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## The relations of the International League Against Epilepsy with the lay organisations

*Harry Meinardi*

### Joint history of the ILAE and IBE

The impact of epilepsy on people is actually the province of two separate organisations. Celebrating the centenary of the oldest of the two, the International League Against Epilepsy (ILAE), should not eclipse the other. The ILAE was founded by physicians, but its original intent was clearly inclusive. Article IV of its first constitution stipulates: ‘Any person, who is interested either scientifically or practically in the work of the League can become a member of the League.’ Before that principle could be put to the test, however, the First World War intervened. When the ILAE re-emerged, in 1936, the wording of the statute regarding membership began simply, ‘The primary consideration for membership is an active interest in the objectives of the League.’ But the article continued: ‘In countries which contain a branch organisation membership in this branch automatically carries membership in the International League.’ Thus was the door for entry of non-medical members de facto relocated to the entry by way of the national chapters. In the aftermath of the Second World War, the stipulation regarding membership was changed yet again, reflecting a long-standing debate about the nature of the relationship between professional and lay epilepsy organisations: ‘The national branches should be primarily medical organisations, which may include in their membership laymen interested in the problems of epilepsy.’ By the time the next revision of the constitution had taken place (1973), the International Bureau for Epilepsy had come into existence.

How did this happen? A search for clues finds them in a report about the meeting which the ILAE held in Copenhagen in 1939. William G. Lennox, then president of the ILAE, suggested in a letter to the secretary-general that:

A special branch of the League, an association of laymen interested in epilepsy be formed. It is a well known fact that in all civilised countries there is among laymen a growing interest in disease. Diseases such as tuberculosis, cancer, rheumatism, syphilis, and, not least, the oriental infections, arouse the attention of the administration of the different countries, and national associations are formed in order to combat these diseases. It is possible too, that in all countries with a high standard of education there are so many intelligent epileptics that they will join our League Against Epilepsy. What is more natural than the idea that those who suffer from the disease themselves should be the most active in assisting the physicians in combating it? If we decide to admit laymen to the ILAE it can be effected in two ways. They may either be admitted as regular or as associate members and receive the existing periodical *Epilepsia*. Or there may be formed a special section for laymen who would get a special periodical on epilepsy, written in a popular form and adapted to laymen’s knowledge. Much speaks in favour of adopting the latter procedure. (Schou 1939, 177–178)

### Lennox’s appeal comes to fruition

Its eloquence notwithstanding, Lennox’s plea was not heeded until 25 years later, in 1966, with the founding of a sister organisation to the ILAE for laymen’s chapters named the International Bureau for Epilepsy (IBE). However, that there was a viable embryo in the egg Lennox had laid in 1936 was already apparent at the 9th Meeting of the ILAE held in Rome in 1961. On this occasion the co-organisers Mario Gozzano and R. Vizioli of the University of Rome permitted the British Epilepsy Association (BEA) to hold a conference titled ‘The Role of the Lay Organisation in the Treatment of Epilepsy’, under the chairmanship of Romanes Davidson, medical director of the Bridge of Weir Colony in Scotland.



George Burden, one of the founders of the International Bureau for Epilepsy. (Courtesy International Bureau for Epilepsy)

### The Mosovich motion

George Burden, general secretary of the BEA, gave the following account of the proceedings:

The meeting in Rome was addressed by Dr A.M. Lorentz de Haas, medical director of the Epilepsy Centre for the Netherlands north of the Rhine with headquarters at Heemstede, and vice-president of the ILAE; Mrs Ellen Grass, president of the American Epilepsy Federation and Miss Irene Gairdner, honorary secretary of the British Epilepsy Association. Dr Karl-Axel Melin of Sweden, Dr Mosovich of Argentina and Mrs Kilgour, the honorary secretary of the Scottish Epilepsy Association, then gave brief descriptions of the activities in their countries.

At the end of the meeting Dr Mosovich asked to be allowed to speak again and moved that an international bureau should be set up to:

- 1 Canalize all possible information about associations to help people with epilepsy and distribute this by means of a newsletter at a certain fixed period;
- 2 Make information available on how to organise a laymen's league and how this should be financed;
- 3 Create an international film library about epilepsy;

4 The emblem of this association should be the candle already adopted by the British Epilepsy Association and by associations in Australia, Canada, Sweden and New Zealand.

