

## 3 International League Against Epilepsy – the third period: 1993–2009

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In the early 1990s, the ILAE was much smaller than it is today. There were far fewer active members and far fewer chapters (40 in 1993), international meetings attracted not many more than 1,000 people, and the organisation had no formal administrative support and no regional groupings. Nevertheless, by then the League was accepted as the voice of international epilepsy and in reality punched above its weight. This was perhaps largely due to three facts: first, the ILAE owned and published *Epilepsia*, which was the leading epilepsy journal; second, it held the only major international epilepsy congresses; and third, it had originated a classification scheme for epilepsy which was by then accepted globally and in widespread use. Over the next 15 years, the ILAE would consolidate its position as the leading global organisation, and indeed at the time of writing is overwhelmingly so. The number of chapters would more than double, the financial assets of the organisation increased by over 10-fold, its congresses increased in size and quality, and it became far more active in many areas. In parallel, its administration was to a significant extent outsourced and became more professional. In this environment of massive growth, the trick was to maintain its character as a voluntary non-profit association, fuelled by the vocational zeal of its officers and active members, and at the same time to render its activities more streamlined and efficient. This is a difficult balancing act, and whether the League has successfully achieved this goal is a question answerable only in later times.

A watershed in the ILAE's history was the 20th International Epilepsy Congress (IEC) held in Oslo in 1993. This was an outstanding success, with over 2,000 participants. In its aftermath, the League started growing 'in leaps and bounds' (Engel 2006). In this period, a number of very significant new initiatives occurred of

which the most important was probably the launch of the Global Campaign Against Epilepsy. Other developments included the systematic structuring of education and the foundation of the European Epilepsy Academy (Eurepa), the rapid escalation in the size and quality of congresses, the growth of regionalisation, and the appearance of the annual reports, the newsletter *Epigraph* and the ILAE website. All these initiatives continue to evolve.

During this period, as its power and influence grew, the ILAE also interacted more with outside agencies and formed more regional groupings. At the same time, and inevitably so, there were various political and regional tensions which it has largely negotiated its way through.

### The Executive Committee and constitutional changes

The 1993 elections were conducted by the ILAE Nominating Committee, and turned out to be a complicated affair. In keeping with changes to the League's constitution made in 1985, in Hamburg, to make the process more democratic, the chapters had been asked to make nominations for the presidential slate. Roger Porter, Ted Reynolds, Peter Wolf and Peter Bladin received the highest number of nominations and so their names went forward to constitute the slate for the presidential election. The presidential vote was initiated in January 1992, with a deadline of June 1992. Then, at the April 1992 Executive Committee meeting, Porter announced, unexpectedly, that he was leaving the National Institutes of Health (NIH) to take a job with a pharmaceutical company. He offered to stand down from the election (and also from his current position) if his new position was considered too great a potential conflict of interest to

assume the leadership position. The officers felt that it was and accepted his decision, but asked him to finish his term as secretary-general through mid-1993. The election was completed with three candidates, and Ted Reynolds received the highest vote. His election was announced in July 1992.<sup>1</sup>

The Executive Committee in 1993 comprised nine members all of whom had voting rights, including two ex officio members (the president and secretary-general) from the International Bureau for Epilepsy (IBE) (Table 1). The committee would meet twice a year, and to support this administration, the president and secretary-general received a small amount of financial support from the ILAE for secretarial assistance in their offices. There was no central administration, no headquarters office and the administrative costs were low. Like its predecessors, the new executive was partly concerned with congresses and the running of *Epilepsia*, with issues arising from the member chapters (for instance, changes in the Yugoslavian chapter following the shifting political scene in Europe) and with its financial position. In 1994 the president and secretary-general also initiated the production of annual reports. Tim Pedley, who was appointed as the new editor-in-chief of *Epilepsia* in 1993, successfully proposed more frequent publication to the executive, and from 1995 the journal was published in monthly issues. A completely new initiative, conceived and led by President Ted Reynolds, was the launch of the Global Campaign

<sup>1</sup> It is not clear whether, by April, any chapters had already voted for Porter and, if so, whether the votes were simply ignored, or whether the chapters had a chance to re-allocate their votes (or indeed whether the chapters were ever informed, even after April, that Porter had stood down). It is also not obvious why the slate contained four names. The constitution ratified in Hamburg in 1985 specified that the Nominating Committee would choose 'three candidates by a plurality of votes' and submit those names to the chapters for voting. The 1997 constitution contains the same wording. In contrast, the constitution currently in effect (2005) stipulates no number at all: 'For the election of the President, the Elections Commission shall submit to the Chapters a list of persons fulfilling the requirements of the Constitution (Article VIII, 3), who are available and willing to serve and will ask each Chapter to vote for one of them. If one of the candidates receives more than fifty percent of all possible votes, that candidate shall be elected' (see Appendix 5). The archives contain a mysterious piece of correspondence from Harry Meinardi to Paolo de Bittencourt dated 18 May 1992 referring to the option of chapters to add 'a fourth name'. But it is impossible to make out what that means. ILAE elections have a habit of throwing up complications – and this one was no exception.

**Table 1** ILAE Executive Committees, 1993–2009.

#### 1993–1997

Ted Reynolds, president (United Kingdom)  
 Peter Wolf, secretary-general (Germany)  
 Jerome (Pete) Engel, Jr., treasurer (United States)  
 Harry Meinardi, past-president (Netherlands)  
 Giuliano Avanzini, vice-president (Italy)  
 Simon Shorvon, vice-president (United Kingdom)  
 Timothy Pedley, editor-in-chief, *Epilepsia* (United States)  
 Hanneke de Boer, president IBE, ex officio (Netherlands)  
 Michael Hills, secretary-general IBE, ex officio (New Zealand)

#### 1997–2001

Pete Engel, Jr., president (United States)  
 Peter Wolf, secretary-general (Germany)  
 Giuliano Avanzini, treasurer (Italy)  
 Ted Reynolds, past-president (United Kingdom)  
 Yoshiaki Mayanagi, vice-president (Japan)  
 Natalio Fejerman, vice-president (Argentina)  
 Timothy Pedley, editor-in-chief, *Epilepsia* (United States)  
 Simon Shorvon, information officer (United Kingdom)  
 Richard Holmes, president IBE, ex officio (Ireland)  
 Michael Hills, secretary-general IBE, ex officio (New Zealand)

#### 2001–2005

Giuliano Avanzini, president (Italy)  
 Natalio Fejerman, secretary-general (Argentina)  
 Ley Sander, treasurer (United Kingdom)  
 Pete Engel, Jr., past-president (United States)  
 Fred Andermann, 1st vice-president (Canada)  
 Martin Brodie, 2nd vice-president (United Kingdom)  
 Robert Fisher, editor-in-chief, *Epilepsia* (United States)  
 Simon Shorvon, information officer (United Kingdom)  
 Phil Lee, president IBE, ex officio (United Kingdom)  
 Ester Cavalheiro, secretary-general IBE, ex officio (Brazil)  
 J. Falk-Pedersen, treasurer IBE, ex officio (Norway)

#### 2005–2009

Peter Wolf, president (Denmark)  
 Solomon Moshé, secretary-general (United States)  
 Martin Brodie, treasurer (United Kingdom)  
 Giuliano Avanzini, past-president (Italy)  
 Emilio Perucca, 1st vice-president (Italy)  
 Fred Andermann, 2nd vice-president (Canada)  
 Chong Tin Tan, vice-president (Malaysia)  
 Simon Shorvon, co-editor-in-chief, *Epilepsia* (United Kingdom)  
 Philip Schwartzkroin, co-editor-in-chief, *Epilepsia* (United States)  
 Edward Bertram, information officer (United States)  
 Susanne Lund, president IBE, ex officio (Sweden)  
 Eric Hargis, secretary-general IBE, ex officio (United States)  
 Mike Glynn, treasurer IBE, ex officio (Ireland)

Against Epilepsy. This proved to be the ILAE's most important initiative over the subsequent decade (see Chapter 8) and undoubtedly also the ILAE's most significant public health measure. The Global Campaign was a partnership not only with the IBE but also the World Health Organization (WHO), and the joint effort on the part of this triumvirate was to achieve an enormous amount in the field of epilepsy – much more than any of the partner organisations could have managed alone. The campaign was dubbed 'Out of the Shadows' with a logo showing an eclipse of the moon.<sup>2</sup> Planning took place between 1995 and 1997, and the Global Campaign was first announced at the European and Asian and Oceanian congresses in 1996. To develop plans for the launch of the campaign and for its public development, Reynolds also sought the assistance of a professional public relations consultant, Don Whiting, who made several presentations to the executive. He was assisted on the IBE side by Hanneke de Boer from the Netherlands. The costs of the Global Campaign were a subject of continuous debate among the ILAE leadership, and large expenditure was opposed.

The campaign was launched first at WHO headquarters in Geneva on 19 June 1997 and then 2 weeks later in Dublin during the 22nd IEC in the presence of the president of Ireland, Mary Robinson. The initial site of the congress was actually to have been Florence but the Italian chapter of the Bureau refused to take the risk of organising the congress, thus forcing the Italian league to withdraw the Italian candidacy. At that point, Richard Holmes, the treasurer of the IBE and president of Brainwave, the Irish IBE chapter, quickly devised a plan to move the meeting to Dublin. In the end, the meeting proved a total success, with attendance figures that surpassed the preceding IEC in Sydney. Details of the Global Campaign were written up in a special supplement of *Epilepsia* (2002) and in other articles (Reynolds 2000, 2001).

The campaign would not have got off the ground were it not for the supportive role of the new director general of WHO, Gro Harlem Brundtland, in 1998 and the administrative support of Hanneke de Boer for the IBE and Leonid Prilipko for WHO. A concept at the centre of the Global Campaign was the so-called treatment gap,

and a major conference on this topic was organised in Marrakech in May 1999.<sup>3</sup> The joint ILAE/IBE Executive Committee (JEC)<sup>4</sup> also had reservations about how to measure the concrete effects or outcome of the campaign. From the perspective of today, however, the substantial achievements of the campaign in raising awareness of epilepsy (Anon. 1997, 2001, 2006; Kale 1997; Reynolds 1997) and in promoting ILAE activities seem very well to justify the relatively small outlay. The Global Campaign achieved the notable goal of being awarded 'cabinet level' status within WHO in 1999. A European declaration on epilepsy was approved in Heidelberg in 1998 and was followed by other regional declarations: Africa, Dakar 2000; Asia, New Delhi 2000; Latin America, Santiago 2000; Eastern Mediterranean, Cairo 2003; and the formal launch of a second phase of the Global Campaign in Geneva that took place in 2001. The ongoing partnership with WHO also spawned a series of important 'demonstration projects' the fruits of which are just beginning to appear. Finally, the inaugural address by Brundtland at the second launch on 12 February 2001, as Reynolds

<sup>3</sup> The term 'epilepsy treatment gap' was coined by Shorvon and colleagues in 1988. The gap was calculated using estimates of the prevalence of epilepsy, the amount of drug supplied to a country (using national drug supply data provided by Ciba-Geigy) and making assumptions about the drug dosage. Simple calculations were made showing what proportion of patients with epilepsy could have been supplied with the drug. The results indicated that, in four of the developing countries studied, only 6–20% of the patients with active epilepsy could have been taking antiepilepsy medication (even at low doses). These figures were a great surprise but were confirmed in subsequent prospective surveys in Kenya, Ecuador and Pakistan. The concept proved to be a powerful lever in the global campaign and could also be used as a long-term measure of the success of any epilepsy intervention.

<sup>4</sup> The JEC meetings are a legacy of Epilepsy International, an ultimately failed effort to fuse the League and the Bureau (see Chapter 2). Members of each organisation had sat on each other's boards *ex officio* since 1973. But the joint meetings began only in 1977 with the inception of Epilepsy International, and outlived it. Initially, the main agenda items were the congresses and arguments about the merger. After 1993, the number of mutual projects increased, including the website, the Global Campaign and the International Epilepsy Resource Centre. For some meetings, the agenda focused on the investment in congresses, as well as issues related to them such as sponsorship and conflict of interest. In 1999, the IBE proposed a constitutional clause that spelled out procedures for joint meetings to be 'set out in identical bylaws to the constitutions of both the IBE and ILAE' (JEC Meeting, April 2000). Such a by-law is enshrined in the ILAE's current constitution (Article XII:1–13).

<sup>2</sup> The name and logo were conceived by Ted Reynolds in 1996. This may have been inspired by a total lunar eclipse that occurred over Europe in 29 November 1993. Similar images had appeared in the national newspapers of the time.

wrote, is perhaps the most important and influential political statement about epilepsy made during the whole of the ILAE history.<sup>5</sup>

Another important development over the 4-year term, initiated by the previous president Harry Meinardi and strongly carried forward by Reynolds and then subsequent administrations, was the institution of regional structures, particularly in Europe, which were to be of great importance in the coming years (see below). Chapter numbers also grew rapidly during this time and, by 1997, the president estimated that the ILAE had 63 chapters and 11,000–12,000 members. Under the treasurership of Jerome (Pete) Engel, Jr., the finances of the ILAE increased substantially and required far more professional accounting arrangements than had hitherto been in place – this, too, proved a major task. The ILAE executive was also keen to improve communication, and in 1994, the ILAE newsletter *Epigraph* was launched.

At the General Assembly in Dublin in 1997, the new executive was constituted. Engel had been elected president, and during his term a range of new initiatives were introduced. Important changes were made to ensure that the administration of the expanding League was more expert and more efficient. These included the outsourcing of ILAE financial functions to a permanent ILAE office run by the American company Association Resources and of the ILAE conference organisation functions to the League's International Director of Meetings (IDM) office. These changes transformed the ILAE into a much more professionally run organisation, and not before time, as the ILAE had by then grown far too big to be managed by its previously rather ad hoc arrangements. Communication functions were also improved by establishing an ILAE website and an International Epilepsy Resource Centre, and appointing an information officer, a newly created position on the executive. The treasury functions were also more formalised. In addition, in 2000 Engel initiated a strategic planning process within the ILAE to try and set the priorities for the next decade. Chapter enlargement continued, and the ILAE congresses became increasingly successful. Engel also oversaw a number of changes to the constitution, the most far-reaching of which was a change in the voting system for electing the ILAE executive. There had been, for a number of years,

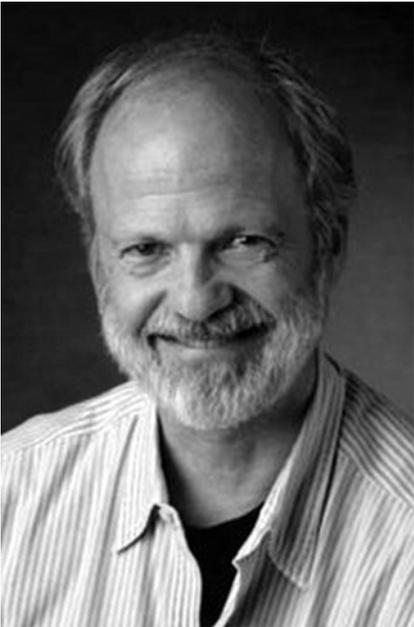
weighting of votes according to chapter membership, but the maximum votes of a chapter were only four. This was perceived by the executive to put the large chapters at a disadvantage and, it was claimed, even kept them sometimes from disclosing their true size because it would only increase their membership fee without getting them any benefits. The count of chapters had grown progressively since 1990, and by 2001 totalled 77. The new chapters were usually small (some with not more than eight members). Pete Engel proposed a revised, weighted voting system with eight categories.<sup>6</sup> Some in the executive objected to the amendment by the executive on the grounds that the weighting was too great and would strengthen the voting power of the largest countries (for instance, the United States and Germany). The alternative of a 'one country, one vote' system was also discussed but not supported. As a result, a modified scheme with six categories was proposed to the General Assembly in Prague in 1999.<sup>7</sup> This was mailed to chapters, a vote was taken at the General Assembly, and the amendment carried. The executive was also expanded from 1999 by the formalisation of the practice (which actually was already in place) of the treasurers of both organisations sitting, in addition to the presidents and secretaries-general, ex officio on each other's Executive Committee.

