Nissl, Santiago Ramón y Cajal, Charles Sherrington, Camillo Golgi, Victor Horsley, John Hughlings Jackson and Harvey Cushing. Amongst the local Montreal personages are Wilder Penfield (twice!), Theodore Rasmussen and Herbert Jasper, who is seen reading the EEG. Penfield is shown also operating on a patient – and is it not too fanciful to think this may well have been a temporal lobectomy, an operation which, if not actually invented there, was perfected at the Institute?

The MNI has from its inception had a major interest in epilepsy, and its directors include three famous figures in the world of epilepsy – Penfield himself, Rasmussen and William Feindel (b. 1918).

Penfield (1891–1976) has been called the founder of Canadian neurology, and was indeed one of the major figures of the 20th century in the field of epilepsy research. He was born in Spokane, Washington, received his B.Litt from



Princeton and spent several years as a Rhodes scholar in Oxford. It was there that he fell under the influence of Sherrington and developed an interest in physiology. He completed his medical training at Johns Hopkins, and then spent time in London at the National Hospital from where he published his first neurosurgical paper, at the Presbyterian Hospital in New York and then in Breslau with Otfried Foerster for six influential months. On his return to Montreal, Penfield pioneered the temporal lobectomy, devised cortical maps of the sensory and motor areas of the brain, conceived a concept of centrencephalic epilepsy and carried out ground-breaking surgical research. His magnum opus, co-written with Jasper, was *Epilepsy and the Functional Anatomy of the Human Brain*, published first in 1951.

Jasper (1906–1999) was a pioneer in the field of EEG and it was he who introduced Penfield to the technique. Penfield persuaded Jasper to move to Montreal where he founded the EEG laboratory at the MNI, and in their famous collaboration Jasper carried out the EEG while Penfield operated. It was probably Jasper who first recognised the importance of the mesial structures, and he trained a whole cadre of electroencephalographers, including Pierre Gloor.

Penfield was director of the institute from its inception in 1934 until 1960 when he was succeeded by Rasmussen (1910–2002). Rasmussen carried out remarkable long-term follow-up studies of surgically treated patients which helped define outcome and prognosis, and also researched the eponymous disease Rasmussen's encephalitis.

Feindel succeeded Rasmussen as director in 1972 and continued in this post until 1984. He was also a Rhodes scholar and distinguished neurosurgeon who continued the tradition of epilepsy surgery at the institute. (Courtesy Montreal Neurological Institute)

expenditure of £44, 1 shilling and 7 pence (see Appendix 4). The delegates then went on a tour of the Filadelfia colony at Dianalund.

Lennox wrote about the congress (Lennox and Lennox 1960): ‘In the midst of this congress the German forces began their blitzkrieg. The banquet was a tragic affair. There were brave speeches for freedom but silence on the part of German colleagues. Delegates who were neighbours of Germany began leaving for whatever fate might meet them.’

The meeting also approved one of Lennox’s personal projects, which was the establishment of a ‘laymen’s league’ in America, whose ordinary members would pay annual dues of \$1.00 (4 shillings) and whose sustaining members would pay \$5.00 (£1) annually. All members would receive an eight-page bimonthly bulletin, and the sustaining members would also receive *Epilepsia*. At its inception, Lennox had managed to attract 223 ordinary members and 147 sustaining members and also a special donation of \$293. The money raised was designed to help *Epilepsia* continue publication in spite of the disturbed world conditions (Lennox 1940, 261–262).

The annual accounts for the years 1937–1939 were published in *Epilepsia*. The maximum income during this period was £105.32.6 in 1938, and this was raised from three sources: membership subscriptions (four chapters and individuals) at £30.12.2; *Epilepsia*, £5.8.9; and donations (‘for *Epilepsia*’), £70.11.5. During the same year, the expenditure was £50.6.8 on *Epilepsia* (printing and translating) and £4.3.5 on costs from the secretary and treasurer. Clearly, Lennox was right when he recognised that the costs of *Epilepsia* could not be met simply through subscriptions, and in those days donations formed the major part of income. The Laymen’s League was the main source of these donations.

At the end of 1939, the secretary reported that there were 140 members of the American branch, 106 members of the British branch and 35 members of the Scandinavian branch. No mention was made of Czechoslovakia or Holland (Lennox 1939b, 174–176). He reported that the American branch had met in Chicago on 8 May, but the meetings of the British and Scandinavian branches were cancelled because of the war. A letter to the American League dated 1 December 1939 and signed jointly by Lennox and Stanley Cobb (then president of the American League) reported that ‘the meetings of the International League against Epilepsy in Copenhagen the 25th and 27th

of August went off well in spite of the very tense political situation at the time. A constitution was adopted, the officers were re-elected, and resolutions were adopted approving the action of the American branch in organising a Laymen’s League against Epilepsy’ (Lennox and Cobb 1939).<sup>62</sup> The meeting was the last of the International League until 1946.

### The ILAE during the war years: 1939–1945

Lennox’s hope that *Epilepsia* could be kept going was realised, and the journal continued in its second series until 1950. However, as war developed, Schou found it impossible to continue to edit the journal. The task fell to Lennox, who became the de facto editor (although Schou continued to be listed as editor on the title page until 1947).