In a business-meeting at Rome held jointly by members of the Board of the ILAE and representatives of the British Epilepsy Association, this was also a point of discussion. Two urgent questions had to be answered. Firstly, from what source and by what means could the necessary finance be raised to make this international bureau work? The International League had offered an initial grant, but if the international bureau was to play the above-mentioned part, it would be necessary to secure an income for three or four years to pay for a secretary and to meet travelling, publications and basic office costs. Secondly, the gathering of information and knowledge is a two way process. Before it is possible to disperse information it must first be received. In this regard it would also be necessary to be clear about what information should be collected, and suggestions about this would be welcome. Some examples of information to be collected were as follows:

1 *Education.* What facilities exist for the education of children with epilepsy; what are the indications for the exclusion of children from ordinary schools; what provision should be made for special establishments including residential accommodation for children with epilepsy?

2 *Employment.* What type of employment is thought suitable for people suffering from epilepsy; is it necessary that the epileptic should be obliged to accept lower grade employment; what steps can be taken to ensure that employers are protected against undue risk or can be informed about such risks as there are when they employ an epileptic? The answers to these questions will no doubt vary to a great extent owing to the diversity of social laws and provisions in the different countries.

3 *Mobility.* In many countries there are difficulties in connection with the epileptics entering and wishing to take up residence. What are the indications for regulations about immigration? With the introduction of joint commercial arrangements such as the Common Market together with the ease of modern travel, what steps can be taken to ensure that the epileptic can move about as freely as any other individual?

4 *Discriminatory legislation.* To what extent does this exist and what is the experience of other communities in repealing such legislation? (Burden 1962, 201–204)

For whatever reason, instead of opening an office (Bureau) to take care of social matters, a section of the ILAE named the International Bureau for Epilepsy was

conceived to which lay organisations, clinics and individuals could belong. This was in contrast to the membership of the ILAE, which was open primarily to national medical organisations devoted to the problems of epilepsy.

### Developing the fledgling IBE

At the General Assembly of the ILAE in Vienna, 9 September 1965, the then president of the ILAE, Francis L. McNaughton, mentioned in his opening speech how in different countries the national chapters may have different roles. In his view, many of the branches consisted mainly of neurologists and functioned as a professional society providing scientific meetings, education and advice to the government. In some countries, branches even offered diagnostic, therapeutic and social services, including sheltered workshops. Subsequently he revealed the intention of the IBE, first conceived as the social arm of the ILAE, to become an independent organisation in 1966.

Two announcements regarding the IBE subsequently appeared in the ILAE's journal *Epilepsia*. The first concerned the Bureau's official establishment at a meeting in Wiesbaden in 1966, and the second a 'European Institute' to be held 2–4 October 1967 at the Hôpital de la Salpêtrière in Paris. This was apparently the first symposium organised by the IBE together with a national ILAE chapter. Such meetings, later named European symposia, were held during the years that there was no congress of the ILAE, and consisted of a cycle of three annual symposia followed by one congress. Both the European symposia and the ILAE congresses were de facto joint meetings. Many years later when the League and the Bureau decided to hold all their major meetings jointly, the numbering system continued the sequence begun by the IBE.

### Living apart, together

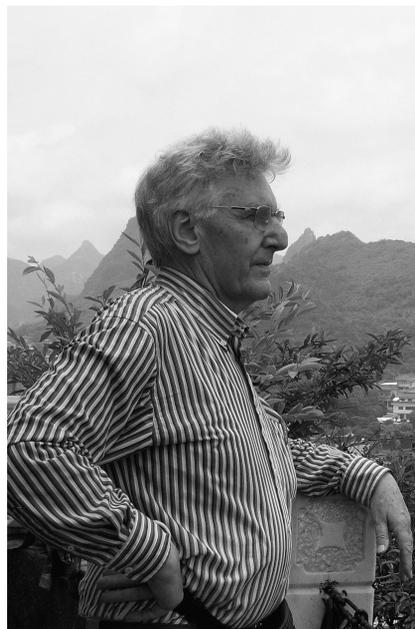
Following the ILAE/IBE joint international congress in 1973, in the spirit of a closer working relationship, both organisations adopted a new constitution which interlocked their Executive Committees. The president and secretary-general of the ILAE also became ex officio members of the IBE, and vice versa. The IBE had in the meanwhile begun a newsletter, and in December 1974, the 39th issue launched a new concept, 'Epilepsy International', which was intended to merge or intertwine both organisations. The concept was embodied in a seven-paragraph declaration of intent, agreed by both executives, that began:

'The two organisations, while retaining their separate identity, aims and objectives, should work together under the name of "Epilepsy International".'

In anticipation, the 40th Newsletter (March 1975) was now named *Epilepsy International Newsletter* and carried the joint logos of the IBE and ILAE. The next congress of the ILAE in 1977 was announced as the 13th Congress of the ILAE and the 9th Symposium of the IBE. Owing to managerial differences between the ILAE and the secretary-general of the IBE, Ellen Grass and George Burden, respectively president and secretary-general of the IBE since its founding, both stepped down.

### The years of Epilepsy International

By agreement, the two new executives of the ILAE and IBE were to implement Epilepsy International and to explore the possibility of a formal merger. Epilepsy International was constructed as the 'agent' of the ILAE and IBE and governed by a board of directors. The presidents of ILAE and IBE and the secretary-generals of the two organisations (for the period 1977–1981 J. Kiffin Penry and Francisco Rubio Donnadieu for the League, and Harry Meinardi and Richard Grant for the Bureau) were ex officio members of the board of directors of Epilepsy International. The



Harry Meinardi, ILAE president 1989–1993. (Courtesy Harry Meinardi)

directors would each take in turn the posts of chairman, vice-chairman, secretary and treasurer for a period of 1 year. There was much debate about the appointment of an executive director and especially about where to locate an office. Finally, Geneva was selected, in the immediate neighbourhood of the World Health Organization offices. Although there were some misgivings about his lack of any language but English, American Richard Gibbs was given the appointment. The influence of the new arrangement was also visible in the terminology used to name the international congresses, which instead of European Symposium and ILAE Meeting (or Congress) was baptised Epilepsy International Symposium.

Unfortunately, by 1980 it had become clear that the financial burden of maintaining a staffed office in Geneva was beyond the means of Epilepsy International. Although the board was grateful for the valuable contributions made by Gibbs, notwithstanding the difficult circumstances he had to cope with, by mutual consent the contract was terminated and the work temporarily handed to Joop Loeber, honorary editor of *Epilepsy International News*. Later Patsy McCall-Castellano took over, and the office moved from Geneva to Milan, Italy.

The next General Assemblies of the ILAE and the IBE, and the election of the Executive Committees for 1981–1985, were held at the time of the Epilepsy International Congress in Kyoto. When the question of a merger with the IBE was put to the vote, a majority of the ILAE chapters were opposed. That effectively spelled the end of Epilepsy International. But because arrangements under its name had been made several years in advance, it was decided to continue the use of Epilepsy International as agent for the ILAE and IBE for another 4 years and to dissolve the organisation at the next General Assemblies to be held in Hamburg (1985).

With the inception of Epilepsy International, the IBE and ILAE had been holding joint international meetings every year since 1977. Now, in the period between 1981 and the next General Assembly of the ILAE in 1985, only two more Epilepsy International symposia took place: one in London in 1982 and the second in Washington in 1983, where it was formally decided to reduce the frequency of the international congresses to biennial meetings. During the in-between years there would be possibilities for groups of chapters to hold regional meetings. Furthermore, committee and commission activities increased, and a number of workshops

were organised where people met by invitation to deal with specific problems of epileptology. The ILAE and IBE each would now manage their own commissions and workshops, but some of these activities – especially those of general interest – were organised jointly.