Another change suggested by Engel was to try to introduce more regional variety on the executive, as well as more professional diversity (with members from different specialties). However, this was considered unnecessary, and the next executive was anyway more geographically diverse. However, the issue bubbled up again and again over the next decade and in 2005 a degree of regional diversity was mandated (in the so-called Danish amendment). The *Epilepsia* contract was put out for tender and awarded

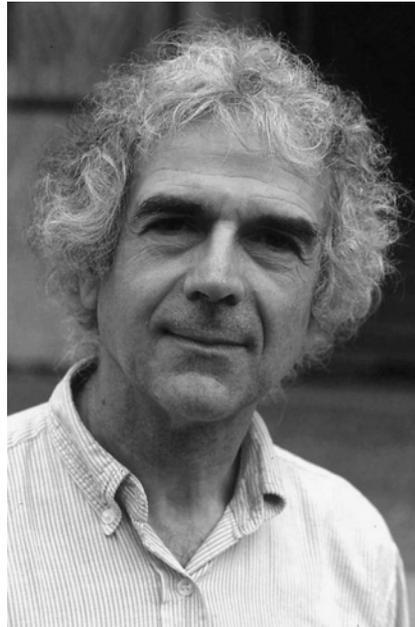
<sup>5</sup> The speech is reproduced as an appendix in the article by Reynolds on the Global Campaign Against Epilepsy (Reynolds 2001).

<sup>6</sup> There was at the time a weighting scheme divided into four categories. The amendment to the constitution proposed by Engel would have changed this to eight categories. The amendment read, 'The number of votes accorded to each delegate shall depend on the number of professional members in good standing in his chapter as follows: from 9–30 members generates 1 vote, from 31–100 members generates 2 votes, from 101–200 members generates 3 votes, from 201–300 members generates 4 votes, from 301–400 members generates 5 votes, and so on with a maximum of 8 votes from any one chapter' (ILAE EC Minutes, December 1997).

<sup>7</sup> The proposed scale was the following: up to 50 members, 1 vote; 51–150 members, 2 votes; 151–350 members, 3 votes; 351–750 members, 4 votes; 751–1,500 members, 5 votes; above 1,500 members, 6 votes.



Jerome (Pete) Engel, Jr., ILAE president 1997–2001.



Giuliano Avanzini, ILAE president 2001–2005.

to Blackwell (see Chapter 7). Engel had a long-standing interest in the classification of epilepsy, and he particularly stimulated activities of the classification task force.

In 2001, a new president, Giuliano Avanzini, and executive were constituted in Buenos Aires. The international situation during Avanzini's presidency had become distinctly less calm, with the attack on New York of 11 September 2001 and the wars in Afghanistan and Iraq, and in the Balkans. These political events had repercussions within the ILAE, especially in relation to the location of conferences. A crisis also arose relating to the IDM office, but Avanzini managed to keep the ILAE on a steady course. During his presidency, he was keen to enhance the activities of the Global Campaign and to democratise the ILAE. By 2003, the League had 92 affiliated chapters with a total of more than 16,850 chapter members throughout the world (ILAE 2004). Avanzini set as a priority for the quadrennium the achievement of full participation of all ILAE chapters in facing the problem of the gap between developed and developing countries. To this end, regional organisations modelled on the existing European and Asian ones were created in Latin America, North America and the Eastern Mediterranean. The process of creating an African organisation was initiated, and an ILAE regional agenda was devised. Moreover, a new initiative

known as the Chapter Convention was put in place to enable direct two-way interaction between the ILAE leadership and chapter members.

The first Chapter Convention took place on 5 October 2002 in Madrid (Spain) during the 5th European Epilepsy Congress, at which more than 40 chapters were represented. During the convention, the main objectives of the League and its policies in relation to regional organisation, the production and circulation of scientific and professional information, educational and research activities, and office organisation were reviewed and discussed. This Chapter Convention was a great success and has continued annually since. Two task forces were established: the Task Force for Regional Organisations (chair, Martin Brodie) and the Task Force for Subregional and Interregional Organisations (chair, Çiğdem Özkara). Both accelerated the regional development of the ILAE. Furthermore, Avanzini was keen to enhance the activities of the Global Campaign, for instance through demonstration projects and special projects on legislation, surgery, stigma and collaborative research. *Epilepsia* moved to its new publisher, Blackwell, in 2001, and after 8 successful years as editor, Tim Pedley handed over the reins of the journal to Robert Fisher, who had formerly edited the supplements (see Chapter 7). Avanzini asked Eureka

president Peter Wolf to elaborate a plan to make Eureka a global ILAE education agency, a process that is still ongoing. The executive was again expanded, this time by the presence of the IBE treasurer,<sup>8</sup> and the administration was additionally enhanced by promoting Peter Berry, the director of Association Resources (see below), from financial director to the new post of administrative director of the ILAE. At the same time, Avanzini opened a new ILAE headquarters office in Brussels under the line management and direction of Berry in Hartford. The new office would be concerned with membership issues, support the work of the secretary-general and help service the executive and ILAE commission meetings. During the 2001–2005 quadrennium, the 5-year contract with the IDM was coming to an end, and Avanzini proposed, and the ILAE executive unanimously agreed, to carry out an independent review of the cost-effectiveness of this new initiative. An external consultant was then engaged to evaluate the performance of the IDM office, an exercise that provided the basis for designing a new contract signed in 2005. Concern had arisen about the performance of the Election Committee at previous elections, and partisan interference with the procedures, but a proposal, by the information officer, that voting should be outsourced to a totally independent organisation (such as the UK Election Reform Society) was rejected. It was agreed that the Election Committee (previously the Nominating Committee, a change that occurred without formal ratification) should remain at five members, and the immediate past-president would serve as its chair. Various other changes were proposed to the constitution and bylaws, including restricting presidential candidature only to those who had previously served on the executive and limiting the number of candidates from a single region or country.<sup>9</sup> Lobbying on the part of staff and the executive was to be severely discouraged; *Epigraph* should include an information page containing statements by the candidates; and only the elected members of the ILAE executive should have a vote – thus removing the vote from the editor of *Epilepsia*, information officer and IBE officers. Finally, the total duration of membership of the Executive Committee

<sup>8</sup> Although since 1993, as an informal arrangement, the IBE treasurer (then Richard Holmes) had attended the ILAE executive and the ILAE treasurer (then Pete Engel) had sat on the IBE executive.

<sup>9</sup> No more than one per country; two members on the management committee from each region; or three of the five officers from one region.

should not exceed 16 years. These changes again reflected the increasing size and geographical diversity of the ILAE and the need to broaden representation.

A new administration, with Peter Wolf as president, was constituted at the General Assembly held in Paris in 2005. This General Assembly had to vote on a revised constitution with all the above and a number of technical changes, but also an additional clause that had previously been circulated by Wolf on behalf of the Danish Epilepsy Society when the elections had resulted in an executive with officers from only North America and Europe. This situation contrasted badly with the two previous executives, which comprised members of three and four regions, respectively, and it failed to reflect the considerable expansion of the ILAE's growth and activities in other regions. The amendment became known as the Danish amendment<sup>10</sup> and allowed the voting in of additional vice-presidents from fully operational regions of the ILAE. At the time, there were serious objections on several grounds, including the concern that this would be the first time that one region alone voted in an Executive Committee member. Nevertheless, following a heated debate, the motion was carried.

Only the Asian and Oceanian region met the criterion of the Danish amendment and so was asked to elect its own vice-president. In 2006, Chong Tin Tan from Malaysia joined the executive. The other change was to appoint two joint editors-in-chief of *Epilepsia* in place of Bob Fisher, who had stood down after 4 years.<sup>11</sup> As Simon Shorvon, having become one of the co-editors,

<sup>10</sup> The amendment reads as follows: 'In the event that after the global elections of President, two Vice Presidents, Secretary General, and Treasurer, and the appointment of Editor-in-Chief and Information Officer, any fully operational region of the ILAE (as determined by the Executive Committee) is not present on the Executive Committee, the Chapters of this region shall elect an additional Vice President. This Vice President will be a voting member of the Executive Committee and not be considered as a regional Vice President but unrestrictedly share the global responsibilities of the Executive Committee'.

<sup>11</sup> The position of editor was advertised, and a range of written applications were received. The Executive Committee discussed these and appointed Phil Schwartzkroin and Simon Shorvon to the editorship jointly. Their application had emphasised the value of having both a basic science and a clinical editor, and a US and non-US-based editor, and this approach struck a chord with the executive. Fisher's departure was prompted by what he felt to be the increasingly onerous task of editing the journal, and by his objection to the view that the editor of *Epilepsia* should not have a vote on the executive – a new ruling brought in during his tenure.



Peter Wolf, ILAE president 2005–2009.

was no longer information officer, it was agreed that from then on the 4-year terms of the appointed officers (*Epilepsia* editor(s) and information officer) would start and end at mid-term of the elected officers. It was felt that decision-making about these appointments would improve if it was carried out by a well-established rather than a new Executive Committee.

Constitutional issues continued to occupy the executive for the next 2 years, and further changes, including the replacement of the Danish amendment, are planned for approval in 2009. Wolf announced that the major emphasis of his presidency would be League activities in the fields of education, improvement of epilepsy care and translational research. Education was focused on transforming Eurepa into a global educational academy, as it was the ambition of the presidency to develop a global and multimodal educational system. To support this priority, an Educational Commission was appointed with Elza Márcia Yacubian (Brazil) as chair. Likewise, a Commission on Epilepsy Care was set up, chaired by the two new co-chairs of the Global Campaign Against Epilepsy, Giuliano Avanzini and Phil Lee. At the time of writing, the work on these priorities advances and continues.

The focus in the first half of this period of office was on education and brought a series of new initiatives

such as the expansion of distance education, which now provides four modules (genetics, EEG, imaging and pharmacotherapy). New residential courses were also instituted of which there are now five in Europe: the annual international advanced course in Venice-San Servolo started by Avanzini in 2001; the biennial Eilat course on pharmacotherapy initiated by Meir Bialer (Jerusalem) in 2005; and two annual courses that were started in 2007 – the ‘Migrating Course’ targeted at central and eastern Europe under the direction of Alla Guekht (Moscow) on behalf of the commission on European Affairs and the Baltic Sea Summer School, an initiative of the Scandinavian chapters in response to a proposal by Wolf. In São Paulo the annual Latin American summer school directed by Esper Cavalheiro (Brazil) took place for the third time in 2009. Yearly francophone courses in West Africa have been held since 2004 under the direction of Michel Baldy-Moulinier, Perrine Plouin (both Paris) and Verena Hézser-von Wehrs of the Eurepa office, supplemented by Lusophone courses that are a joint activity of the Portuguese and Brazilian chapters under the direction of Yacubian and José Lopes Lima (Lisbon), again with Eurepa support. A similar Anglophone series will hopefully soon be implemented by the chapters of the United States, United Kingdom and Australia. These courses feature a combination of train-the-trainer and educational courses, partly addressed at the various professionals allied with medicine who carry much of the burden of epilepsy care in the developing world. Other summer schools have been organised ad hoc or are under discussion as permanent events. All these courses are very popular among young clinicians and researchers considering a career in epileptology, and it is precisely the ILAE’s hope that good educational programmes will have a key role in attracting outstanding talent to the field.

The focus in the second half of Wolf’s presidency was epilepsy care, with special attention paid to sub-Saharan Africa and other developing areas. A strategy in Africa is to join forces with other organisations such as Basic Needs and the Working Group for Cysticercosis in South and East Africa.

### ILAE finances

As of December 1989, the League had reserves of \$138,323. This was the first time in its history that the League had substantial financial resources, and the question of how

to disperse the funds and how best to manage and account for them arose then and has continued ever since. Up until that point, the League was an essentially amateur organisation financially, with few funds and poor accounting. In 1990, the newly created Management Committee was charged with providing a plan for staffing and financial management services for the ILAE not later than the spring meeting of 1991. The minutes of the 1991 meeting include no such report, but a memorandum from Harry Meinardi dated 24 March 1993 contains a specific reference to the 1990 mandate and details, among other things, the advantage of continuity of a central office, the disadvantage of distance and suggests that the IBE provided a workable model. On 7 April 1993, Ted Reynolds circulated to the executive, 'which would have to live with the consequences' of structural change, a list of 'Additional comments for consideration'. He, like others, pointed to the stipulation in the ILAE Constitution that 'the Headquarters of the League is the office of the Secretary-General'.<sup>12</sup> At the executive's April 1993 meeting in Basle, a 'prolonged discussion ensued' on the matter, and Seino, Reynolds and Meinardi were to confer and report to the leadership in Oslo.<sup>13</sup> What transpired between April and July is unrecorded. The 7 July 1993 Oslo minutes of the 'new' executive contain a single statement: 'An administrative office will, for the first time, be established at Bielefeld, this being the residence of the SG.' For the time being, it seemed, the executive had put any major change on hold.