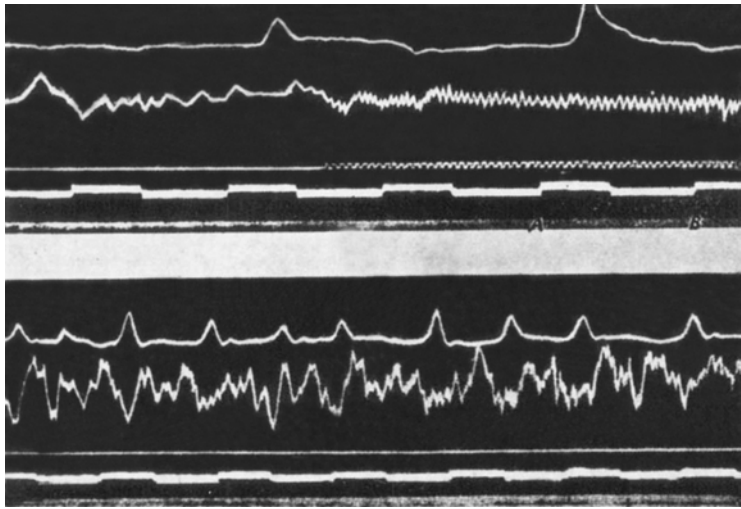
The League also continued to exist throughout the war years, in contrast to its collapse during the First World War, although the only activity was in America. In this sense the organisation was no longer international. But without the American branch the League would certainly have ceased to exist, and it is doubtful that its recovery after the war would have been as rapid as it was. Not only did the American branch keep the flame burning (as Lennox put it), but it also ensured the continued publication of *Epilepsia*.

The membership of the American branch rose from 136 in 1940 to 194 in 1946. The dues collected on behalf of the International League (50% of the dues) were used to defray partly the costs of *Epilepsia*, and in those years the journal in effect belonged to the American chapter,

<sup>62</sup> On 31 January 1939, Lennox had already written to the American branch, ‘The 1939 issue of *Epilepsia* with announcement regarding the Copenhagen meetings should be in your hands this spring. Our editor, Dr Schou, has many difficulties with which to contend and for fear the issue may be delayed I announce that the business meeting of the International League will be in Copenhagen August 24th at the time of the International Neurological Congress. The League will not hold a separate scientific program. Those who wish to read papers on epilepsy should submit them through the regular channels of the Neurological Congress, membership in which is readily obtainable’ (Lennox 1939a).



The first published photograph of an EEG in epilepsy. The record reads from right to left, the uppermost trace IV being the heart, III the cortex, II the stimulus and I the time line. The lower strip (numbered 4) follows the upper one. (From N. Cybulski and S. Jelenska-Macieszyna, *Bulletin of the Academy of Sciences Cracow*, Ser. B, 776–781, 1914. This was published by Mary A.B. Brazier, *Epilepsia* 1, 328–335, 1959/60.)



comprising only the annual reports of the American chapter and the Laymen's League, a few papers concerned with US epilepsy practice and developments, and Lennox's annual review of the published epilepsy literature (taken from the newly formed *Cumulative Index Medicus*). Most of the pages of this journal were written by Lennox, and his influence was all-embracing.

Lennox later remembered 1939 as a 'good year' (Lennox 1941, 12). A seemingly bizarre sentiment, but in one sense he was curiously right, as it was indeed an important year in the field of epilepsy. Phenytoin was being investigated in clinical settings for the first time and the new technology of electroencephalography (EEG) was being assessed, with EEG machines being installed in several North American institutions. In Lennox's annual review of the epilepsy literature in 1939, there were 285 articles and, as he noted, the principle contributions, in contrast to previous years, were articles on EEG and on the use of phenytoin. Both remained the topics that were to produce the greatest single number of scientific articles throughout the war, along with those on the effects (surgical, social, psychological) of war on epilepsy. The interest in eugenics and heredity disappeared. By 1945, however, the pace of change had weakened and Lennox's annual review contained 195 publications. He wrote, 'No startling discoveries have been announced. Electroencephalography continues to attract investigators' (Lennox 1945, 14).

The vigour of the American branch can be seen from the programmes of its meetings, which were published annually through the war years in *Epilepsia* (meetings were held each year except 1945), and which included regular presentations from such figures as Lennox, Frederic Gibbs, Wilder Penfield, Herbert Jasper, Ernest Spiegel, Israel Wechsler, Houston Merritt and Tracy Putnam. In 1943, a special session was held on the subject of post-traumatic epilepsy in relation to war, with a guest lecture from Geoffrey Jefferson from Manchester titled 'The Post-operative History of One Hundred Craniotomies Performed During the Last War'. Lennox was opposed to the publication of the lectures of the branch on grounds of cost, but it remains a pity that at least the abstracts of the lectures given during this period were neither preserved nor published in *Epilepsia*.