### **Epilepsy International exit**

At Hamburg in 1985 a new Executive Committee was ushered in for 1985–1989. Epilepsy International was dissolved, and commissions that existed under Epilepsy International such as the Commission on Drivers' Licencing and the Commission on Developing Countries were put under the jurisdiction respectively of the IBE (drivers' licensing) or the ILAE (education) or were split (developing countries). *Epilepsy International News* was returned to the IBE and its name changed to *International Epilepsy News*. (From March 1991 till September 1994 a special section on ILAE affairs edited by the ILAE was included in *International Epilepsy News*. From then on the League and Bureau had separate newsletters.)

Despite the failure of the attempt to merge the two organisations, close ties remained. The business meetings of the Executive Committees were always held both separately and jointly at the same location and time. The ex officio participation of at first the presidents and secretaries-general and later also of the treasurers in each other's Executive Committees was continued, and several joint activities covered fields where professional and lay input was essential. In particular, the organisation of the international congresses remained a joint venture. However, both organisations agreed to encourage countries worldwide to create separate chapters of the ILAE and IBE.

In the years between the (now renamed) ILAE/IBE International Epilepsy Congresses (IECs), both ILAE and IBE member organisations were wont to hold separate congresses, often in languages other than English, such as the meeting of French–Italian–Spanish leagues, or meetings of the German-speaking branches. For example, the IBE established a conference series known as the European Congresses on Epilepsy and Society. In the early 1990s, regional issues became increasingly important. At a meeting called Epilepsy Europe, organised by British and Scottish Epilepsy organisations, it surfaced that a movement was burgeoning to create a European epilepsy society. A battle between lumpers and splitters appeared in the offing. The golden mean was found by creating inside

the ILAE a European Commission charged among other tasks with organising biannual European congresses.

Until 1999, financing the International Epilepsy Congresses was primarily the responsibility of the national chapter of the country where the congress would take place. Henceforth, the ILAE and IBE were to take full control, including financial control. Surpluses would be divided 75% to ILAE/IBE and 25% to the local committee. A further development was to hire an International Director of Meetings (IDM), an investment that would prove beneficial to the League and the Bureau, although it took a while to work out an effective structure for communications between the new office and the Joint ILAE/IBE Executive Committee (JEC). Eventually, in addition to the International Epilepsy Congresses, the IDM also took on the responsibility of arranging regional congresses. Now into the new millennium, both the ILAE and IBE face a number of major challenges with respect to congress activity, including the complexities of building strong chapters in developing countries and how to finance meetings in an era of decreasing support from the pharmaceutical industry.

Operational independence and financial dependence of interested parties is a sensitive matter for volunteer organisations such as the ILAE/IBE. By 1998, the presidents of ILAE and IBE together had begun to invite industry to attend periodic corporate roundtable meetings to discuss the relationship between them.

### **ILAE/IBE/WHO Global Campaign Against Epilepsy: Epilepsy out of the Shadows**

In his speech to the ILAE General Assembly in 1997, ILAE outgoing president Ted Reynolds had this to say about a newly established joint effort of the ILAE, IBE and WHO called the Global Campaign Against Epilepsy:

Both ILAE and IBE are non-governmental organisations affiliated to WHO. In view of the political neglect and low profile of epilepsy referred to in my inaugural report and in this report, I proposed to WHO in January 1996 a global initiative for this worldwide problem. Following a meeting and workshop of the Developing Countries Commission in Geneva in June 1996, the WHO agreed in principle to this idea ... The Global Campaign Against Epilepsy thus became a joint initiative of three world-wide organisations, the ILAE (professional), the IBE (lay) and the WHO (political). It was formally launched in Geneva on June 19th 1997 and Dublin on July 3rd 1997.

### **Mission**

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

### **Objectives**

- 1 To increase public and professional awareness of epilepsy as a universal, treatable brain disorder.
- 2 To raise epilepsy on to a new plane of acceptability in the public domain.
- 3 To promote public and professional education about epilepsy.
- 4 To identify the needs of people with epilepsy on a national and regional basis.
- 5 To encourage governments and departments of health to address the needs of people with epilepsy, including awareness, education, diagnosis, treatment, care, services and prevention.