By 1993, the ILAE had resources of \$633,000 and needed urgently to take measures to formalise the accounting procedures. When Pete Engel assumed the position of treasurer, he set about radically improving the accounting position, and progressively introduced a raft of important changes. In previous years, the ILAE had maintained accounts in various countries, usually held by officers and not managed centrally. Indeed, it was quite unclear how many accounts existed, and one of Engel's early objectives was to try to identify and consolidate these. From the perspective of today it seems an extraordinary position for

the ILAE to have been in, but reflected the rather amateur position of previous years. Then, as now, the League derived its income from three main sources: its journal (an annual payment from the publisher), congresses and chapter subscriptions. Accounting for the congresses in particular was very difficult, and Engel pressed for better reporting.<sup>14</sup>

In November 1994, Engel decided to set annual budgets (the budget for 1993/4 provided for an income of \$172,500 and expenses of \$135,000). Engel also proposed to establish a long-term account to increase interest income with a view to keeping the League's capital and spending only the interest. According to the constitution, the ILAE was required to keep proper books and to have them certified by a qualified auditor at the end of each fiscal period, but in fact there had never been an official audit (ILAE EC Minutes, 8 May 1987; Engel 2006). An initial plan to hire a local accountant was abandoned in favour of hiring the Los Angeles branch of the international firm of Deloitte & Touche to set up a computerised bookkeeping system for the treasurer's office at a total cost of \$5,600 (ILAE EC Minutes, November 1994<sup>15</sup>). Engel also realised that decisions should be made about how much reserve money to place in short-term and long-term investments. Currently, the money was in a short-term account and earning relatively little interest.<sup>16</sup>

<sup>14</sup> The income in 1994 from these sources was \$428,668 from *Epilepsia*, \$74,985 from the Oslo conference and \$9,706 from chapter subscriptions. There was also in 1994, a large transfer (\$255,619) into the ILAE accounts which was the result of Pete Engel's efforts to centralise all the small accounts held by ILAE offices and commissions. The existence of these funds was previously not known centrally by the executive and had not previously been accounted for.

<sup>15</sup> This firm was chosen as they were already providing services for Richard Holmes who was treasurer of the IBE, pro bono. Engel hoped the ILAE and IBE might be able to join forces and the accountants persuaded to provide pro bono services to the ILAE as well. As it turned out, the cost was quite steep and the service, in Engel's view, not very helpful.

<sup>16</sup> One major item of expenditure was travel. In 1994, this amounted to \$54,186 (out of a total expenditure of \$484,719). In November 1994, the executive considered the issue of ILAE guidelines for travel on official duties for the ILAE, for example to Executive Committee meetings. The officers agreed that officers could apply to the treasurer for payment of business-class round-trip fares for intercontinental flights if no other source of funding was possible for transcontinental travel. This represented a change in practice (previously, only economy class travel was allowed).

<sup>12</sup> On 1 April 1993, Mazakasu Seino, then treasurer, replied to Meinardi that a centralised office implied a change to the ILAE's structure and would require an amendment to the ILAE Constitution. 'Frankly', he wrote, '[I] feel uneasy about it.'

<sup>13</sup> In Basle, Meinardi argued the advantages of having the administrative office in Holland, under his direction, and 'offered his own time at no cost'.

The issue of chapter dues was also problematic. Before 1990, there has been no formal accounting, and many chapters were not in the habit of paying dues or even knowing how many members they had, and had fallen in arrears. Engel proposed to write off past unpaid chapter dues, and plans were made for changing the system. Benefits for membership such as reduced rates for *Epilepsia* subscriptions and a personal copy of *Epigraph* sent through the post were introduced. Going forward, it was decided that chapters that had not paid or not responded to requests would be sent formal dues invoices in English or Spanish, where appropriate.<sup>17</sup> At this time dues amounted to a fixed fee of \$3 for every member in good standing. For some chapters in developing countries, even that rate was too high, and in 1999 the treasurer, Giuliano Avanzini, suggested that a variable fee be calculated as a fixed percentage of the national membership fee (agreed at 3%). For small chapters, however, the amounts would prove to be so low that they did not even cover bank charges for processing them, and a minimum was set at \$10–20 (lowered in 2001 to \$5).

In September 1995, at the 21st IEC in Sydney, Australia, Engel reported that revenues for the year were running well ahead of the proposed budget. The new accounting system had been in effect for 9 months and was working well. It had substantially eased the process of preparing the League's income tax return. Now, too, the executive moved to establish a long-term investment account with the intention of supporting the ILAE administrative offices. (The investment would be managed by Wertheim Schroder, and was expected to yield 7–10% annual interest.) In spring 1996, an accountant (Denis Rosenberg) was hired for bookkeeping, who donated to the ILAE part of the money he received for his work.<sup>18</sup>

<sup>17</sup> Some countries reported difficulties paying dues. Brazil would have to pay extremely high bank fees (\$400) to get the money out of the country. Indeed, bank fees would practically double the dues of the Lithuanian chapter, which preferred to send the money in cash when someone from that country came to Europe. Simon Shorvon wondered, in view of the fact that so little money was raised through dues, whether it would be simpler not to charge dues at all. But this option was rejected on the grounds that the chapters would then not feel any commitment to the League. Instead, at the suggestion of Berry and Avanzini, a solidarity fund was created to support the annual dues of chapters that could not afford to pay them to the ILAE.

<sup>18</sup> Rosenberg was a local Los Angeles-based accountant hired by Engel.

The ILAE's relationship with drug companies was beginning to be formalised during the 1990s. This was necessary as the marketing arms of pharmaceutical companies became more dominant and as their commercial activities became more intrusive. Tensions arose then and continued to surface over the next years. Indeed, the reason for the rapid increase in size of the congresses was the increasing financial support by the industry – through satellites and also the funding of delegates to the meetings (which usually amounted to providing the costs of travel, accommodation and registration fees). Previously, there had been few rules or guidelines, but by the early 1990s marketing departments began to push the boundaries beyond what the ILAE executive felt comfortable with. Commercially sponsored 'satellite' symposia first made their appearance at the Epilepsy International meeting in London in 1982. At the September 1983 executive, Fritz Dreifuss raised the question of potential competition with the League's activities, and the general consensus was that add-on meetings, superfluous committee meetings and commercially sponsored satellite symposia should be avoided as far as possible. But apparently the ILAE and IBE together had reconsidered, provided these events not clash with the main congress (Manelis 1986). The 17th IEC in Jerusalem in 1987 featured four satellite symposia, sponsored by Ciba-Geigy, Merrell-Dow, Warner-Lambert and Hoechst-Roussel.

Accommodating the increasing involvement of industry, however, proved difficult. During the 1989 congress in Delhi, criticism was voiced regarding the too visible involvement of Ciba-Geigy with the main theme on epilepsy and education. At the League's November 1994 Executive Committee meeting, the president reported that he often received requests for ILAE sponsorship guidelines. A working group on the topic was formed, and at the December 1996 executive, its activities were reported. The committee had met with representatives of industry sponsors at the 2nd European Epilepsy Congress at The Hague and worked out a set of guidelines. A revised version was circulated to all participants of the meeting, and to the Executive Committees of the ILAE and IBE. The guidelines covered 10 separate areas, ranging from general responsibilities of the academic sponsor through commercially supported social events to satellite symposia and support of travel and entertainment for participants. These guidelines are still largely in place, although the topic is one that arises periodically within the League executive.

The surplus income from the 20th IEC in Oslo reported by the treasurer at the Executive Committee meeting in March 1995 was \$74,985 and from the 21st IEC in Sydney, in 1996, \$100,000.<sup>19</sup> The League produced its first annual report for 1994; a second report, for 1995, followed. The financial demands of the Global Campaign triggered a decision by the executive to draw up a new bylaw stating that any decision involving a sum greater than 10% of the approved ILAE budget would need the confirmation of the entire executive.

Even considering the costs of public relations for the Global Campaign, the figures for 1996 showed that the ILAE had maintained a surplus in relation to the annual budget. Chapters had made an extra effort to pay their dues. As an audit by Deloitte & Touche was determined to be prohibitively expensive, the executive moved to have a limited audit (involving only the operational account, and the accounts held by the three officers, *Epilepsia* and *Epiglyph*) without requiring a major firm to do it. A fee of \$40,000 for the audit was approved. At the spring 1997 executive, the treasurer sounded a note of caution. Despite the League's healthy financial situation, revenues for 1997 would probably be down and expenditures up. Congresses were unlikely to yield as much money as in the past, and the ILAE had already dispensed a total of \$67,700 in loans to Eureka and to the organisers of the 3rd European Epilepsy Congress in Warsaw. Moreover, the League had committed considerable amounts to the Global Campaign, an audit, a website and an administrative review.

He need not have worried, for the financial situation continued to improve. By 31 December 1996, the total assets of the League were \$1,617,562 of which \$1,280,953 was in the operating account (ILAE Treasurer's Report, 18 March 1997). The officers were not, however, particularly happy with the way the League's endowment fund was being managed and would seek proposals for moving the ILAE accounts. At the end of 1997, the balance of the ILAE's fund had risen from \$1,526,668 to \$1,987,625. The amount in the Schroder account had returned 8.4% and stood at \$1,564,910. In 1997, the ILAE raised \$279,673 in cash compared with \$20,470 for 1996 (ILAE Treasurer's Report, 3 May 1998). Royalties from Lippincott-Raven

for 1997 were down with respect to 1996, owing in part to the discounted rate offered to ILAE chapter members, but subscriptions were up 19%. In 1998, the executive decided to close the Schroder account. An investment committee was created to work out guidelines for investment policy and to consider the possibility of hiring a professional investment manager.

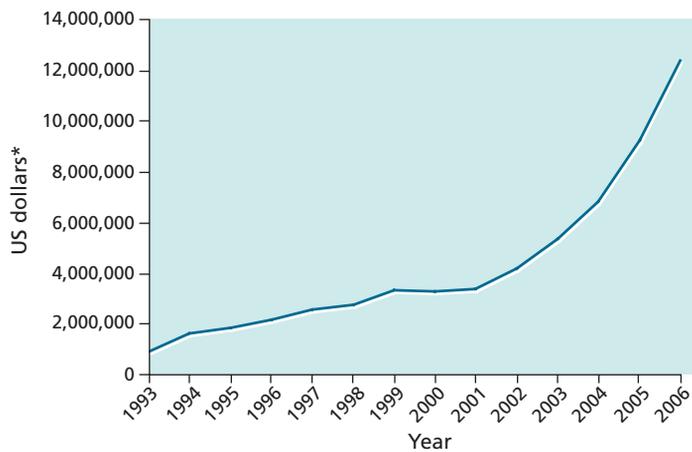
The quarterly report of the new treasurer, Giuliano Avanzini, for 1 July to 1 October 1998 confirmed a total fund balance for the year to date of \$2,194,720, up \$108,066 over the amount calculated on 30 June.<sup>20</sup> The investment policy was still being evaluated. Each commission now disposed of a budget of \$8,000 (\$4,000 each for 1997 and 1998). The ILAE had put aside \$90,000 in a discretionary fund as seed money for special projects. The intention was to raise further funds from industry. Some commissions had carryover funds from prior commissions. They would be asked to clarify what they planned to do with the money, and would be given a 2-year limit to spend it in.<sup>21</sup> Continuation of the rigorous financial policy started by the previous treasurer made it possible for the first time to have an official audit for the year ending 30 June 1999 (ILAE EC Minutes, December 1999).

In short, the League's financial situation was healthy. To carry on with innovative strategic actions, however, it would be prudent to look for some new fundraising possibilities to spare the ILAE reserve fund. Based on the recommendations of an independent auditor, the executive moved to set up formal agreements for congresses and to eliminate the practice of having dedicated funds

<sup>20</sup> Beginning with 1998, the League decided to change the date of its fiscal year-end from 31 December to 30 June (ILAE EC Minutes, December 1998). As this date coincided neither with the tax calendar year nor precisely with the meetings of the executive, amounts stated at various times differ.

<sup>21</sup> Over the years, the practice of funding commissions became increasingly more refined. In December 1998, the executive decided in principle to support commission activities if they fit into the League's objectives and if no money could be raised by the organisers themselves. Commissions were automatically awarded \$4,000 and could apply for additional funds, which were allocated on a competitive basis; but they were encouraged to raise their own monies for their activities. The Commission on Neurobiology had been drawing basic scientists to international congresses but had thus far received no money from the ILAE. In 1998 it asked for and received \$15,000 for a workshop on the neurobiology of epilepsy (WONOEP). This special funding of the WONOEP workshop continued, as it was recognised that the basic science activities of the ILAE were unlikely to find sponsors easily.

<sup>19</sup> ILAE treasurer's report, March 1996. Both amounts would increase. Surpluses tend to trickle in over a number of years, however, and the exact overall total is hard to specify.



Financial growth of the League 1993–present. \*In 2007 US dollar equivalent figures.

for each commission. Meeting on 20 August 2000, the executive decided that, from the 2002 European congress onward, surplus funds for the regional congresses would be distributed 25% to the local ILAE chapter, and of the remaining 75%, the ILAE would allocate 50% to the new European Commission (see below). In exchange, the ILAE centrally, not the local chapter, would carry the financial risk of the congresses. In principle, funds from external sources were to be applied to the specified commitments.

At that same meeting, the League's assets were reported to be \$2.8 million. Merrill Lynch representatives were invited to present an assessment of the ILAE investment strategy at the next executive meeting in Los Angeles. Following the presentation, the officers concluded that the League was holding too much cash, and moved its holdings in the Schroder fixed-income fund to a mixed portfolio managed by Merrill Lynch (\$252,251). It further moved to draw up a cash flow sheet showing approximately how much was needed to run the League's operations.

By September 2001, the League's total assets stood at \$2.6 million (ILAE EC Minutes, December 2001). This amount was down slightly from the previous reporting period owing to the decline in the stock market. The change of publisher of *Epilepsia* (see Chapter 7) was providing unprecedented levels of royalties, and in 2002 *Epilepsia* would deliver \$832,989 (ILAE EC Minutes, March 2002). The supplements programme had exceeded all expectations. Advertising was below budget, but sales of reprints to industry did very well.

In December 2002, the League's fund balance had swelled to over \$3.5 million. Expenses were \$1.1 million. Royalties from *Epilepsia* continued to be substantially higher, and expenses were reduced under the new publishing contract. In each of the following years, *Epilepsia* delivered a royalty surplus to the ILAE of over \$1 million and supplement revenue was also up against 2002.<sup>22</sup> The League's balance at 30 June 2003 was \$4.8 million. Following the treasurer's presentation to the executive in Lisbon later that year, the officers brought up once again the ILAE's independence of pharmaceutical companies as desirable, not just owing to conflict of interest but also because epilepsy drugs were becoming a lower priority for some big firms and the money could disappear (ILAE EC Minutes, October 2003). Individuals on the executive were also heavily involved with the pharmaceutical industry, and this was felt by some to represent a conflict of interest. Lessening dependence did not, of course, mean cutting ILAE ties with the industry completely. The executive asked the League's Finance Committee to brainstorm on the issue and to generate some best case/worst case scenarios, as well as to identify ways of diversifying revenues.

<sup>22</sup> The journal income only began to fall in 2006 in which year a number of pressures began to build. Also, Blackwell was taken over by Wiley in November 2006. The lower surplus was due largely to a reduction in advertising income as the world economy began to falter, but also to diminished income from supplements, as well as fewer requests for reprints and colour printings. An added and worrisome factor was the disturbance to publishing quality caused by the publisher's merger. In fact, the ILAE held high-level meetings with Wiley-Blackwell to discuss the situation.