The absence of another topic – the treatment of epileptic patients in institutions by the Nazi government during the war – is a striking omission from the pages of *Epilepsia*. This was the time when patients whose epilepsy was considered hereditary and who were fit to reproduce, were compulsorily sterilised in several countries, and later in Germany put to death. The (pseudo-) intellectual underpinning of this policy was based on the work of the eugenicists of the period. Lennox, Stauder and Schou were all active eugenicists and supported compulsory sterilisation in their own countries – and in the United States and a number of continental European countries,



Cemetery for victims of euthanasia killed at Hadamar, Germany, 1945. The euthanasia programmes of the Nazis of the handicapped were carried out initially in an action called 'T4' and later by other programmes. Doctors provided the names of the victims, and assessment forms were completed. The victims were moved to former psychiatric hospitals, castles or prisons, such as at Hartheim, Sonnenstein, Grafeneck, Bernburg, Hadamar and Brandenburg, where they were killed by gassings or legal injections. Workers then removed the corpses, extracted gold teeth, and burned large numbers of bodies together in crematoria. Physicians using fake names prepared death certificates falsifying the cause of death, and sent letters of condolence to relatives. It has been estimated that between 200,000 and 250,000 mentally and physically handicapped persons were murdered from 1939 to 1945 under the T4 and other 'euthanasia' programmes. (Courtesy Holocaust Memorial Museum)

this policy was actively pursued.<sup>63</sup> In Germany the policy initially of sterilisation, which affected both patients living in society and also those in institutions, was then to be extended to actual murder (euthanasia), a policy that Lennox had earlier advocated for the United States justified on economic grounds (Lennox 1938). In September 1939, the Nazi government sanctioned the mass killing of

the severely handicapped living in institutions on the grounds of racial purity and economics (Burleigh 1997). Over 700,000 'hopeless' cases living in institutions for the mentally and physically handicapped were exterminated under a 'euthanasia' programme by the notorious Aktion T4, and its aftermath, and amongst them an unknown number of people with epilepsy.<sup>64</sup> Selection had to be made by the psychiatrists in charge of each institution, and if these did not cooperate, the institution would be visited by a committee who took over. At least half of the victims of Aktion T4 came from the asylums run by the Protestant Inner Mission and the Roman Catholic Caritas Association. Furthermore, the asylums during this period in Nazi-dominated Europe deteriorated physically and morally to a state described during later trials as a reversion to the psychiatry of the Middle Ages (Burleigh 1997, 228). There were exceptions, and notable among those who tried to prevent the full impact of the killings was Karsten Jaspersen, chief psychiatrist at

<sup>63</sup> The first papers on eugenics in *Epilepsia* appeared in 1913. Indeed, the minutes of the League's 1912 meeting in Zurich make plain the need to distinguish cases of hereditary epilepsy from other sorts to 'advance eugenics' (Secretaire 1912, 86). It is possible that this particular influence was American, although by then the appeal of the science was frankly universal. In any event, W.N. Bullard, Everett Flood, J.F. Munson and E.E. Southard, all American ILAE members, comprised the Committee on Heredity of Epilepsy of the Eugenics Record Office, in Cold Spring Harbor, as early as 1910. The purpose of the office (whose members included Alexander Graham Bell) was to study records and 'to educate the public as to classes of fit and unfit marriages'. In 1914, it published a report titled 'The Best Practical Means of Cutting Off the Defective Germ-Plasm in the American Population'. Among the various classes of the 'socially unfit', epilepsy constituted its own group: 'No clearer cases of specific hereditary degeneracy than those of epilepsy have been established' (Laughlin 1914, 25). However, the report was careful to specify that in its goal of breeding 'good Americans', euthanasia was no option: 'Preventing the procreating of defectives rather than destroying them before birth, or in infancy, or in the later periods of life, must be the aim of modern eugenics' (p. 55). The distinction is one that would later set Lennox apart: for in certain cases he did unapologetically argue for euthanasia (Lennox 1938).

<sup>64</sup> An analysis of patients who were victims of mass killings under the Aktion T4 programme, some of whose brains were removed for examination, shows a decided predilection among Nazi doctors for targeting the congenitally feeble-minded and all epileptics for such treatment. For example, out of a total of 32 minors with epilepsy killed on 11 June and 28 October 1940, all but one had their brains removed. By comparison, of 46 patients with developmental disabilities, brains were removed in only 15 cases (Pfeiffer 2005, 27, 28).

Bielefeld-Bethel and Nazi Party member, who, evidence suggests, contrived to mitigate the policy.<sup>65</sup>

All of this should have been of great concern to the ILAE, and yet no mention was made of it or eugenics in the pages of *Epilepsia*. History should be confronted – and not to do so betrays its victims. The ILAE failed to speak out for its patients and this is a subject still in need of full documentation. Lennox seems to have had a blind spot for the international issues of the time, and thus the extent to which the ILAE lost its international perspective during these years.

### ILAE during the early post-war period: 1945–1949

In the delayed publication of the 1945 volume of *Epilepsia*, without much ado, Lennox bid farewell to the ‘blackness of war’ and looked forward to ‘renewed interactions with the League’s transatlantic friends’ (Lennox 1945, 7). Schou stood down formally as editor of *Epilepsia* (he had in any case not carried out this function since 1939), and Lennox, who had acted as editor during the war years, was formally appointed. Two thousand copies of *Epilepsia* were printed that year, and advertising appeared (of Dilantin) for the first time in 1945, raising \$35 (£297 in today’s figures).