### **Programmes**

To achieve the above objectives, the campaign is developing two parallel and simultaneous programmes over the next 4 years:

- 1 A global public awareness programme.
- 2 A programme of practical assistance to governments and departments of health working through the worldwide network of ILAE/IBE chapters and epilepsy organisations, and the WHO network. This will take the form of encouragement, guidance, advice, information and assistance, especially in identifying the needs of people with epilepsy, and in the education and training of public and professionals.

Individual chapters, countries and departments of health will be encouraged to develop their own national campaigns, depending on local needs and resources ... The Global Campaign is being developed and monitored by an International Consultative and Collaborative Committee made up of members of the three organisations and of which I am currently chairman. (Reynolds 1998)

As the Global Campaign Against Epilepsy is discussed in another section of this book (see Chapter 8), only incidental mention is made here of its progress, although it is a standard topic of the JEC meetings.

Demonstration projects were gradually activated in several regions. In 2003, funds from the Dutch foundation EPICADEC (Epilepsy Care in Developing Countries), which was closing down, were transferred to the IBE and ILAE subject to their use to support local initiatives in agreement with the Global Campaign. In Africa, after finalising a project in Senegal, which was reported at the IEC in Lisbon in 2003 and published in *Epilepsia*, a second

project was terminated in Zimbabwe. The influence of the political situation in Zimbabwe had seriously interfered with the proper implementation of the project. Nevertheless, sufficient results had been obtained to report them at the 26th International Epilepsy Congress in Paris in 2005. With financial support from the Fogarty International Center in the United States, a pilot study for a project on collaborative research on the stigma of epilepsy was carried out in China and Vietnam.

In 2006, the Global Campaign was about to enter its third phase, which would complete ongoing and planned demonstration projects; develop regional atlases of epilepsy resources; review existing legislation relevant to epilepsy; develop projects on surgery and stigma; and establish research plans for multicentre collaborative studies involving developed and developing countries.<sup>1</sup>

### EUCARE

European Concerted Action and Research in Epilepsy (EUCARE) originated in 1998 as a partnership between the ILAE Commission on European Affairs and UCB Pharma to raise the profile of epilepsy across Europe (Brodie 2003). The IBE was later invited to join as a third partner, and EUCARE also eventually created a Scientific Advisory Board. In 2001, at the European Parliament in Brussels, EUCARE launched a detailed public health statement on epilepsy known as the 'White Paper on Epilepsy'. The paper was later published as a supplement to *Epilepsia* (2003). A response to the White Paper called the EUCARE Action Pack, developed to help organisations improve epilepsy care through media campaigns and advocacy, was launched at the Epilepsy and Society meeting in Malta in March 2004 for circulation to all IBE and ILAE chapters and to other interested parties. In May 2005, the newly created EUCARE Political Action Group met for the first time to draft an action plan aimed at promoting epilepsy as a public health priority among governments and health authorities. Two other initiatives, a prospective observational study of the pharmacological and lifestyle consequences of newly diagnosed epilepsy (FONDE, Following Outcomes in Newly Diagnosed

Epilepsy), and a EUCARE questionnaire to test European Parliament members' knowledge of epilepsy are ongoing.

### An international epilepsy resource centre in Zurich

Like many activities of international organisations, the plan to create an international epilepsy resource centre resulted from individual initiatives (aided by friends and local organisations) that were big enough to be of global interest. In 1998, the JEC moved to hire a professional to compile the information to ensure high quality. A draft contract was received from the Swiss Epilepsy Centre in Zurich in 1999. In the meanwhile, the IBE had supplied the centre with its collection of videos and also most of its training literature. The idea was eventually also to provide copies of the ILAE's publications. By 2001, an electronic database had been created and all available IBE material added to it. But the gathering the ILAE materials had fallen behind. Moreover, advances in technology had made the original plan for the centre obsolete. \$50,000 and 3 years into the project, the JEC terminated the contract with the Swiss Epilepsy Centre. The IBE's collection is still housed at the centre, for a low storage cost, as are the League's archives from 1960 to 1997, which were transferred there from Bielefeld in 2005. A catalogue of the archives was made available on the ILAE website in 2007, where it is publicly accessible.