In April 2004, the administrative director reported on the efforts of the financial office and Blackwell to come up with a marketing plan to increase the worldwide sales of online access to *Epilepsia*. A scale of prices was agreed that ranged from \$45 for high-income countries to \$25 for lower-middle-income countries. Low-income countries could access the journal free of charge. Phase I of the marketing plan, which targeted high-income countries, had already begun. At 31 January 2004, the League's total cash and investments amounted to \$5.2 million. Following the treasurer's report, discussion focused on the need to prepare for decreases in financial support from the pharmaceutical companies for the congresses. Moreover, the strategic plan needed to be updated. Finally, now was the time to consider stepping up research in developing countries. In April 2004, the executive agreed to calculate more carefully the administrative and routine expenses for a single fiscal year with an eye to putting money into a special projects fund to support educational, congress, editorial and research activities.

In December of that year, the executive moved to diversify the League's investments by including operating, intermediate and long-term reserve funds (60% of ILAE funds). The Finance Committee concluded that the League could afford to spend \$500,000 on new projects 'without putting the League in financial trouble'. Mechanisms would have to be devised for applying for projects as well as deciding how to allocate money to them. Despite the League's apparent prosperity, the impact of its fixed costs (such as that of the administrative offices) had to be kept in mind and the costs of the Hartford officer were continuing to rise sharply (ILAE EC Minutes, February 2005).

In March 2006, the new treasurer, Martin Brodie, told the executive that the League's operating budget was approximately \$2 million, 'and is as it should be' but the ILAE needed to be thinking about alternatives to the pharmaceutical companies for raising money for activities such as congresses. Possibilities included fundraisers, wealthy people with family members suffering from epilepsy and business-through-education schemes.<sup>23</sup> The auditor had

<sup>23</sup> The idea of fundraising on behalf of ILAE has been raised periodically throughout its history but never realised. Prior to 1960, the ILAE had occasionally received one-off donations from other epilepsy organisations but has never embarked on systematic fundraising, surviving on the monies raised from its subscriptions, investments, *Epilepsia* and congresses. The great improvement in the final position of the ILAE in the past 8 years has been due largely to the increased income from the latter two sources.

pronounced the ILAE's financial situation good, although there were a few issues of accounting and reporting to be dealt with. In March 2007, Brodie announced that he and Donna Cunard, of the Hartford office, were working on a finance book that would contain all the League's financial information, including a congress section with information about the losses and surpluses for each congress, to be updated for each executive meeting.

In 2006, the League decided change its fiscal year to accord with the tax year (December to December) and, in July, Brodie gave the Executive Committee a report of the 'short year' ending 31 December 2006. Net congress income from the three regional congresses held during the period was \$1,233,577: the congresses in Helsinki and Kuala Lumpur had returned surpluses; Guatemala had lost \$65,100. The League's net income was \$2,383,000. Investments had returned roughly \$620,000 (6.86%). Total ILAE assets at 31 March 2007 were \$13,387,282 but the next year, the League's operating budget was in deficit, partly a result of the loss on the Guatemala meeting and costs associated with a meeting in Sharm el-Sheikh (see below) which had to be moved to Luxor. The question of to what extent the ILAE should subsidise loss-making congresses in order to meet its global mission is one that is perpetually debated within the ILAE, now more than ever.

### ILAE administration

In 1993, as throughout its history, the League was in many ways an amateur affair. Every task, no matter how large or small, was undertaken by the Executive Committee members themselves or their colleagues, including, for instance, answering general queries, organising meetings, and visiting and evaluating the sites for congresses. From 1993, funds were made available for a half-time secretary in the office of the secretary-general and secretarial assistance with the office of the president,<sup>24</sup> but apart from this modest expenditure, there was simply no organised administrative support. As the organisation grew, conducting the business of the League with such minimal levels of support became increasingly difficult, and new steps towards bureaucratisation were phased in gradually over the next 10 years.

<sup>24</sup> \$10,000 was approved for 'secretarial and logistical support' (ILAE EC Minutes, May 1990). The only other administrative support was for the cost of accounting paid to Deloitte & Touche or Rosenberg.

In December 1996, at the invitation of ILAE treasurer, Peter Berry of Association Resources, based in Hartford, made a presentation to the executive meeting in San Francisco on the subject of association management (Berry 2006). In a separate but related move, at the spring 1997 meeting in Basle, Walter Schaw, a self-employed international consultant in leadership and management, was invited to propose solutions to the League's need for professional assistance. With the growing number of ILAE cost centres and the increasing complexity of the accounts and publications, the ILAE was having trouble keeping control over its finances. For example, as treasurer, Pete Engel had been able to manage the League's financial affairs only because he had access to professional staff at UCLA and because he had hired a professional accountant (ILAE EC Minutes, April 1997). Schaw envisioned three options: no change, outsourcing finances and accounting, or employing an association management organisation. He preferred the latter. At its first informal meeting in Dublin in July 1997, Engel's new administration considered a report Schaw had submitted in the interim. Schaw's intention was to present multiple competent management firms in the United States (including Association Resources) and Europe, but he felt an American firm should be chosen for the accounting function due to the complexities of the rules for non-profit associations incorporated in the United States. The officers decided to leave the ILAE secretariat in Bielefeld, and to hire Association Resources, with Berry as financial manager, to administer the ILAE's financial affairs.<sup>25</sup> A 2-year contract was agreed on, at a cost to the ILAE of \$24,000 per year.

Once into his presidency, Engel continued to streamline administrative activities. He decided that the minutes would henceforth be recorded in 'decisive' style, listing actions decided and naming the people in charge. He introduced a system for categorising commissions. Moreover, from May 1998, officers responsible for overseeing commissions would be required to give formal reports at executive meetings. The annual report, too, would become more formal, and beginning December 1999, the financial reports provided to ILAE Executive Committee members included statements on the assets and fund balance.

<sup>25</sup> Association Resources was already managing the affairs of the AES, with the obvious advantage of knowledge of the field but the disadvantage of appearance of conflict of interest. Peter Berry founded the company in 1983 and would be in charge of the ILAE contract. His wife, Sue Berry, was in charge of the AES contract.

Schaw was then asked to provide a further administrative review, and he proposed that the League be run according to corporate principles, with the president acting as chief executive officer. However, this proposal was rejected. The executive was clearly uncomfortable with the scope of the suggested change, which it recognised would alter the character of the ILAE. Interestingly, a similar proposal was made in 2007 when other management consultants were brought in, and again rejected, probably wisely. The secretary-general did nevertheless draft an amendment of a bylaw to define the role and scope of the president's activities and responsibilities.<sup>26</sup> Schaw led a meeting to devise a 'strategic plan' and a 'vision' statement, as well as a statement of 'values'. This was a costly and, some feel, a futile exercise, but very much in line with contemporary US management culture.

Back in 1991, in Rio, the ILAE secretary-general had noted that the current plan of having a minimal office at the locus of the secretary-general was quite different from that of the IBE, and that the ILAE office's ability to respond suffered accordingly.<sup>27</sup> The committee agreed that, at some point in the future, a permanent secretary and office might be needed. As president, Pete Engel also wished to see the administration centralised, and in August 2000 Schaw was asked to propose options. But decisions were left to the incoming executive. Among Engel's colleagues, only Giuliano Avanzini wholeheartedly supported the idea, and when Avanzini became president in 2001, he asked Berry to investigate the feasibility of opening an office in Europe given the preponderance of ILAE chapters (over 40) located there. After some months, Berry contracted with a management company in Brussels, Ernst & Young, to provide a bilingual staff of two people to serve as primary contacts with ILAE chapter leaders. Berry's own title changed from financial manager to administrative director. His charge included

<sup>26</sup> In April 2000, the executive moved to change ILAE bylaw 1.06 (Duties of Offices) to read, 'The President shall *set the general aims and policies for his period of office. The President shall* preside at meetings of the Executive Committee and the General Assembly, and shall appoint special committees and commissions.' The same meeting considered the results of a strategic planning meeting that had taken place the previous day. Opinion of how it had gone was mixed, with some members asking whether the incoming executive should be tied down by the strategic planning vision of the current executive and others querying the value of the whole exercise.

<sup>27</sup> When Peter Wolf became secretary-general of the ILAE, in 1993, he was given a staffed office for the first time in the League's history.

implementing new programmes previously carried out by volunteers, for example producing the annual report and working with the president to organise the League's administrative meetings, as well as helping the chapters to manage themselves better (Berry 2006). One reason for the initiative was to reduce the costs of the president's, secretary-general's and treasurer's offices – although of course, and perhaps inevitably, the reverse occurred, and even those on the executive who were in favour of the proposal guessed rightly it would end up costing more – in the 18 months to December 2007, the expenses of administration were over \$1.7 million compared to less than \$50,000 in the year 1998. There was also anxiety expressed in 2000 that a permanent central office might in the end become too powerful, as the executive changed each 4 years but the office would remain. The 'Yes, Minister' analogy of the British civil service was discussed. The step would be a big one for the ILAE. Was it really necessary? Could the League afford it? Would the new focus on process erode the commitment to epilepsy? In the end, the group moved to proceed, but gradually, rather than in a single step.

The amount of work required to conduct ILAE business was increasing. In 2000, the executive decided to meet three times a year, instead of twice, reflecting the greater amount of activity of the ILAE and its larger size and financial responsibilities. By 2002, however, this frequency proved too arduous for the officers (who were volunteers and had many other commitments), and the meetings reverted again to twice a year with the addition of one Management Committee meeting per year.<sup>28</sup> The Management Committee could go through the budget after their meeting and then circulate the report to be approved by mail. ILAE and IBE Joint Executive Committee (JEC) meetings were also helping to crowd the calendar. Moreover, the business to be conducted at meetings had mushroomed. At the December 2002 executive in Seattle, the administrative director announced that in future, minutes would be kept to 15 pages and would be proofread by a native English speaker. In April 2004, a new approach to the annual report was proposed that would provide slightly different information in odd-numbered years.<sup>29</sup> A decision of the 1997–2001 Executive Committee

that the annual report would bear the number of the year in which it was published rather than the previous year, to allow for updates until printing, had in the meantime been forgotten but was revived in 2007. Finally, at its December 2004 meeting in New Orleans, the Executive Committee members were presented with a draft of job descriptions for the posts on the committee. A committee consisting of the information officer, both vice-presidents and one IBE representative was appointed to review the job descriptions and present them to the next Executive Committee meeting.

### Congresses

Since its very inception in 1909, one of the most important activities of the ILAE has been to organise conferences and congresses. These were initially small affairs and often tacked on as an extra day to the congresses of the World Federation of Neurology (WFN), for instance, or held in conjunction with the international EEG and clinical neurophysiology congresses. (The converging development of congresses of the ILAE and IBE is described in Chapters 2 and 9) Since 1983, the joint international congresses of both organisations are held every 2 years and have been growing in size. An attendance of 1,000 persons was exceeded for the first time in Hamburg in 1985. The 20th IEC held in Oslo in 1993 attracted over 2,000 delegates – easily a record – and the meeting was an outstanding success. This change in scale was fuelled by greatly increased sponsorship from the pharmaceutical companies, eager to advertise the raft of newly licensed antiepileptic drugs, and in 1993 new companies were beginning to enter the field (in 1993, notably the global industry leaders Johnson & Johnson, the manufacturers of topiramate, and Glaxo Wellcome, the manufacturers of lamotrigine).

Attendance continued to increase. The 1995 conference in Sydney attracted over 3,000 delegates, and the congress in Prague in 1999 had 4,260 participants (ILAE EC Minutes, December 1999). As the congresses grew in size,

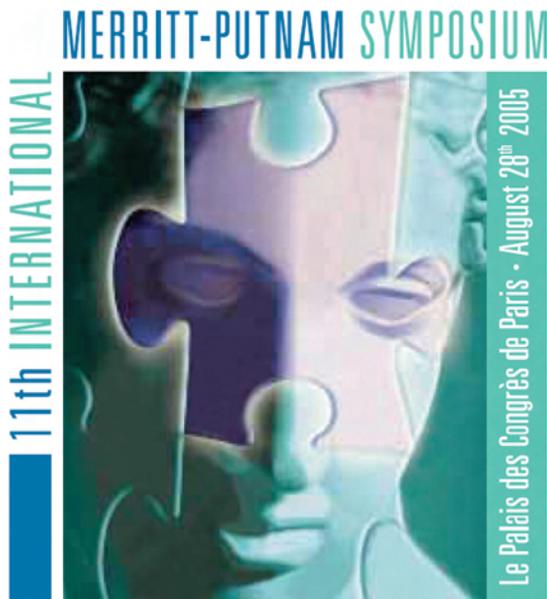
<sup>28</sup> At this same meeting, the suggestion was made to increase the length of the Executive Committee meetings to 2 days, as the League's activities were expanding.

<sup>29</sup> In odd-numbered years, the annual report would be called annual report/directory and include rosters, lists of chapter officers and chapter reports. In even-numbered years, the report would offer information on selected League programmes and some feature articles. This pattern was in fact never completely instituted.

Launch of the Global Campaign Against Epilepsy in Geneva – the joint initiative between the ILAE, IBE and WHO. Shown in the photograph (from left to right) are Dr J. Engel, Jr. (ILAE), H. de Boer (IBE), Dr Yach (WHO), Dr Gro Harlem Brundtland (Director-General of WHO), Dr B. Saraceno (WHO), Dr L. Prilipko (WHO), Dr E. Reynolds (ILAE) and P. Lee (IBE). (Photograph: courtesy E. Reynolds)



Merritt–Putnam Symposium announcement, 2005. The Merritt–Putnam Symposia were founded to commemorate the work of Houston Merritt and Tracey Putnam, who are credited with the discovery of the antiepileptic action of phenytoin. The symposia were initiated in 1987, on the 50th anniversary of this discovery and now take place in each International Epilepsy Congress, and also many of the regional and some of the national congresses. The symposia have become a highlight of the meetings.



number, and in terms of financial cost and surplus, the question of organisation became a pressing one. Up until then, each conference appointed its own organising company, almost always a local firm, and drew up a contract with them. The organisation was often haphazard and at times calamitous. Financial problems were not uncom-

mon, and were sometimes so serious that they threatened the well-being of the League (for instance, at the London congress of 1982). At core the problem was that the job of organising the conferences was left to the local ILAE members (often senior neurologists) who often had little time to devote to the task and inadequate organisational

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1994	1st European Congress on Epileptology	Oporto, Portugal
1996	2nd European Congress on Epileptology	The Hague, Netherlands
1998	3rd European Congress on Epileptology	Warsaw, Poland
2000	4th European Congress on Epileptology	Florence, Italy
2002	5th European Congress on Epileptology	Madrid, Spain
2004	6th European Congress on Epileptology	Vienna, Austria
2006	7th European Congress on Epileptology	Helsinki, Finland
2008	8th European Congress on Epileptology	Berlin, Germany

**Table 2** ILAE regional congresses: European Congresses on Epileptology.

know-how.<sup>30</sup> In May 1998, the ILAE executive considered the situation and concluded that the issue was not really lack of guidelines but a loss of control of the process. Accordingly, the ILAE and the Commission on European Affairs (see below) appointed a working group to guarantee better standards of preparation, and to ensure that future European congresses benefited from advances in standardising the international meetings. Richard Holmes, then president of the IBE, who had already taken part in discussions on congresses held in Florence and Madrid (Table 2), was appointed a member of this working group.