The British branch was reconstituted and held its first meeting at Queen Square on 7 December 1945. The programme was interesting for several reasons. There was an emphasis on the diagnosis of epilepsy in the military, with lectures on ‘Some Problems of Epilepsy in the Royal Navy’ (Fergusson), ‘The EEG and Water-Pitressin Test in the Diagnosis of Epilepsy in Service Cases’ (Dick) and ‘The Diagnosis of Unconsciousness in Aircrews’ (Alcock).

<sup>65</sup> Karsten Jaspersen’s actions were contentious. He was once a Nazi, and he complied with the Nazi government’s requirement to complete registration forms on the inmates of his institution. However, it is said that he did this in such a way as to obscure the extent of the handicap and thus save some from extermination. Peter Wolf points out, too, that they were very slow deliberately in completing forms and also ‘rewrote’ the patients’ files’. Jaspersen also collaborated with the religious authorities, especially the catholic bishop of Münster, Kardinal von Galen, who spoke out publicly against the policy in Sunday mass, and the leaders of the protestant institutions Lobetal (Pastor Braune) and Bethel (Bodelschwingh) who spoke against Aktion T4 behind closed doors. Although their action was clandestine, some residents of Lobetal and Bethel were spared, and Aktion T4 was subsequently called off.

There was also a new emphasis on EEG, and a lecture on the treatment of epilepsy by electrically induced convulsions (Caplan). Tylor Fox lectured on the ‘Progress in America on the Social Side of Epilepsy’, no doubt discussing the evolution of the Laymen’s League.

In America, the Laymen’s League made great progress during the war years. In 1946, its president, Mrs Gertrude Brooks Potter, was able to report that there were 1,989 members, that 7,000 or more sets of printed material had been distributed (articles, pamphlets and books), 10 articles published in the professional literature and three nationwide surveys completed. Chapters were being set up locally (at the city, state and regional level), and sample bylaws were produced for these chapters centrally. In 1945, the Laymen’s League had turned itself into a company with a new name – the American Epilepsy League, Inc.<sup>66</sup> In 1946, both it and the American ILAE chapter made presentations to a Congressional Labor Subcommittee which was investigating aid to the physically handicapped (the Kelly Committee). It seems clear that the dual approach of both a professional and lay organisation was a powerful lobby even in those days. The American Epilepsy League also distributed 5,000 copies of books by Lennox and Putnam,<sup>67</sup> and financially supported the continued production of *Epilepsia*. By now the organisation had 4 officers, a ‘board of medical advisors’ (8 persons – Abbott, Gibbs, Lennox, McQuarrie, Merritt, Penfield, Putnam and Ziskind), a ‘board of Sponsors’ of 10 persons, including Mrs Franklin Roosevelt, and a ‘Board of Directors’ of 11 persons. Mrs Potter, who had been the dynamo behind the setting up of the lay organisation, resigned as president in 1946 and was succeeded by Mrs Peter Miller.

<sup>66</sup> The objectives of the League were laid out in these sample bylaws, which give the perspective of the new organisation: 1. To encourage research in epilepsy; 2. To assist epileptics by developing in them a sound understanding of their ailments, by informing them of the opportunities for medical assistance and by making constructive suggestions to them relative to their education and employment; 3. To increase the public’s knowledge about and understanding of epilepsy; 4. To widen the opportunities of epileptics for education and employment (*Epilepsia* 1945, 87–89).

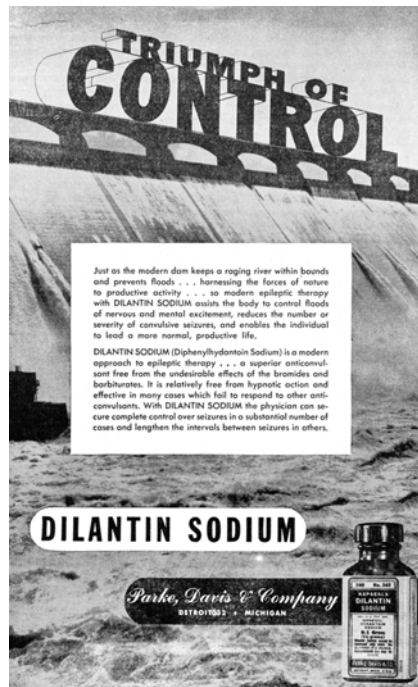
<sup>67</sup> The two books were probably Lennox’s *Science and Seizures* (Harper, New York), a book for laymen which entered a second edition in 1946; and Putnam’s *Convulsive Seizures: How to Deal with Them; A Manual for Patients, Their Families and Friends*, 2nd edn. (Lippincott, 1945). Lennox reviewing this latter book wrote: ‘A worthwhile publication of permanent value like this is dressed by war in thin shoddy clothing while papers and magazines are overdressed. All readers of *Epilepsia* should have a copy of this book’ (Lennox 1945, 16).