### Awards

When the IBE and ILAE first intensified their cooperation, they also began to confer a number of awards jointly. The Ambassador for Epilepsy Award, established in 1968, entitles the prizewinner to a pin bearing the IBE candle symbol. The Social Accomplishment Award is given every 2 years to one person for outstanding achievements aimed at the social benefit of people with epilepsy. The Michael Prize, awarded biennially, was set up in Germany in 1963 and now consists of a fund of 15,000 euro for young research epileptologists under the age of 45. Young Investigator Awards go to fund International Epilepsy Congress delegates under the age of 35 whose abstracts are considered of excellent quality. A new award, the Morris-Coole Prize, consists of 10,000 euro given annually in recognition of an outstanding paper published in *Epilepsia* the previous year in any field of epilepsy research. Finally, since 1995, although a bit irregularly, the Lifetime Achievement Award constitutes the highest honour presented by the IBE and ILAE.

<sup>1</sup> Leonid Prilipko, who was responsible for the World Health Organization (WHO) part of the Global Campaign Against Epilepsy (GCAE) collaboration, later retired from WHO but continued to work for the GCAE on a consultant basis. On 23 April 2007, he died. His commitment and contribution to the success of the Global Campaign should not be underestimated.

Other awards come and go, such as the Ciba-Geigy–ILAE–IBE Epileptology Prize for outstanding detection and treatment of epileptic disorders, established in 1993 for 20,000 Swiss francs. The name of the first awardee is lost to history, although the winner of the second (and apparently final) prize, in 1995 in Sydney, was Fritz Dreifuss.

For many years, prizes for young investigators were announced in *Epilepsia*. Several of those were funded by pharmaceutical companies, and some by private foundations. At first only awards in which the ILAE executive played an active part were presented at its congresses. But later others, such as the Michael Prize, were also included.

### Members of the ILAE and IBE and their interactions

Originally the ILAE was not concerned about the profession of its membership. Later, however, the terms of membership stipulated that national chapters primarily have professional members. It is beyond the scope of this work to examine in detail the collaboration of people working with epilepsy and persons with epilepsy or those who are interested in their cause for other than professional reasons. Instead, we will limit our discussion to illustrative examples of developments in a few countries.

It is difficult to obtain information from each and every chapter about how collaboration between members of the League and of the Bureau proceeds at the national level. Moreover, sometimes information can be gathered only indirectly. The result is an incomplete, variegated picture. For example, the Armenian League Against Epilepsy at first sight appears to be a typical ILAE chapter consisting of members who are medical doctors or professionals working in the field of epilepsy. Yet two of its four goals are to assist with the social integration of persons with epilepsy and to promote improvements in the legal field vis-à-vis persons with epilepsy. The chapter mentions among its activities projects as diverse as ‘performing MRI studies in 30 patients’ and ‘social integration of patients with epilepsy in Giumri’.

Most information regarding collaboration at the national level between ILAE and IBE members comes from the chapters of either organisation. One exception was, as the informants called it, ‘The short but hectic history’ of the Caritas Malta Epilepsia Association (CMEA, an IBE

member) and the Epilepsy Society of Malta (an ILAE member), furnished together by Victoria Dimech and Janet Mifsud, the secretaries-general of these organisations. It was only in 1996 that a few people, mostly patients with epilepsy, their relatives and friends, got together to set up the first informal support group in Malta. At first, the group only had about 20 members, but it has slowly increased to more than 300 members, which is excellent for a country with such a small population (404,039 according to the November 2005 census). CMEA is autonomous, although it is linked to a church social support service on whose premises it meets.

CMEA was accepted as a full member of the IBE in 2001. The association collaborates as much as possible with the local ILAE chapter on matters of policy or other mutual interest, such as supply and provision of medicine to enhance service for people with epilepsy and their families. Through this interaction, both parties have the opportunity to share perspectives on the various issues under discussion. The Epilepsy Society of Malta was accepted as a member of the ILAE in 1999. Because there are only a few neurologists in Malta, it is very small, and in fact it is open to other health care professionals in the country, such as pharmacists, EEG technicians and nurses. Dr Janet Mifsud, who is the secretary of the ILAE chapter in Malta, is one of the founding members and also an advisor to CMEA. She is a very important link between CMEA and the ILAE chapter, facilitating the contacts that support the endeavours undertaken by CMEA.