In 1999, Pete Engel went a step further and proposed that the ILAE appoint its own in-house conference organising company to manage both the regional and international congresses. Holmes, who had gained extensive valuable experience by being previously treasurer of the IBE, a task that involved dealing with congress budgets and other matters such as choice of site, and also leading the organisation of the 1997 IEC in Dublin, offered to step down from the IBE presidency to head up the League's International Director of Meetings (IDM) office. This development sparked intense discussion within the ILAE Executive Committee. There was, first, no agreement about whether an in-house conference organiser

was needed or wise; second, the sense that an officer should not take up this position; and finally, a feeling that if the League was to outsource its conference organisation, it should do so by tendering in open competition. Eventually, the Executive Committee accepted Engel's proposals, and Holmes was appointed without putting the post out to tender. The presidency of the IBE passed to Philip Lee. Holmes later set up a limited company, Chancel, to conduct this work, with the proviso that the League and the Bureau would remain his sole clients. A level of fees was agreed. These developments were the source of considerable dissention and difficult discussion amongst the executive.<sup>31</sup>

Holmes responded to the demands of his new post with great enthusiasm and skill. Over the next decade, the IDM arranged all the international and regional conferences of the ILAE and IBE, and there is no doubt that the organisational standards and the quality of the meetings were greatly improved. Holmes and his staff (particularly Soazig Daniel) brought order to what had been to date an extremely chaotic system. Over the next few years, the IDM role grew. A system of bids for conference location was formulated, and the IDM assessed each location and provided the JEC executive with his detailed opinion about each competing bid. The programmes of the international conferences were standardised and the current format was established: plenary, post-plenary, parallel, breakfast and poster sessions, and slots for pharmaceutical company-sponsored satellites. The current model of a Scientific Advisory Committee and an Organising

<sup>30</sup> The experience of the 3rd European Congress in Warsaw illustrated to the ILAE executive the lack of control. In 1996, the League loaned the congress organisers \$30,000 from the proceeds of a congress held in Oporto (see below). In 1997, the organisers asked for another \$20,000 to support participants from Eastern European countries. The executive balked, and the organisers were told they should first approach drug companies for support. Guidelines for European congresses are very similar to those for the international IBE/ILAE congresses, but unfortunately were not adhered to by the local organisers. There was anxiety that the conference would make a loss and the liability reflect on the ILAE centrally despite the fact that they had no fiscal control over the organising company. In the event, the congress was a great success, with an excellent turnout and a good scientific programme, and made a satisfying surplus.

<sup>31</sup> Up to then, potential congress sites had to be scoped out by members of the ILAE and IBE executives themselves, taking time and effort. Moreover, the actual organisation of the meetings had to be left to the local chapters who usually employed local companies, and the quality was highly variable and the expense often excessive. The League executive had the impression that this system was providing poor value and 'pouring money down the drain'.

Committee was set up, and guidelines for the composition and operation of these committees were formulated, and their meetings were organised and run by the IDM office. An online system for submitting and scoring abstracts was introduced in 2002, first for the European congresses. The IDM also negotiated with the hotels, conference venues and vendors of such items as conference bags. Systems for evaluating congresses were also introduced, and an ILAE working group produced a lengthy and influential report analysing the 2003 Lisbon conference, on the basis of the IDM's findings.

At the April 2000 executive, Holmes reported on the 4th and 5th European Congresses, and broached several general policy issues. Obtaining support from the drug companies was getting increasingly harder. The industry was insisting on being allowed to do product advertising both in the exhibition halls and in abstract books. A reduction in support seemed possible. Moreover, the ILAE had chosen Buenos Aires as the location of its 2001 congress, and companies were indicating that they would prefer not to go there. Holmes also mentioned that the pharmaceutical companies had taken to organising their own standalone meetings, where they were freed from the constraints and regulations imposed by the ILAE, and had drawn back from the next European congress in Florence. The executive voted in some minor lessening of regulations (allowing, for instance, advertising on the covers of the abstract books) and asked the IDM to set up a corporate round table between the industry and the ILAE on the topic of support from drug companies.<sup>32</sup> In the event, the 24th IEC in Buenos Aires in 2001 was a

success, attracted around 3,000 attendees and generated a \$230,000 surplus.<sup>33</sup>

Drug company sponsorship was not the only congress-related problem the League had to contend with. The original location of the 2001 international congress was chosen to be Indonesia. But then the Portuguese chapter objected because of political difficulties with East Timor, putting the executive in a dilemma. The officers were let off the hook, as it were, when Indonesia backed off because of the financial crisis in South-East Asia (P. Engel, personal communication). Safety, too, turned out to be a recurring issue with regional congresses. In 2006, the Asian/Oceanian congress that had been planned for Bali was moved to Kuala Lumpur when a terrorist bomb struck at a place rather close to the expected congress venue. In a remarkable spirit of good neighbourliness, the Malaysian chapter co-hosted the event together with the Indonesian chapter. In the same year, another bomb attack hit close to the planned site for the 1st Eastern Mediterranean Congress, Sharm el-Sheikh, and this meeting was postponed and moved to Luxor. Israel's long-standing offer to host the European congress (the 1987 ILAE/IBE congress was held in Jerusalem) has repeatedly been thwarted by delegates' fear that it is an unsafe destination. Once again, however, the spirit of friendly cooperation that is rightly a source of pride to the ILAE prevailed, and the German chapter invited Israel to be co-hosts of the 2008 European Congress of Epileptology in Berlin. Portugal's complaint raised the larger issue of to what extent ILAE congresses should be chosen to avoid political dissention. This question is a recurring one, particularly in relation to less democratic countries, and has to be balanced against the need to hold conferences in different regions (Indonesia in 2001 and Singapore in 2007 are recent examples). Furthermore, when Tunisia was chosen as the

<sup>32</sup> Discussion of whether to form a corporate advisory board (corporate roundtable) had been brought up in 1998 and deferred to the spring meeting. The objections now were the same as earlier: the ILAE could be seen to be unduly influenced by the pharmaceutical industry. Another potential problem was a lack of continuity caused by constantly changing staff owing to the rapid pace of pharmaceutical company mergers. The benefit of such a roundtable would be that it would open a dialogue with industry. In addition, the IBE and ILAE would be able to raise important funds for clearly defined projects. Warsaw would provide a test case. But there was no clear mandate from the ILAE and IBE to pursue the effort, and it was stopped. A meeting to discuss the issue was planned for Prague. At the December 1999 Executive Committee meeting in Orlando, Florida, Pete Engel reported that the pharmaceutical companies were pushing heavily regarding the industry guidelines to get permission on product advertising at congresses. In particular, they wanted product advertising to be permitted outside the exhibition halls. This was not allowed.

<sup>33</sup> The local league was not happy with the surplus and outcome of Buenos Aires and questioned the accounting procedures. Accountants hired by the ILAE and IBE for the congress were asked to evaluate and answer the report sent by the accountants of the Argentinean league (ILAE EC Minutes, December 2002). As of April 2004, the issue had been determined to involve return of VAT for registrations and was still outstanding. In December 2004, the president reported that despite a forensic audit finding no evidence of fraud, the local chapter decided to report the situation to the General Inspection of Justice on the grounds of alleged mismanagement of the IEC. The case was eventually dismissed, and the whole episode viewed by some protagonists as vexatious and based on personal enmity.

location of the 25th IEC in 2003, it was reported that the pharmaceutical companies would not sponsor satellites there and that US participation would be minimal.

These considerations were major challenges for the ILAE executive, and erratic decisions were made (for instance, reversing the decisions to hold the conference in Indonesia and Tunisia but accepting Singapore). The need to support developing countries was emphasised by the new president, Giuliano Avanzini, who recapped the experience of Prague, pointing out that of the 4,260 delegates overall, 50% had been sponsored by pharmaceutical companies, but of the 753 delegates from developing countries, only 3 had been sponsored by the industry. The importance of pharmaceutical industry investment was demonstrated by the Prague congress, where it was estimated to have amounted to \$7 million, \$5.5 million of which was allocated to support delegates from developed countries. What Avanzini was questioning was whether this division fulfilled the ILAE primary objective of filling the gap between developing and developed countries.

The planned congress in Tunis posed a special problem. Tunisia had been chosen as there had been no international congress in Africa, and the ILAE was deliberately trying to reach out to underdeveloped chapters and to bridge the gap between the developed and developing world. However, the worsening global security situation following the attack on New York on 11 September 2001 and the wars in Afghanistan and Iraq were then considered to make going to Tunisia more hazardous. The IDM was against the decision for other reasons: the congress venue was problematic, the Tunisian colleagues had no experience with organising large congresses, special arrangements for transportation would have to be made, and the pharmaceutical industry was threatening to reduce sponsorship. Indeed, one company wrote to say they would not attend as there were 'other neurology congresses organised in better and safer places' (ILAE EC Minutes, December 2002). Finally, there was clear anxiety, especially from the IBE, that the congress would lose money, which the IBE could not afford. A vote was held at the JEC, and although the committee was split (Avanzini and Shorvon voting against a move), the majority favoured a switch and Lisbon was proposed as an alternative. Avanzini pointed out that: (i) the International and regional congresses are not meant to generate profit but to provide the ILAE members with a privileged opportunity for scientific updating and fruitful exchange

of experiences; (ii) advice from the IDM was to be considered as a helpful contribution to the discussion, but the duty of the IDM is to put into effect the ILAE and IBE decisions and not vice versa; (iii) Tunis was chosen according to the ILAE's strategic priority of bridging the gap between the 'developed' and 'developing' worlds; and (iv) the ILAE Executive Committee decision was to be considered only a recommendation, because according to the constitution and bylaws, the final decision was up to the General Assembly. Accordingly, a ballot was circulated among the ILAE chapters, and the voting process was completed on 13 March 2003: out of 129 votes, 67 votes were in favour of moving the IEC away from Tunis.

Avanzini then travelled to Tunisia and Saudi Arabia personally to explain the matter to regional representatives, who were extremely disappointed with the decision. The congress was ultimately moved to Lisbon. This experience chastened the ILAE executive, who were in no mood to change congress sites again, and it became a factor in future decisions. Avanzini was keen to reassure the African and Arab nations that the decision did not mean a weakening of the resolve of the ILAE, nor his own deep commitment towards the developing world.<sup>34</sup>

<sup>34</sup> Avanzini wrote in the ILAE Annual Report: 'Originally the 25th International Epilepsy Congress was to be held in Tunis under the leadership of Amel Mrabet in recognition of the outstanding activity of the Tunisian epileptological community and of the strategic priority of the African continent in ILAE/IBE policy. However, the international political situation led the ILAE and IBE to move the congress away from Tunis. On behalf of the ILAE EC and General Assembly I would like to express here our great appreciation for the tremendous effort of Amel Mrabet and her collaborators in organising the meeting until that time and our discomfort and sorrow for not being able to confirm the original destination ... In no way should this change of location of the 25th International Epilepsy Congress be seen as due to a lessening of ILAE commitment to Africa and to the developing world in general; rather the ILAE EC decided that a substantial part of the expected surplus generated by the congress will be used to create a bursary system to promote the participation of delegates from developing countries. Thanks to this resource it will be possible in Lisbon to hold the Convention of African delegates to start the process of creating an ILAE African Regional Commission' (2003). However, this only partially compensated for the frustration of being forced to transfer the congress from Tunisia, which was a step backward in our mission towards the African continent. This led the present ILAE Executive Committee to reconsider the League's organisation and propose a number of constitutional changes aimed at avoiding the risk that our policy may be conditioned by undue external constraints in the future.

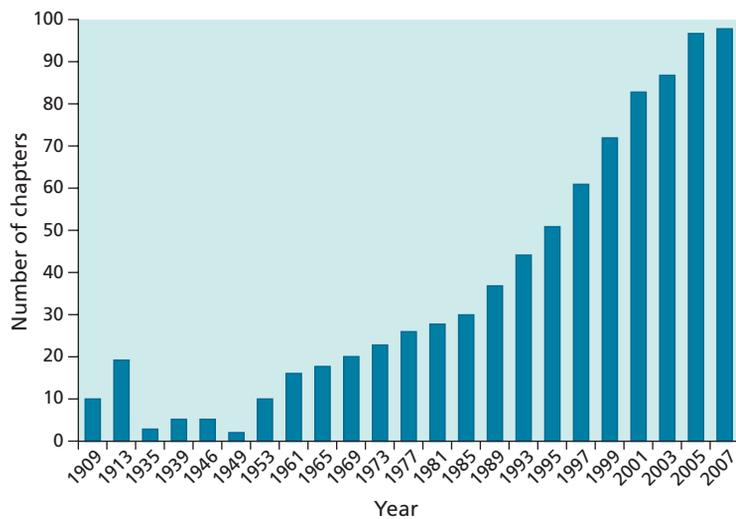
One argument in favour of appointing Chancel to run ILAE conferences was the skill of the IDM in negotiating with the pharmaceutical industry would yield greater financial returns to the ILAE as well as the other benefits. Holmes had agreed to show how his appointment would increase congress revenues, but over the next few years this proved difficult to do, not least because the surplus from congresses was often only finalised years after the event. Indeed, at the August 2000 meeting of the ILAE executive the point was made that the costs for running the office of the IDM should be considered as an investment that was not expected to turn a surplus until it had been running for a number of years. Indeed, it has proved difficult to estimate exactly what, if any, was the financial value of appointing the IDM – although the improved quality of conference organisation has been very clear. The international congresses were turning in healthy surpluses, but the regional congresses did not necessarily follow suit. Whereas the European congresses were large and well sponsored and very profitable for the League (the Madrid conference, for instance, produced a surplus of 750,000 euros), those in other regions were less profitable. The 2nd Latin American Epilepsy Congress in Iguazu Falls had returned a surplus of \$65,000. In contrast, the 4th Asian and Oceanian Epilepsy Congress in Nagano, Japan, was unlikely to deliver any surplus owing to the high costs (ILAE EC Minutes, December 2002). In 2003, a row erupted when the ILAE treasurer instigated,

without the knowledge of the Executive Committee, an investigation into the finances of Chancel. A variety of reports were commissioned, and claims and counter-claims made. The president and other executive officers were annoyed by the actions and in the end the matter was not pursued. Another problem was the question of the location of the 2007 IEC, this time because of the recent experience of Simon Shorvon in Singapore.<sup>35</sup> Avanzini and his executive affirmed their support for Shorvon, and made arrangements for the conference that were acceptable to him. Finally, a further spurious row also blew up relating to financial aspects of the Buenos Aires conference which required the ILAE to provide legal support to Natalio Fejerman, the previous ILAE secretary-general. The affairs of the league were difficult at times, and Avanzini steered the ILAE executive skilfully through these choppy waters.