## 36 International League Against Epilepsy 1909–2009 A Centenary History

On 13–14 December 1946, the American branch of the ILAE held its first post-war meeting, in New York, jointly with the Association for Research in Nervous and Mental Disease (it was the 26th annual meeting of this organisation, to which Lennox had been appointed president the year before). This was a remarkable meeting with an excellent programme demonstrating the range and scope of American epileptology. The discipline had greatly developed during the war, stimulated by the introduction of EEG and of new drug therapies, and also the depressing fact that epilepsy was a common consequence of war injury. There were 44 lectures from members of the American branch, and one given by a foreign invited speaker (in the session on EEG by Grey Walter from Bristol titled ‘Analytical Means of Discovering the Origin and Nature of Epileptic Disturbances’). The papers from the American branch included contributions by Penfield, Jasper, Margaret Lennox, William Lennox, Merritt, Erna and Frederic Gibbs, Earl Walker, Pearce Bailey, Ziskind, Livingston, Robert Schwab, Potter and Fay. As Lennox wrote, ‘This two day session covered the various aspects of research in epilepsy with a completeness never attempted before’, a statement it is hard to disagree with. The pro-



Waldorf Astoria Hotel, site of the 1946 ILAE congress. (Courtesy the Picture Collection, the Branch Libraries, New York Public Library, Astor, Lenox and Tilden Foundations)



The first advertisements to appear in *Epilepsia* after the war were those for the antiepileptic drug Dilantin – in the style of the period, with an architectural image of power and control in the Albert Speer mode.

gramme included investigations in history, aetiology and experimental studies dealing with transmission of nerve impulses and electrophysical aspects. Major emphases of the conference were on EEG and newer therapies such as diphenylimide, Mesantoin, Tridione and dimethylethyl oxazoladine. Traumatic epilepsy as a byproduct of war was considered in five papers, including new techniques for operative surgery. Four papers dealt with psychosocial studies. In many ways, this conference was a prototype for the subsequent meetings of the American Epilepsy Society. However, a more international involvement had to wait until the next meeting of the International League, which was in Paris in 1949.

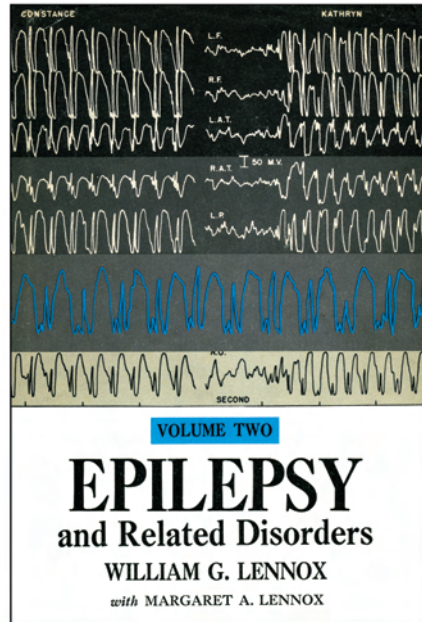
In 1946, Holland and Argentina formed branches of the League, bringing the number of branches to five. At the business meeting held on 13 December 1946, the officers of the League were elected as follows: president, Lennox (re-elected); secretary, Schou (re-elected); vice-president, B. Ch. Ledebøer (Heemstede, Holland); treasurer, Denis Williams (London, England); and editor of *Epilepsia*, Lennox (re-elected).

Tylor Fox from Lingfield stepped down as treasurer (and also as superintendent at Lingfield) as his health was failing. He died 2 years later. He was replaced by Williams, who was the doyen of British epileptology at the time, and who remained treasurer of the ILAE until 1953. This, too, was the year when Ledebøer, who was to become secretary-general in 1953, first appeared on the international body, and that saw the re-establishment of Holland, after the death of Muskens, as a leading country in the epilepsy movement.<sup>68</sup> This also constituted the last appearance of Schou on the international body. By 1948, he was no longer a member of the editorial board of *Epilepsia*. There were no Scandinavian chapter reports from these years and no mention of Schou nor thanks for his long service.<sup>69</sup> With his departure and the death of Tylor Fox, of the persons originally officials of the ILAE at its re-emergence in 1935, only Lennox remained active.

At the 1946 business meeting, Lennox was asked to appoint an editorial board for *Epilepsia* with representatives from each chapter (those chosen were Schou, Tylor Fox, Ledebøer, Cantlon from Argentina and C. Wesley Watson from the United States). Lennox also successfully moved that the American Epilepsy League (the lay organisation) should be named an affiliate of the International League and share editorial as well as financial responsibilities for the publication of *Epilepsia*. As a start of this collaboration, Lennox published in *Epilepsia* (1947) an article titled 'The Higher Education of Epileptics' by himself, Merle McBride and Potter of the American Epilepsy League. This was the only article in the issue, and presented the results of a survey of 1,676 US higher education institutions and the enrolment of epileptics in

<sup>68</sup> The Dutch branch later reported that during the German occupation, the Nazi takeover of Heemstede effectively put an end to all activities, 'the whole medical and nursing staff and the patients having disappeared "underground" or brought back to their relations at home'. The 'fresh start' that beckoned after liberation in 1945 was hampered, among other insults, by a 'scarcity of paper' (Glastra van Loon 1949, 11, 12).