The Colombian League Against Epilepsy was created on 11 September 1964 in Cartagena de Indias, which is situated on the Caribbean coast of Colombia. The founder and first president was Dr Jaime Fandiño-Franky, who has been the league’s motor from the early beginning until now. In 1966, the Colombian league joined the IBE. Their aim to improve conditions for persons with epilepsy obliged the league to acquire properties such as laboratories, outpatient clinics and to have its own staff of doctors and laymen. Eventually, a neurological hospital was also established, where epilepsy surgery is performed at remarkably low cost. In 1982 the Colombian league also became a member of the ILAE. In order to comply with the constitution of the ILAE, all ‘profit-making’ properties were transferred to a new organisation, the Foundation Centro Colombiano de Epilepsia y Enfermedades Neurológicas (FIRE), which is the current Colombian member of the IBE.

The ILAE chapter in Uruguay – the Uruguayan League Against Epilepsy (ULAE) – was founded in 1980. It had actually previously been a member of the ILAE beginning in 1961. But at the time it was not a legally registered organisation in Uruguay. Although this chapter was mainly a medical organisation, it included other professionals and also relatives of patients. In 2005 the ULAE helped to establish an organisation for non-professionals interested in epilepsy, the Uruguayan Association Against Epilepsy, which became a member of the IBE.

An interesting statement about the interlaced existence of ILAE and IBE chapters comes from Mike Glynn, of Ireland. According to his report, in most countries, the creation of an ILAE chapter is followed by the setting up of an IBE member association some years later, usually at the behest of one or more of the key epilepsy specialists involved with the League chapter. Ireland is an exception to this process, and the Irish Epilepsy League did not come into being until fully 28 years after the creation of its Irish IBE counterpart, Brainwave, the Irish Epilepsy Association. However, it is important to note that Brainwave came about mainly through the work of concerned medics who were involved with efforts to set up an association for all those interested in epilepsy long before Brainwave emerged in 1966.

According to Vinod Saxena, in India, too, the organisation associated with the IBE formally came first. The medical community in India, particularly specialists, understood that despite the country's wide diversity, most patients with epilepsy could still come under some kind of treatment umbrella. The main challenge was to make the patients aware that treatment existed and that early intervention would help them. In the late 1960s, a few senior members of the Neurological Society of India realised that a separate organisation should focus on various aspects of epilepsy. This was essential to ensure proper care for patients. Dr Anil D. Desai, Bombay, was designated secretary of the Epilepsy Section within the Neurological Society of India. In the period 1967–1969, he, along with Drs Eddie P. Bharucha and Noshir H. Wadia, worked hard to realise the objective of forming a new society. The impact of epilepsy on the personal and social life of patients made it apparent that medical professionals alone were inadequately equipped to handle these issues. Drs Bharucha and Baldev Singh (later to become founder members of the new association) rather prophetically remarked, 'It is felt very strongly that in

the long run running the Association with non-medical persons would pay much greater dividends than if the Association was to be manned exclusively or mainly by medical people.' The new society, the Indian Epilepsy Association (IEA), incorporated the essential objectives and rules under the Societies Registration Act 21 of 1860 to register it with the relevant authority on 21 March 1970 in Bombay. The first meeting of its newly formed governing council was held on 27 January 1971, in Bombay, with four founder and seven invited members. To ensure effective work in all important cities, the gathering decided to form local chapters or branches of at least 15 members each. Gradually, the movement spread to other parts of the country, resulting in the formation of several new chapters (currently there are 23). The decision to seek affiliation with the IBE was taken on 18 December 1973. At first, the IEA was aligned both with the IBE and ILAE. Both these organisations underwent constitutional changes that then forced country chapters to seek separate affiliations. Lay and social organisations aligned with the IBE, and medical and professional groups with the ILAE. Since the IEA was dealing with both aspects of patient welfare, it was asked to form a separate body for professional people for affiliation with the ILAE. An independent body, the Indian Epilepsy Society, consisting of only medical professionals, was formed and joined the ILAE in 1997. Both the IEA and IES, however, continue to work jointly in many tasks, including WHO's Global Campaign Against Epilepsy.