### ILAE chapters and chapter enlargement

In 1993, the ILAE executive was determined to try to increase the number of its chapters, which then amounted to 40. At first, however, lines of communication with the existing chapters needed to be established. The office of the new secretary-general was faced with an almost complete lack of organisational structure. About half of the contact addresses of the existing chapters turned out to be wrong or outdated, which made clear how few people actually had participated in the organisation's life in the previous years, including the elections. This improved when multilingual Irene Kujath in the secretary-general's office chased everybody down by mail, phone and fax (e-mail was not yet in use) and made it her priority to establish a reliable chapter database. This was a difficult task that took time and much effort, and by September 1995, still only 21 chapters were in good standing, 18 chapters had not responded and 7 had never paid dues. An important step forward was a society booth at the international congresses which the ILAE instituted in 1995, and where the secretary met many chapter representatives face to face. Foreign currency transactions remained a problem in the collection of dues. Cuba was maintaining an escrow account in local currency, and Romania had been offered a similar option. Morocco could not pay dues because it did not know how many members it had. Brazil was experimenting with paying via a credit card account.

<sup>35</sup> In 2000, Simon Shorvon was seconded from his London post (professor of neurology at Queen Square) for up to 3 years to the directorship of the National Neuroscience Institute in Singapore, and awarded a large research grant to carry out genetic research into epilepsy and other neurological conditions. In 2003, Dr Lee Wei Ling, who was his deputy, complained about the conduct of the research project, and this resulted in a series of inquiries. The British General Medical Council dismissed the complaint and the Singaporean authorities then took the General Medical Council to judicial review in the UK High Court. The High Court verdict was a withering rebuttal of the Singaporean position. Shorvon considered the complaint totally without foundation and the result of other issues. These were made known to the ILAE executive, and his university in London, and both expressed their support of his position. He had in 2001 successfully promoted Singapore to the ILAE executive as the site for the 2007 IEC, and the ILAE executive debated whether to move the conference away from Singapore in view of the attack on one of its members. Partly in the light of the painful experience in Tunisia (and Indonesia), it was decided to go ahead with the conference, but without Lee involved in its management.



Between 1993 and 1997 alone, an additional 20 chapters joined the League.

Overall, the policy for dealing with non-payment of dues remained unclear.

In July 1993, Turkey, Burkina Faso and Taiwan were provisionally approved for membership, as was India, although contingent on complete and formal separation of its IBE and ILAE chapters within 4 years.<sup>36</sup> By April 1995, the Czech Republic, Egypt, Greece, Moldova and Lithuania were ready for provisional acceptance, and new contacts had been made with Belgium, Bosnia, Honduras, Iceland, Iran, Malta, Macedonia, Tunisia and Zimbabwe. Secretary-general Peter Wolf tried in many countries without chapters to identify colleagues with an interest in epilepsy and encourage them to establish national branches. Thus, on the way to the Executive Committee meeting in Rheinfelden in April 1995, he buttonholed<sup>37</sup> a group of 54 doctors from 12 Eastern European countries on visit in Bonn, and gave them copies of the League's roster.

In March 1997, ILAE past-president Ted Reynolds attended the First Pan-Arab Congress in Riyadh, Saudi

Arabia, which attracted over 400 delegates. As of 1997, the secretary-general (Wolf) estimated that the League had 11,000–12,000 individual members. At the close of Reynolds' administration, the chapters numbered 62 (Reynolds 1998). By March 2001 there were 77 chapters,<sup>38</sup> according to the president, Pete Engel. The establishment of Kyrgyzstan in a short 3 years was thanks to a visit by the Global Campaign and Wolf.

The number of chapters kept growing. One of the main objectives of the new headquarters office in Brussels was to maintain the contacts with chapters that had been established in Bielefeld, and integrate the new chapters into the structure. In 2002, when the Brussels office started its work, of the League's 86 provisional and approved chapters (based on the minutes), 82 had responded to requests for information and now – for the first time – there were good lists of the officers of each chapter. An effort to obtain members' lists was less

<sup>36</sup> At its April 1997 meeting, the executive announced that India had established an ILAE chapter under the name Indian Epilepsy Society, and moved to accept it as a full chapter of the League despite some concern that 'personalities active in the field of epileptology' were missing from the roster.

<sup>37</sup> He also visited St Petersburg and clarified some of the problems of the Russian chapter, including internal politics and the death of the chapter's president (and consequently loss of information) before a functioning structure had been established.

<sup>38</sup> Algeria, Argentina, Australia, Austria, Brazil, Bulgaria, Burkina Faso, Canada, Chile, Colombia, Republic of Croatia, Cuba, Czech Republic, Denmark, Dominican Republic, Ecuador, Egypt, Finland, France, Georgia, Germany, Great Britain, Greece, Guatemala, Hungary, India, Indonesia, Ireland, Israel, Italy, Jamaica, Japan, Jordan, Kyrgyzstan, Latvia, Lebanon, Lithuania, Macedonia, Mexico, Moldova, Morocco, The Netherlands, Norway, Panama, Peru, Poland, Portugal, Romania, Russia, Saudi Arabia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Taiwan, Thailand, Tunisia, Turkey, Ukraine, United States, Uruguay, Venezuela, Yugoslavia, Zaire.

successful.<sup>39</sup> Bringing chapter constitutions into line with the ILAE's constitution was another persisting problem. The ILAE and IBE prefer to retain separate organisations, but some countries have joint chapters. Many constitutions did not limit the terms of officers. It is important that the chapter has broad representation within a country, and not a single group, but in some countries this was difficult to ensure. Even the definition of a 'country' causes problems, as the application of Hong Kong showed. These were difficult issues requiring tact and judgement.<sup>40</sup>

### Regional groupings

One of the major achievements of the ILAE since 1993 has been to establish meaningful regional organisations which hold congresses, conduct educational activities and provide a framework for the professional development of epilepsy within the region. When it started, this was a new phenomenon. Previously, the ILAE simply comprised

its national chapters and international executive. The regional agenda developed first in Europe, which had the largest number of chapters and the most active ones, and then was quickly taken up in Asia and Oceania and in Latin America. Subsequently, the ILAE executive developed plans for further regional activity in North America, the Eastern Mediterranean Region and in Africa.

The new attention to this issue was in fact precipitated by events in Europe. In September 1992, a scientific meeting entitled Epilepsy Europe was held in Glasgow. The conference represented the culmination of several years of activity aimed at establishing a European epilepsy grouping – an independent effort spearheaded by Martin Brodie from Glasgow who at the time held no position in the ILAE. Brodie constituted a group calling itself the European Society for Epilepsy to solicit support from pharmaceutical companies. Archival correspondence reveals the initial responses of the ILAE leadership to this initiative, which was perceived as a threat to the League's dominant position in Europe. The matter was discussed at length during the spring 1992 Executive Committee meeting. On 30 June 1992, Harry Meinardi sent a letter to all the chapters and to the executive that read, in part, 'As president of the ILAE I have the following message: When the United States of Europe will have come into existence[,] the ILAE constitution requires the formation of one national organisation, the European Epilepsy Society. As long as this is not the case[,] each nation has the right to its own national organisation which is a chapter of ILAE. At present there is no place for [a] European Epilepsy Society separate from the ILAE and its national European chapters.'

The parties met for discussion in Glasgow and, confirming an agreement which was reached there, on 11 December 1992 Meinardi sent a more conciliatory letter to the ILAE executive and to those of the ILAE chapters in Europe, which read, 'A commission is preparing a memorandum for the executive of the ILAE to advise on the best way to cope with regional needs, in particular the European desire for more coordinated activities.' The issue was debated at the ILAE executive's Basle meeting in April 1993, and Ted Reynolds proposed that the recommendations of the 'Working Group on European Coordination' be accepted. Following 'considerable discussion ... regarding the appropriateness of these activities for the League', the motion passed by a vote of 6 to 1 with 2 abstentions.

<sup>39</sup> On a number of occasions, the information officer, Simon Shorvon, raised this point with the executive. Between 1909 and 1939, membership lists were regularly published in *Epilepsia* – and he looked forward to the time that this practice would be resuscitated. It seemed to him absurd that the ILAE did not have a list of individual members and that the absence of a list was a significant impediment to efficient administration. Numerous advantages of a centrally held membership list were suggested. However, some countries were reluctant to release their lists. It was also suggested that direct approaches from the executive to individual members would change the nature of the ILAE, which was acting currently (but not always in its history) as what was essentially a federation of national chapters. For these reasons, to date, no comprehensive list has been formed.

<sup>40</sup> At its October 2003 meeting in Lisbon, the executive agreed 'country' would be defined using the convention for WHO regions. Still problems persisted. In December 2002, the secretary-general had reported to the Executive Committee that health authorities in the Republic of China were willing to create a chapter of the ILAE only if Taiwan changed its name to Taiwan-China. Taiwan, however, would not contemplate a name change. In February 2005, the executive agreed not to ask Taiwan to change its name. To China, the executive responded that the current constitution did not allow more than one association per country, but that an amendment to this was in process. An amendment was devised and approved by the General Assembly in 2004, and the People's Republic of China joined the league in August 2005 at the Paris General Assembly (ILAE 2005). Subsequent applications by Gibraltar and Palestine, which were not 'countries', meant that the constitution might also have to be changed again. In December 2004, the ILAE executive moved to refer the issue of defining 'country' to the Constitution and Bylaws Task Force.

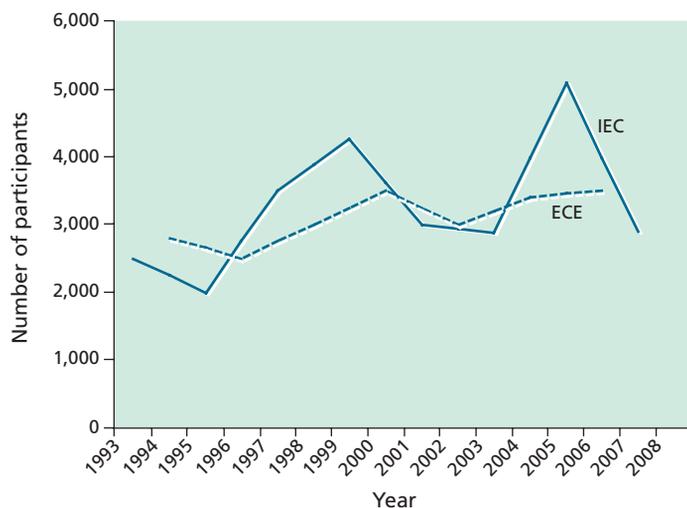
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When he became president, later in the year, Reynolds in consultation with the other European members of the executive set up two important structures – the Commission on European Affairs (CEA; originally the European Commission, the new entity was renamed to avoid confusion with the similarly named administrative body of the European Union in Brussels) and the European Advisory Council (EAC). The commission comprised eight members, and its remit was to improve lines of communication within Europe and to further the objectives of the League regionally (Reynolds also asked the incoming chair of the commission to ensure that the evolution of a breakaway group was stopped). The EAC was designed to be a ‘parliament’ for the European chapters, with every chapter having a single seat and a single vote. Each chapter chooses its own representation. This structure – of a commission and an advisory group – was established with the intention of giving each chapter a stake in the work and activities of the region and to act as a buffer against any more extreme ideas. It functioned exceedingly well and became a model for other regional commissions in later years. It was undoubtedly one of the major accomplishments of the Reynolds presidency. Reynolds appointed Simon Shorvon as chairman and Martin Brodie as secretary of the first European commission and Raffaele Canger, Péter Halász, Svein Johannessen and Heinz Gregor Wieser as other members. As ILAE president and secretary-general, Ted Reynolds and Peter Wolf were ex officio members. Brodie’s appointment into this new ILAE structure defused the desire to set up an alternative

organisation. Although the Glasgow conference was held, the concept of a European Society for Epilepsy withered away, and no further alternative conferences were planned. Later, the regional commissions evolved a system by which some members were elected by the chapters of the region (this differed from the traditional commissions whose membership is entirely appointed by the president after consultation with the executive).

The first European regional congress was held in Oporto in 1994 and drew 2,380 delegates. In 1995, guidelines for the European Congresses of Epileptology were drafted by the commission and approved by the ILAE Executive Committee meeting in spring 1997. These serve still, with modifications, as a model for regional international congresses. Among other things, the guidelines provided for a distribution of surplus monies – 50% to the European Commission and 25% to the ILAE centrally and to the local chapter. Due to the success of the European congresses, the CEA thus rapidly accumulated funds.

The commission also became an active and influential grouping within the ILAE. It made, immediately on its inception, ambitious plans for a European agenda, and the funding provided by congresses provided support for these. Politically, Europe had just experienced dramatic changes, and most of the Eastern half of the region had to be brought on level with the progress of epileptology in the Western world in the previous decades. Two immediate approaches were taken. The first was to create a document on standards of care across Europe (Brodie *et al.* 1997) that could be used as a health political instrument in



Numbers of participants at the International Epilepsy Congresses and the European Congresses for Epileptology, 1993–present.

all countries. The second was to establish the European Epilepsy Academy (Eurepa, see below). Another priority was to evolve a series of European epilepsy congresses that would compare in quality to American Epilepsy Society (AES) meetings, which had international participation and were acknowledged at the time to be often better scientifically than the biennial IECs. (Indeed, the European congresses are now considered to rival those of the AES in scientific content.<sup>41</sup>) In 1997, the chairmanship of the commission passed to Brodie, and by that time it had matured into an effective structure. It has remained very active ever since, and been the instrument for real progress in European epileptology – much as Brodie had wished for the European Society of Epilepsy, but within the structure and purview of the ILAE. In 2001, Brodie was replaced by Svein Johanassen from Norway, and in 2005 Michel Baulac from Paris took up the chair.

In the wake of the great political changes in Europe in the late 1980s, the CEA accorded a very high priority to helping integrate Central and Eastern European countries by promoting education in modern epileptology and by standardising quality of care throughout Europe. Peter Wolf felt that, since some transnational European money would need to be administered for the planned educational and research activities, a legal corporation was required, which neither the CEA nor the EAC were, and proposed the idea of creating a spin-off agency as part of the European league structure. This corporation – the European Epilepsy Academy (Eurepa) – was officially founded at The Hague on 31 August 1996.<sup>42</sup> The

CEA devolved responsibility for teaching and research to the academy and, in December 1996, also decided to turn educational courses at future European Congresses of Epileptology into Eurepa activities and to badge other conferences where possible with the Eurepa brand (whether or not the Eurepa office had any involvement). The first of these was held at the upcoming European congress in Warsaw. The administrative relationship of Eurepa to the ILAE was not well defined, but it reported to the ILAE via the CEA and there were ILAE members on its executive board. But this issue would resurface later and cause many problems. Eurepa was based in an office in Germany with at first one, and later two part-time staff. In its first 2 years it received seed money from the ILAE with surplus funds from European congresses, but had the stated intention of becoming economically independent as rapidly as possible. By 1998, the academy was attracting increasing attention and membership in Eastern European countries. A system of European certification in epileptology with a curriculum designed by Avanzini was in the works. At the ILAE's December 1998 Executive Committee meeting, Wolf pronounced Eurepa 'operative', and a year later reported the increasing scope of the academy's activities. A discussion followed on the situation of Eurepa as an 'affiliated' organisation, and concerns were expressed over the exact meaning of affiliation and that no competition on financial support should arise between Eurepa and the ILAE.<sup>43</sup> Avanzini, the then president, suggested that the academy should be established as a worldwide education agency. This turned out to involve some intricate international legal and taxation issues which the Executive Committee of 2005–2009 has, at the time of writing, not been solved.