<sup>69</sup> In reporting the news of the Scandinavian Medical Society for the Study of Epilepsies to another journal, H.P. Stubbe Teglbjaerg, Schou's successor in the society as well as the ILAE, wrote, 'On account of [Schou's] severe illness he was hindered in 1949 to join in the former Scandinavian neurological congress ... N.E. [the Scandinavian society] has since then been in a languishing state. The distribution of *Epilepsia* and of reprints of Scandinavian papers on epilepsy has been stopped for the last three years as well as the collection of subscriptions from the members of N.E.' (Stubbe Teglbjaerg 1954).



Lennox's two-volume opus, written with his daughter Margaret, was published posthumously in 1960.



Macdonald Critchley, urbane ILAE president from 1949 to 1953. (Courtesy Institute of Neurology, National Hospital for Neurology and Neurosurgery, Queen Square, London)

the institutions. The article gave advice to the admitting colleges and recommendations for action. The article was then distributed to the same institutions. It was the first of a series of surveys carried out by the American League and interestingly reflected the original idea that a primary function of the ILAE should be the collection of data for lobbying purposes.

On 14 September, Lennox (1948a) wrote to Francis McNaughton in Canada saying that he was ‘making a new letterhead’ in preparation for the League meeting in Paris.<sup>70</sup> He also said that he would like to see Adolf Meyer, head of the American chapter, replaced by Penfield, and would McNaughton ask him. He asked, too, for a progress report from the branch. The Americans must have been slow, for on 13 October, Lennox wrote McNaughton again saying that he could no longer delay the printing of *Epilepsia* waiting for a statement about the American Epilepsy League and encouraging McNaughton to help with a membership drive. ‘This action ought to be taken fairly promptly so that people will realise the [American] organisation is not a dead one.’ Another letter followed a week later saying Lennox was having made ‘a cumulative author and subject index for the past 12 years of the second series of *Epilepsia* – a laborious job’ (Lennox 1948b).

### 1949 Epilepsy Congress in Paris

In 1949, the International League met in Paris, in conjunction with the Congresses of the International Society of Electroencephalography and the International Neurological Congress. There were three sessions on epilepsy. The business meeting of the ILAE was held in Paris on 8 September 1949, and reference was made to a successful meeting which presented ‘a striking demonstration of the tremendous increase in knowledge and interest in epilepsy, especially through the domains of electroencephalography and drug therapy’. At the business meeting, a number of developments were recorded. It was agreed that there should be a secretary-general of the League stationed in Europe in order to stimulate the foundation of branches in Switzerland, Belgium, Spain and Italy. The League also accepted the application for membership of the French branch and the Argentinian branch. The French chapter must have been established rapidly, for only 1 year earlier, the absence of interest in the league

in France was lamented. In contrast the formal approval of the Argentinian branch was surprisingly late, for in fact, Argentina had been listed by *Epilepsia* as a member since 1947 and had published its annual chapter report since that time. This growth of chapters was the beginning of a process which was to continue to the present day. Thanks were sent to the American Epilepsy League for their contribution to the League in the past and for paying for the printing of *Epilepsia* (the 1946 number had cost \$1,900). By now it had been agreed that individual member dues would be paid to the national chapters and not the central body. It is not clear how this change came about, but possibly reflected the difficulties of international currency transfer rather than any strategic or conceptual change within the ILAE. One can presume, however, that it catalysed the transformation of the ILAE from an international membership organisation to what it is today, more a federation of national chapters. This is an important shift of emphasis which seems not to have engendered written commentary. It was agreed that each chapter should remit one-third of the sums collected from the dues of its members to the parent body. Officers of the ILAE were elected as follows – now an enlarged body, with some new positions (not mentioned in the constitution) and with a geographic representation which included all chapters except Argentina: president, Macdonald Critchley (London, England); secretary-general, Ledebøer; vice-president, H.P. Stubbe Teglbjærg (Dianalund, Denmark); recording secretary, Antoine Rémond (Paris, France); treasurer, Williams; editor of *Epilepsia* and honorary president, Lennox; assistant editor, Jerome K. Merlis (Framingham, United States).

This 1949 meeting was a watershed for the ILAE. Its business was conducted in a manner that set a pattern that was to continue to the present day (perhaps reflecting the influence of Critchley (by then with great experience of international bodies – and later to be appointed president of the World Federation of Neurology).<sup>71</sup> The appointment of Critchley is interesting in another

<sup>70</sup> An undated circular letter from Lennox reporting a ‘list of reprints by fellow workers and myself’ covering 1922–1948 bears the letterhead ‘La Ligue Internationale Contre L’Epilepsie’ (Lennox 1948a).