Certainly in the early days, even before the ILAE was founded, non-medical people concerned with the fate of persons with epilepsy organised themselves to do something about it. Often this meant creating hospices or even special hospitals. For example, in Finland in 1895 the national inspector of relief for the poor demanded government action for persons with epilepsy and proposed founding an institute. He had calculated that almost one-fifth of people with epilepsy in the country were from the region of Kuopio, in eastern Finland. His words were heeded, and the first epilepsy association, the Association for the Care of People with Falling Disease, was established in Kuopio. The then Imperial Senate ratified its statutes in July 1898. It was soon followed by further associations in different parts of the country. They were all lay organisations. The Vaajasalo centre in Kuopio remained the only special hospital for epilepsy, because soon medical treatment became integrated in the services

offered by the well-developed specialties of neurology and child neurology. The national treatment and care plan of 1974 officially stipulated that treatment and rehabilitation of epilepsy had to be organised by the neurological unit of the so-called Central Hospitals. As a consequence, in 1977 the Vaajasalo Epilepsy Centre in Kuopio was incorporated into the University Central Hospital. The activities of the epilepsy associations founded in the early part of the 20th century gradually petered away, but in 1967 a new lay association was founded in Helsinki, soon followed by three similar organisations in different parts of the country. In 1969, an umbrella group, the National Epilepsy Organisation, was founded. These were all lay associations, but from the outset professionals have served as members of their boards and even chairpersons. Encouraged by the ILAE in 1980, the National Epilepsy Organisation set up a scientific board, and this group was destined to act as a member organisation of ILAE. However, it was too small a body to meet the tasks and requirements of the ILAE, and in 1992 the then president of the National Epilepsy Association, Matti Sillanpää, called the members of the Finnish Neurology Association to a founding meeting of the Finnish Epilepsy Society. This society then took over as the Finnish chapter of the ILAE, and as of December 2006 had 150 members.

The Netherlands has been a member of the ILAE from the very beginning, as one of the four founders, L.J.J. Muskens, was a Dutch neurologist. He became secretary-general of the ILAE, and both maintained the organisation during and after the First World War and helped restore it in 1935 at the International Neurology Congress in London. To comply with the proposed new constitution of the ILAE (adopted in 1939), all persons and organisations in the Netherlands concerned with epilepsy in 1936 founded a new national umbrella organisation, the Federation for the Fight Against Epilepsy, which became the Dutch chapter of the ILAE. In the

1960s this federation was bequeathed a sum of 4 million guilders. A few years later, a group of parents of persons with epilepsy started a new foundation which they called 'Our Right'. When this organisation applied for membership in the predominantly medical federation, similar to the vote in Kyoto on the merger of the ILAE and IBE, the professionals feared that a large influx of laypeople would focus on short-term improvements in care and would neglect research about epilepsy, thus 'squandering' the federation's capital. It was therefore decided to safeguard the capital in a charity foundation which also would be able to fundraise. Under Dutch law such charities are run by a board of limited size that elects its own members. This new foundation would obtain and administer the capital of the old federation. Two new organisations were created, the Netherlands League Against Epilepsy (with only professionals as members) and the non-professional Epilepsy Vereniging Nederland (Dutch Epilepsy Society), which was open to anyone who was interested in its objectives. This new situation was legally finalised in December 1979. Every year, both organisations applied for and obtained grants from the National Epilepsy Fund to support their activities, in the same way as anyone else who had a justifiable request for financial support of epilepsy-related objectives. The lay and professional organisations have their own objectives but collaborate wherever there is a need or opportunity to do so.

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And thus begins the endless round of doctors, for my brother and my parents.



They go see our family doctor. He sends them to his teacher, who no longer practices.



He sees them anyway. His diagnosis: epileptic seizures. He refers them to a Parisian neuropsychiatrist.



His diagnosis reflects his hourly billing.



The social side of epilepsy is the focus of the International Bureau for Epilepsy. (Image from *Epileptic*, by David B., published by Jonathan Cape, London. Reprinted by permission of The Random House Group Ltd.)