The agreement of the ILAE and IBE with WHO on the Global Campaign Against Epilepsy opportunistically triggered another series of events in Europe. When the

<sup>41</sup> The European Congresses have been exceptionally well organised and have a successful formula which was closely overseen by the CEA. Each congress lasts 5 days, with five main themes and plenary and post-plenary sessions devoted to these themes, and a range of other topics chosen after canvassing the European chapters. A presidential symposium instituted at the Madrid congress has been held annually ever since. A system of bursary awards was put in place after 2001, and a European Epileptology prize of 10,000 euros awarded for a lifetime contribution to epilepsy was introduced in 2002 (the 2002 prize was awarded to Peter Wolf, the 2004 prize to Charlotte Dravet, the 2006 prize to Guiliano Avanzini, and the 2008 prize jointly to Uwe Heinemann and Simon Shorvon).

<sup>42</sup> Eurepa was incorporated in Bielefeld, Germany, on 3 March 1997 and opened its office on the same day. Non-profit status was accorded by the German authorities on 11 August 1997. Peter Wolf was based in Bielefeld at that time, was closely personally associated with the organisation and maintained a personal interest and oversight of its activities.

<sup>43</sup> At the December 1999 executive, the officers moved to introduce a new bylaw 'VI: Affiliated Corporations ... Any organisations which are established in accord with Article IV.6 of the Constitution, such as regional epilepsy academies or others, shall be affiliated to the League by a Resolution of the Executive Committee which shall approve their Constitution and By-Laws, and define their position relative to the structures of the League.' This bylaw was to be presented to the General Assembly in 2001. It must not have passed, for it does not appear in the current bylaws (1997; online at [http://www.ilae.org/Visitors/About\\_ILAE/Bylaws.cfm](http://www.ilae.org/Visitors/About_ILAE/Bylaws.cfm)).

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1993	20th International Epilepsy Congress	Oslo, Norway
1995	21st International Epilepsy Congress	Sydney, Australia
1997	22nd International Epilepsy Congress	Dublin, Ireland
1999	23rd International Epilepsy Congress	Prague, Czech Republic
2001	24th International Epilepsy Congress	Buenos Aires, Argentina
2003	25th International Epilepsy Congress	Lisbon, Portugal
2005	26th International Epilepsy Congress	Paris, France
2007	27th International Epilepsy Congress	Singapore
2009	28th International Epilepsy Congress	Budapest, Hungary

**Table 3** The International Epilepsy Congresses (IECs) 1993–2009.

1996	1st Asian and Oceanian Epilepsy Congress	Seoul, South Korea
1998	2nd Asian and Oceanian Epilepsy Congress	Taipei, Taiwan
2000	3rd Asian and Oceanian Epilepsy Congress	New Delhi, India
2002	4th Asian and Oceanian Epilepsy Congress	Nagano, Japan
2004	5th Asian and Oceanian Epilepsy Congress	Bangkok, Thailand
2006	6th Asian and Oceanian Epilepsy Congress	Kuala Lumpur, Malaysia
2008	7th Asian and Oceanian Epilepsy Congress	Xiamen, China

**Table 4** ILAE regional congresses: Asian and Oceanian Epilepsy Congresses.

campaign was announced by WHO, one Friday towards the end of 1997, Wolf (at the time ILAE secretary-general) received a call from the WHO contact person in the German Ministry of Health and was informed that some money was left over in the 1998 budget for WHO purposes. The ministry was willing to spend it on an epilepsy meeting in Germany, provided they received a proposal and preliminary programme by the following Monday. As there was no time to consult anyone, Wolf wrote and submitted the proposal and programme over the weekend. It was accepted by the Ministry, and ILAE and IBE approval was obtained a posteriori. The result, with a little additional sponsorship from the European Union and the pharmaceutical industry, was a conference held in Heidelberg in October 1998 titled ‘Epilepsy as a Public Health Problem in Europe’. This successful health political conference ended with the acceptance of a European Declaration on Epilepsy which helped to promote the activities of the Global Campaign and was followed by similar conferences and declarations in other regions, all endorsed by the ILAE, IBE and WHO (Wolf 2002). In Europe this development was followed up with a more detailed health political instrument titled the ‘European White Paper on Epilepsy’ (EUCARE 2003) (Table 3).

The success of the European regional initiatives did not go unnoticed elsewhere, and in spring 1995, Masakazu Seino reported to the Executive Committee that he wished to form a Commission on Asian and Oceanian Affairs

(CAOA) modelled on the European organisation.<sup>44</sup> In 1996, the ILAE executive approved this suggestion and officially founded the CAO, with 12 members. This was the Asian/Oceanian grouping of the League, and stepwise subsumed the role of the Asian and Oceanian Epilepsy Organisation (a grouping that included representatives from countries that did not yet have an ILAE chapter). The goals of the new commission were to develop mutual cooperation, exchange of scientific information, and better understanding among the Asian and Oceanian countries. The first meeting of the CAO took place in tandem with the 9th Asian and Oceanic Congress of Neurology in Seoul in September 1996, and biannual regional conferences were thenceforward organised by the CAO (the Asian and Oceanian Epilepsy Congresses – AOECs; Table 4).<sup>45</sup> In the region, an academy was also formed in 2002, based

<sup>44</sup> Epilepsy in Asia: the first truly international epilepsy event in Asia was the ILAE International Congress in Kyoto in 1981. More than 1,000 participants attended, including a sizeable number from Asia. The next step in the organisation of epilepsy activity was the foundation in 1991 of the Asian and Oceanian Epilepsy Organisation (AOEO) during the 25th annual meeting of the Japan Epilepsy Society (the Japanese ILAE chapter). The purpose of the AOEO was ‘to strengthen the further kinship among medical professionals in Asia and Oceania involved in epilepsy’ (Seino 2005, 59).

<sup>45</sup> The ILAE regional congresses in Asia: the 1st AOEC took place in Seoul in 1996, and since then conferences have been held regularly (see Table 4).

on the example of Eurepa, called the Asian and Oceanian Epilepsy Academy (Asepa).<sup>46</sup> The CAO A had a number of unique problems caused by the small number of chapters (it had only 10 initially, and only Japan and Australia had any sizeable membership – a number of countries, such as Singapore, had fewer than 10 members), the size of the region and the recent economic crisis in Asia. Meanwhile, under the able stewardship of Seino (Japan), Chong Tin Tan (Malaysia) and Shi-Hui Lim (Singapore) who acted as subsequent chairs of the commission and the academy, this region became a successful and effective ILAE grouping, with chapters growing in number and size, a well-structured educational programme reaching out to the less-developed countries in the region, a certified regional EEG course, a fellowship programme and another series of regional congresses that have steadily improved in attendance and quality. The cooperation of this regional grouping helped President Avanzini negotiate the many obstacles to forming an epilepsy association in China, which became an ILAE chapter in August 2005 and was officially inaugurated in June 2006. In 2008 the new chapter had already become the host of the regional epilepsy congress in Xiamen.

These first regional commissions led quickly to other regional and interregional organisations. In setting up these groups, it was decided in principle to follow loosely the regional system of WHO but to give individual chapters the liberty to join another region if they found it more appropriate. Thus, Pakistan opted to be in the Asian and Oceanian rather than the Eastern Mediterranean region, and North America preferred to form its own region (WHO has a Pan-American Health Organisation; PAHO). In May 1998, the prospect of confused and unrestricted growth motivated Pete Engel to appoint a task force, with Giuliano Avanzini as chair, to establish an official policy for League interactions with such organisations.<sup>47</sup>

The ultimate aim of this task force was to explore the possibility of creating ILAE-affiliated regional organisations whose members would come not only from chapters in the region but also from countries that did not have ILAE chapters. This would allow greater ILAE participation in regions such as Africa where many countries could not meet criteria for being chapters, but could benefit from affiliation with ILAE. The hope was that these countries would eventually be in a position to develop chapters. The task force therefore was partly conceived as a chapter-building effort (ILAE Archive, President's Report, March 2001). Later, in 2001, a separate task force on regional commissions was created, consisting of Martin Brodie, Peter Wolf, Yoshiaki Mayanagi and one representative from each regional commission. The purpose of this group was 'to develop the philosophy, structure and function of the regional commissions of the [ILAE and to] link the work of the regional commissions with the executive committee of the ILAE and vice versa' (ILAE EC Meeting, August 2002). At the April 2004 executive committee meeting, Brodie reported that the Task Force for Regional Commissions had met in Lisbon in October 2003. They had concluded that a cohesive global programme would not be possible until all the regional commissions reached the same stage of development. The CEA was working very well, and the CAO A was well led and almost self-supporting. The Commission for Latin American Affairs would need more time. One complicating factor, brought up in conjunction with a meeting of the commission at the 4th Latin American Epilepsy Congress in Guatemala in 2006, was that representatives from the region preferred to travel to Europe than to Guatemala. Nevertheless, the regional congresses of the Latin American Region were reasonably successful and fruitful, and the Latin American commission that started to work in 2005 with Marco Tulio Medina (Honduras) as chair, Alejandro Scaramelli (Uruguay) as secretary, Salvador Gonzales Pál (Cuba) as treasurer and Elza Márcia Yacubian (Brazil) as educational officer held a very well-attended regional chapter convention at the Guatemala meeting from which they developed a proactive agenda. At the occasion of the highly successful first Latin American Summer School on Epilepsy which was organised in 2007 by Esper Cavalheiro (Brazil), the commission resolved to follow the example of Europe and Asia/Oceania and establish another regional academy, the Academia Latino-Americana de Epilepsia (Alade) with a

<sup>46</sup> The academy is based very closely on the European model. It intends to undertake the following activities: organisation of educational courses and certification through them, responsibility for educational activities during the regional conferences, education of epilepsy trainers, adoption of a curriculum to qualify as an epileptologist, establishment of an educational network and a website academy (Seino 2005).

<sup>47</sup> The members of the task force were Amadou Gallo Diop, M. Dumas, Louise Jilek-Aall, Saleh A. Deeb, Farouk Koura, Jorge Malagon-Valdez, Amel Mrabet, Çiğdem Özkara and Antonio Russi (ILAE President's Report, March 1998).

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2000	1st Latin American Epilepsy Congress	Santiago, Chile
2002	2nd Latin American Epilepsy Congress	Foz do Iguacu, Brazil
2004	3rd Latin American Epilepsy Congress	Mexico City, Mexico
2006	4th Latin American Epilepsy Congress	Guatemala
2008	5th Latin American Epilepsy Congress	Montevideo, Uruguay

**Table 5** ILAE regional congresses: Latin American Epilepsy Congresses.

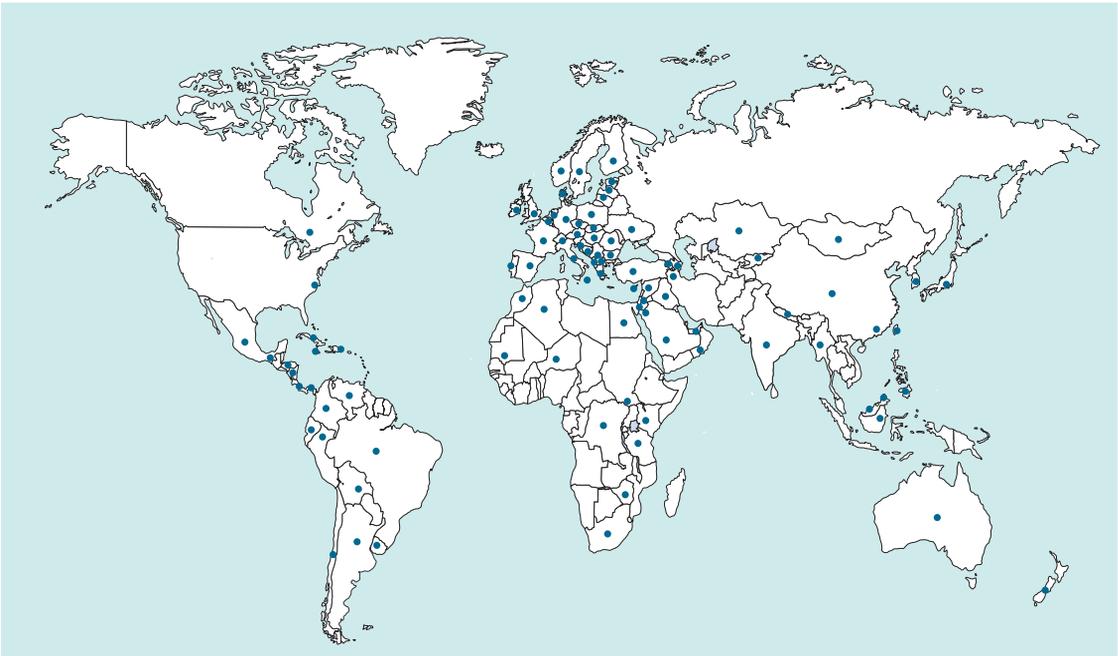
permanent secretariat in São Paulo under the direction of Cavalheiro (Table 5).

The Commission on North American Affairs was unusual in that it had only two chapters, and one was the AES.<sup>48</sup> Moreover, there was a question of which region the Caribbean Islands and Central America should belong to. Ultimately, Jamaica joined the North American Commission, and Cuba, the Dominican Republic, Guatemala and Mexico the Latin American Commission. By February 2003, the president of the ILAE and the presidents of the Canadian and American chapters agreed to reconstitute the North American Commission. It was agreed that the commission would consist of the presidents of both associations and one other member who would be ex officio. The AES president automatically became the chair of the commission. In 2007, the Commission for North American Affairs held its first meeting in conjunction with the AES. This was a significant step and represented the first attempt of the AES to engage administratively with the international efforts of the ILAE. Up until this point, the AES meetings were notionally the national meetings of the American chapter, although a survey of members had shown that few realised the AES was in any way connected to the ILAE. A delicate issue was the ILAE rule, which applied for other commissions, that the ILAE would organise the regional conference (through the IDM) and share the proceeds. This was not acceptable to the AES, which had organised successful annual conferences for many years. It was then agreed that the AES conferences would not require IDM support and that the income derived from the mandatory *Epilepsia* subscriptions of all AES members would be treated analogous to the congress surpluses of the other regions, i.e. that 25% would remain with the AES, 50% would be made available to the North American commission, and

only 25% go to the ILAE. The successful setting up of the North American commission, with Sam Wiebe (Canada) as chair, stimulated great activity, and in cooperation with Latin America, the commission has rapidly developed a series of programmes to improve epilepsy care, education and research in the Americas. One priority of these efforts is the Caribbean subregion, with a special focus on the island of Hispaniola.