<sup>71</sup> Macdonald Critchley (1900–1997) was one of the most famous neurologists of his time. He was born in Bristol and qualified from Bristol University. His career was based at the National Hospital for Nervous Diseases at Queen Square. In his obituary in the *British Medical Journal*, Sir Roger Bannister had this to say about him: ‘His career was one of apparently effortless promotion on the national and international neurological scene, and he seemed to become president of every organisation of which he was a member (such as the Association of British Neurologists and the World

respect, for it was the last time that a general neurologist, without any particular specialism in epilepsy, was appointed to the presidency of the ILAE. This reflected the increasing specialisation in medicine generally in the second half of the 20th century, but also the rise of epileptology. The isolation of epilepsy from neurology would have been anathema to Critchley and carries risks evident even today. In 1945, Lennox began a sustained effort to persuade the American government to treat epilepsy as a particular specialty. As Lennox said to the Kelly Committee: 'Of all the handicaps which you and your committee are studying, epilepsy without doubt is the least understood by both the medical and general public and is the most neglected. Like the lepers of ancient times, epileptics still "dwell without the city" of public understanding and philanthropy ... Epilepsy', Lennox exclaimed, 'is not obvious. It has been neglected. It needs a place in the sun.' Partly as a result of his lobbying, the National Epilepsy Act of 1949 was proposed which included various training programmes, establishing a federal epilepsy information centre, providing facilities for research and admitting voluntary patients for treatment, awarding grants and establishing a National Epilepsy Council, consisting of governmental and private experts. This focus was ahead of its time, and the act was dropped. In response to the demands of several voluntary national health groups, however, Congress did establish the National

Federation of Neurology). Because of his eloquence and erudition he was much in demand, giving distinguished named lectures to many learned societies. A secret of his success was a facile and punctilious command of the written and spoken word. He also had an insatiable curiosity about medicine and people, coupled with an immense capacity for disciplined hard work. He was equally fastidious about dress and manners and for many years he hardly seemed to age. A particular characteristic was a wit which sometimes had a sharpness he was unable to restrain but it enlivened any topic on which he chose to speak or write. Few other neurologists this century, trained in the era before laboratory science was applied to neurology, had comparable linguistic and intellectual skills or applied them so widely or so successfully' (Bannister 1998). His contributions depended on clinical observation, not technology, and he had an extraordinary power of meticulous observation of human behaviour and cognition. His made definitive contributions to varied areas of neurology, especially to studies of parietal lobe function, dyslexia, migraine and Huntington's chorea. In all he published 19 books, masterpieces of style and conception, and his biography of Hughlings Jackson, written jointly with his wife, was published posthumously in 1998. He was interested in epilepsy but it was never his predominant concern. His contributions to epilepsy were to its more esoteric manifestations – and in particular to the study of reflex epilepsy, especially musicogenic epilepsy.

Institute of Neurological Diseases and Blindness in 1950 (Epilepsy Foundation of America 1974).

For the first time since the war, the ILAE had a truly international representation, but this development was accompanied by a reduction in the American contribution. For the first time in 15 years, the international body was not dominated by Lennox, and one senses that his interest and energies were beginning to wane. The American chapter also had grown enormously, and possibly also itself lost interest in the international cause. By 1950, its membership had risen to approximately 700, and it was now able to establish various national committees concerned with a variety of national issues. The Cold War was beginning. International hostility was increasing, and barriers were being raised in many areas of national life. The chapter had held its 1949 annual meeting 3 months before the Paris meeting, and one suspects there were



Letter from William G. Lennox to Paulo Niemeyer congratulating him on creating an ILAE chapter in Brazil, 1949. (Courtesy Elza Márcia Targas Yacubian)

few American contributors to the latter meeting. Perhaps most significantly, the American Epilepsy League also decided to reduce or withdraw its funding for *Epilepsia*. The precise reasons are not clear, but this action was instrumental in terminating the second series of the journal. The lay organisation itself merged in 1949 with the National Association to Control Epilepsy,<sup>72</sup> the focus of which was to provide national services at the state level. Presumably *Epilepsia* was not considered to be a priority for funds. It is not clear what Lennox's view about this was, but he must have been disappointed, as it ended the arrangement he had engineered and which had maintained the journal through the war years. The last issue appeared in 1950, in a very slimmed down form, and the ILAE executive then discontinued the production temporarily while a committee was set up to study its value and viability. Lennox ended his last contribution to the journal (the literature review of 1949) with a characteristic plea: 'The threat of war, or war itself, must not smother our interest or efforts' (Lennox 1950, 13).

### Afterword: The American chapters of the ILAE (section contributed by Howard P. Goodkin)

The influence of the American branch of the League throughout its history has been such that, at this juncture,

<sup>72</sup> It is not entirely clear why the American Epilepsy League merged with the National Association to Control Epilepsy, or indeed exactly what this latter organisation was. It may have been a section of the National Society for Crippled Children and Adults, a larger body which provided services at the state level and which, with the merger, agreed to make epilepsy one of its major interests. The merger seems to have changed the name of the epilepsy section to the National Epilepsy League. *Epilepsia* records the officers of this body, with some names familiar from the American Epilepsy League, as follows: president, Mrs Peter Miller; first vice-president, Fred S. Markham; second vice-president, Mrs Brooks Potter; treasurer, Walter J. Cummings; assistant treasurer, Paul C. Butcher; secretary, Gerard Ungaro. There were 14 directors and 32 members of its medical advisory board. *Epilepsia* also records that 'The Lay League desires full cooperation with the Physicians' League in their great joint task.' This new organisation seems to have been an effective one. Amongst its activities were assistance in drafting a law to provide compensation to an epileptic injured at work without penalising the employer; participation in a conference sponsored by the Federal Office of Education on special assistance in the education of children with epilepsy; and conferences with various state boards on the licensing of motor vehicles to persons with epilepsy (*Epilepsia* 1949, 4:9).

it is worth recapping its origins. The end of the 19th century in the United States saw the development of specialised hospitals and institutional colonies for people with epilepsy and the founding of the National Association for the Study of Epilepsy and Care and Treatment of Epileptics, an organisation solely devoted to improving the lives of people with epilepsy through research and education. This organisation was founded on the efforts of men such as the philanthropist William Pryor Letchworth, one of the founders of Craig Colony for Epileptics in Sonyea, New York; William P. Spratling, the colony's first superintendent; Frederick Peterson, president of the colony's board of managers; and General Roeliff Brinkerhoof of Ohio. Membership was open to all persons 'interested in the scientific study of epilepsy, or in the study of ways and means to improve the condition of epileptics, or in the sociological subjects generally' (Letchworth 1901). The association's earliest members included Pearce Bailey, William N. Bullard, L. Pierce Clark, Charles Dana, Abraham Jacobi, William Osler and Wharton Sinkler. In 1907, L.J.J. Muskens was listed as an associate non-voting member. In 1912, the association formally aligned itself with the ILAE, thus becoming the first American Chapter of the League (Shanahan 1913). When the ILAE met later that year in Zurich (6 and 7 September 1912), David Fairchild Weeks<sup>73</sup> of the National Association would preside over the meeting as the ILAE's president.

<sup>73</sup> David Fairchild Weeks was the first American president of the ILAE. Born in Newark, New Jersey, on 31 July 1874, Weeks was the son of Henry M. Weeks, the first superintendent of the New Jersey State Village for Epileptics at Skillman. After graduating from high school, Weeks worked in his father's office for 2 years (1893–1895) before entering medical school at the University of Pennsylvania. While at Penn, Weeks quarterbacked the football team to a national championship in 1897. After graduating in 1898, he served as a resident physician at McKeesport Hospital (McKeesport, PA), Cooper Hospital (Camden, NJ), and the Philadelphia Orthopedics Hospital and Infirmary for Nervous Diseases (Philadelphia, PA) as well as in unspecified epilepsy colonies in Europe. Before succeeding his father as superintendent at Skillman in December 1907, Weeks had a private practice in Trenton, New Jersey, specialising in treatment of nervous and mental diseases. He remained superintendent at Skillman up to the time of his untimely death of a presumed heart attack on 15 March 1929, at the age of 54. Weeks' research interests centred on the genetics and eugenics of epilepsy. Along with the eugenicist Charles Davenport, Weeks co-authored *A First Study of Inheritance of Epilepsy* (1911), which was based on pedigrees obtained from 177 patients at the State Village. In addition to his service to the ILAE, Weeks was active in a number of other professional societies, including an early incarnation of the American Association on Mental Retardation.



From the outset, the National Association had difficulty with finances (Spratling 1906; Munson 1911; Fine *et al.* 1994). In addition, it failed to attract a large membership because of its focus on the care of people within the epilepsy colonies. By the time of the reorganisation of the ILAE in 1935, the National Association was no longer autonomous, having merged in 1925 with the American Psychiatric Association (APA) (Collier 1945). Two years later, the National Association would become the APA's Section on Convulsive Disorder. As interests among its membership changed, the section's name, too, was modified, to Convulsive Disorders and Brain Function in 1957 and then Brain Function and Behavior in 1963. Eventually the section disbanded as the APA moved to a central programme committee to plan its annual meeting (M. Fink, personal communication).

Having been elected president of the newly reorganised ILAE in 1935, Lennox quickly set out to establish a new independent professional body to serve as the ILAE's American chapter. The founding meeting for this new organisation, initially named the American League Against Epilepsy, occurred in Kansas City, Missouri, in the Muehlbach Hotel on the evening of Tuesday 12 May 1936, during the 87th Annual Meeting of the American Medical Association (Lennox n.d.; Lennox 1936a,b; Goodkin 2007; Goodkin 2009). In addition to Lennox, others in attendance at that first meeting included the Gibbsses, Temple Fay, Ernst Spiegel, Leon Kanner, Dan Renner, Henry Woltman and Mynnie Peterman. The schedule of events included several scientific presentations, the election of officers and the skeletal drafting of a constitution.

In 1951, under the leadership of Francis M. Forster, a new constitution was adopted. Articles of organisation were filed in 1953 and legal establishment made official in 1954. In 1957, the chapter changed its name to the American Epilepsy Society (AES), a name that Lennox described as 'colorless and uncooperative'. His own preference would have been Epilepsy League of North America, which he argued recognised the ILAE's 'Canadian members and would display some originality' (Lennox and Lennox 1960). The name change was officially acknowledged in 1971.

Today, the AES serves as the US chapter of the ILAE. However, in keeping with Lennox's initial intent that the AES should be an inclusive professional society representing the interests of those in the United States

as well as other North American countries (Lennox 1956; Lennox and Lennox 1960), the AES has grown to a membership of more than 3,000 people from approximately 50 countries. The goals of the AES are to promote research and education of professionals dedicated to the prevention, treatment and cure of epilepsy. The AES support of these endeavours occurs in multiple forms, including its annual meeting, publication of *Epilepsy Currents* and research awards.

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