ILAE activities in Africa also posed delicate problems. To avoid 'adverse reactions' (ILAE Minutes, August 2002), Avanzini proposed to collect addresses of relevant people in Africa and invite them to a meeting during the then planned congress in Tunis. The role of the ILAE would only be to facilitate the meeting: it should be perceived as an African initiative to discuss how to proceed in establishing an African ILAE commission. To a question raised by the officers whether the African chapters would have the option of which region to belong to, the president replied that a certain degree of flexibility was advisable, although it was not possible to belong to two regions. In 2003, after the Tunisian debacle, the ILAE, applying the WHO regional formula, set up an Eastern Mediterranean regional commission, which was officially inaugurated on 15 January 2004 and was planning its first regional meeting in 2005. The African Commission, however, was in a more difficult situation. A first African Convention had taken place in March 2004 in Cotonou, Benin, and a second at the 25th IEC in Paris in 2005. Neither was a success. By 2007 the League concluded that language and logistical problems would make it hard to set up a commission for the foreseeable future. Moreover, even forming chapters was a challenge, owing to problems of money and some countries not having sufficient numbers of neurologists. Recently, however, new chapters in Africa have been established as a result of the Eureka-related educational activities in the French- and Portuguese-speaking countries and a similar course initiated by the AES together with the International Brain Research Organisation (IBRO): Uganda was definitively accepted at the General Assembly in 2007, Guinea and Ghana were provisionally accepted,

<sup>48</sup> The North American Commission was formed in 1997 by Pete Engel, but was not very functional nor very engaged with the ILAE centrally until the AES agreed to make its 2007 meeting a joint meeting with the commission.



World map of ILAE chapters in 2008.

and additional chapters are in different stages of development in Mali, Mozambique, Togo and still other countries. The achievement of an African commission was by 2009 close to realisation.

At the time of writing, there are 98 chapters in the ILAE: 10 in the African region, 17 in the Asian and Oceanian region, 9 in the Eastern Mediterranean region, 42 in the European region, 17 in the Latin American region and 3 in the North American region. At least three new chapters will be proposed to the General Assembly in Budapest 2009. The regional structure is working well, and there are plans to ensure better participation of the regions on the ILAE executive, through vice-presidents elected from each region. This development will signal a major change in the structure of the ILAE as it enters its second century.

### Communication: *Epigraph*, *Epilepsy Digest*, the ILAE website and an international epilepsy resource centre

Communicating with ILAE members was a pressing issue for the incoming executive in 1993. The threat of a European Society for Epilepsy no doubt spurred the

Executive Committee to create a more cohesive League, a task that became more difficult as the organisation grew. The concept of an ILAE newsletter resurfaced – an idea that had been mooted several times in the past (most recently in 1989; ILAE Long-Range Planning Commission Minutes, October 1989). The IBE had gone ahead in the late 1980s and produced their own newsletter (*International Epilepsy News*), and at the 1990 executive, the ILAE decided (after heated debate) to pay the IBE \$4,000 to carry four pages of ILAE information in the newsletter. This was done, but at the 1993 meeting of the new Executive Committee it was decided to create the League's own regular newsletter, similar to the newsletter of the WFN, and distribute it to all individual members of the chapters. Simon Shorvon was chosen as editor, and asked to draw up a publishing proposal. He suggested the name (*Epigraph*) and proposed an eight-page newsletter with the primary objectives of giving members a greater sense of belonging to the ILAE by providing a forum for notifying members about activities, a vehicle for the ILAE to disseminate information centrifugally, and a platform for ILAE news and opinion. Twice-yearly issues were envisioned, at a possible cost of production and distribution of up to \$40,000, and sponsorship from

the pharmaceutical companies would be sought (the actual cost came in much lower). The plan was accepted, and Burleigh Press from Bristol were chosen as publishers. The first issue was published in August 1994 and was widely circulated at the meetings in Oporto, the AES meeting, the Mediterranean ILAE meeting and the Pan-American meeting in Cuba in January 1995. The mailing list – derived partly from national membership lists received through the secretary-general and from other sources such as attendance lists of major meetings – was 8,000.

By December 1996, the print run had grown to 16,000. Marion Merrell Dow, which provided annual support of \$25,000 for the first few years,<sup>49</sup> withdrew in 1997 and was replaced by Janssen-Cilag. The editor debated with the Executive Committee whether or not to accept advertising (decided not), whether to seek multiple sponsorship (decided not) and whether to publish in full colour – the original *Epigraph* was a two-colour production (black and ‘ILAE’ red). In 1998, the production moved to full colour. The newsletter quickly established a house style (as the editor put it in the 2005 edition, *Epigraph* ‘struck a chord’ and in the next 10 years did continue with 2–3 editions a year. It retained throughout this period the same format, design, distribution method and the same editorial approach’) and, particularly during Pete Engel’s presidency, provided detailed information about Executive Committee activities to the ILAE members.<sup>50</sup> With the development of online communications, it was decided to distribute the publication electronically, and essentially

to turn *Epigraph* into an online newsletter. Its format was slightly changed, and *Epigraph* then was printed in three online issues each year (winter, summer and autumn), with a single additional print edition produced in the spring for inclusion in the conference bags of the ILAE regional and international meetings. This manoeuvre was also intended to save postal costs, although the transfer of production from the office of the editor (where the magazine was produced at no cost to the ILAE) to the ILAE office in Hartford began to incur production costs and in fact has not resulted in savings.

At the Executive Committee’s spring 1995 meeting, Tim Pedley circulated a proposal by Rajendra Kale, working in London for the *British Medical Journal (BMJ)*, for a new publishing initiative called *Epilepsia Digest*. The idea was to address the inequitable distribution of information about epilepsy in developing countries by publishing a quarterly journal at reasonable cost.<sup>51</sup> The model was the *BMJ* and the *Journal of the American Medical Association*, which had been successful in bringing out local editions that contained articles selected or excerpted from the weekly versions. Some articles appearing in *Epilepsia* would be reproduced in full; others in part (condensed, or as abstracts). Raven Press would be requested to publish the first six issues of the journal, after which it could be printed in India less expensively. Kale would be asked to develop a detailed 5-year plan to present at the 1996 congress in Sydney.<sup>52</sup> In the event, Kale described a

<sup>49</sup> The sum was insufficient. By 1996 the cost of distributing *Epigraph* by post had exceeded its support by \$17,000, which the League provided.

<sup>50</sup> The theme of the first edition for 1995 was ‘epilepsy worldwide’ and the ILAE’s commitment to epilepsy education. The issue featured the ILAE Education Prize winners in developing countries, along with articles on the Commission on Tropical Diseases and an article by an Indian author titled ‘Emancipation from Mystic Prejudices’. That year’s second issue mainly treated the Sydney conference and a historical perspective of the ILAE, but also presented articles on the Commissions for Education and Constitutional Affairs. Topics broached in subsequent issues included research in epilepsy, and epilepsy and the ILAE in the United States. In addition, the newsletter carried reports of the executive officers, a column for the editor of *Epilepsia*, chapter reports, notices of fellowships, reviews of epilepsy-related topics, details of meetings and so on. From 1994 to 1999, the newsletter was edited by Simon Shorvon, from 1999 to 2001 co-edited by Shorvon and Ley Sander, from 2001 to 2004 edited by Sander and from 2004 to 2007 again by Shorvon. In 2007, the editorship was taken over by Ed Bertram.

<sup>51</sup> In his report to the Executive Committee of December 1996, Tim Pedley pointed out that, in India, the cost for an individual subscription to *Epilepsia* was equivalent to the average monthly salary of a lecturer at one of the Indian medical colleges.

<sup>52</sup> It was also noted that owing to a deeply flawed address list, the treasurer had stopped the process of sending free subscriptions of *Epilepsia* to each dues-paying chapter. Instead, it was agreed that chapters should be asked to name a library to which the free *Epilepsia* copy should be sent. Moreover, because the ILAE paid Raven Press to send out the ‘free’ copies, they were not actually free to the ILAE. For this reason, Raven Press would be asked to donate these and further copies for developing countries. Distribution of free copies financed by the Christian Society of the Netherlands would be handled by the Commission on Education. By September 1995, Raven Press had guaranteed 50 free subscriptions to *Epilepsia* per year that were being used for the complimentary subscriptions for chapters. In addition, in response to complaints by chapters regarding bulk rates granted to Japan and the United States, Raven agreed to a new bulk rate schedule of 33% discount for 50–500 subscriptions, 50% for 501–1,000 and 67.5% for over 1,000 subscriptions.

document that would be in A4 format and contain at least 40 pages. There would be no original articles, and a special effort would be made to include articles relevant to developing countries. The type of paper used would be cheaper than that used for *Epilepsia*, and photographs would be avoided. Raven Press would be asked to do the design and layout, and they should supply films for articles reproduced in full from *Epilepsia*, but the digest would be printed in India. Hindustan Ciba-Geigy had agreed to sponsor the publication for 3 years, at a cost of approximately 35–50 rupees per copy plus 10 rupees per copy for postage. Ciba-Geigy could arrange to mail the journal to about 1,500 doctors in India. The company further confirmed that they would not have any involvement regarding editorial content, but would have their advertisements on the cover pages. The total cost for the first year, not including an honorarium for the editor, costs incurred by Raven in preparing negatives for the cover, masthead, condensed articles and mailing, and any costs incurred by the publisher of *Epilepsia*, would be 436,000 rupees (\$13,300). The Executive Committee voted unanimously to proceed with the proposal, starting in January 1996, provided a written agreement with Hindustan Ciba-Geigy was obtained and presented to the ILAE Management Committee for approval. Tim Pedley was asked to act on behalf of the Executive Committee in conjunction with Kale.<sup>53</sup> By 1996, the digest had been piloted in India to 2,000 neurologists, neurosurgeons, paediatricians and psychiatrists. Feedback from readers was positive. The main problems were publishing delays and recruitment of subscribers. By December 1998, the digest was nearly 3 years old but had not yet become self-sufficient. A plan to make it available in Spanish and French for countries of South America and Africa had run into logistical problems related to distribution.<sup>54</sup>

<sup>53</sup> The Executive Committee agreed to pay Kale a minimum honorarium of \$2,000 for the first year. The editorships of *Epilepsia* and *Epigraph* were unpaid positions (the ILAE Constitution prohibits payments to the Executive Committee members).

<sup>54</sup> As a way of sampling interest beyond India, the League decided to send 40 complimentary copies of one issue of the digest to chapters in the low- and lower-middle-income economies group. The countries were Algeria, Bulgaria, Burkina Faso, Chile, Colombia, Cuba, Czech Republic, Dominican Republic, Ecuador, Egypt, Guatemala, India, Indonesia, Morocco, Panama, Peru, Poland, Romania, Turkey and Zaire. Slovenia and Taiwan were not classified for lack of World Bank Data.

At the end of 1999, Rajendra Kale resigned from ILAE activities (see below) and the Executive Committee temporarily suspended the publication of *Epilepsia Digest*. When Blackwell were appointed as the new publishers of *Epilepsia*, it was agreed that they should take on the responsibility for producing digests. This was successfully achieved, using the local Blackwell offices and appointing local editors, with sponsorship from local pharmaceutical company budgets. At the time of writing, digests are being published in Italy, Japan, China, Turkey, Argentina/Brazil and India.

At the December 1996 Executive Committee meeting in San Francisco, Engel reported for the Joint IBE/ILAE World Wide Web Committee on proposals to develop a website for the two organisations. Called the Epilepsy Home Pages, the site would serve as an epilepsy information resource for clinical research and educational activities as well as for epilepsy societies, institutions and related organisations. Proposals had been solicited from a number of Web page developers, but only one, from Cyber-Consult, was substantial enough to be considered along with a proposal already presented from a company called WebSciences. The committee disagreed on whether the IBE and ILAE should have a common website and what that website should include. The executive moved to constitute a smaller committee to make a final proposal on an abbreviated Web page for discussion and activation at the JEC spring meeting. The committee consisted of Harry Meinardi, Michael Hills, Bill McLin, Don Whiting and Pete Engel. In December 1997 Engel reported that the home page was finished, but that material to fill inside pages was needed to attract people back to the website.

In 1998, Simon Shorvon was appointed as the League's information officer.<sup>55</sup> His overall objective was to enhance information flow within the ILAE and improve two-way communication. *Epigraph*, which now appeared regularly

<sup>55</sup> Pete Engel proposed making the information officer a full member of the ILAE board, which would require a change in the constitution. The secretary-general proposed that a new bylaw be introduced, which would read, 'Bylaw VIII: Information Officer ... In view of centrally collecting all professionally relevant information on epilepsy and of making it available to professionals throughout the world, the Executive Committee appoints an information officer who is a nonvoting member of the Executive Committee.' A further proposal to make the information officer a full voting member of the executive was circulated for approval by the General Assembly in Prague (ILAE EC Minutes, May 1998).

twice a year, had established a pattern which provided the ILAE executive with a voice to its membership. The idea of appointing an information officer was conceived by Engel. He recognised the advantages to the League and its chapters of bringing all ILAE written and electronic communications under the purview of a single person, and developing an information policy. The big task was to introduce an ILAE website,<sup>56</sup> and this indeed was to prove complex. Work began in 1998 to accumulate content for the website, with the original intention of providing a relatively modest joint site, in conjunction with the IBE, confined to profiling the two organisations. Engel elicited the assistance of Michael Chase, a previous UCLA colleague, who had created WebSciences, a new Web design company in San Francisco. Chase proposed a more extensive site, and his ideas were outlined in the second 1999 issue of *Epigraph*. Rajendra Kale, who was then on the executive of the IBE and a member of the JEC, presented a proposal from the editor of the *BMJ* (Richard Smith) by which the *BMJ* would host the ILAE website, with Kale as editor, and develop a much more ambitious epilepsy portal which would become the predominant epilepsy resource on the Web. The *BMJ* proposal was large-scale and would cost \$250,000 annually. The *BMJ* proposed that the finances should be raised from pharmaceutical sponsorship and website advertising. Smith attended the ILAE Executive Committee meeting in Basle in 1999 to discuss the proposition, but eventually the ILAE decided that the financial risks were too high. With the collapse of the negotiations with the *BMJ*, the ILAE decided to ask WebSciences to enlarge the site beyond its original conception, but to a more modest level than proposed by the *BMJ*. Violent disagreement erupted over these developments, and Kale resigned from the IBE (and JEC) over this issue, and the IBE decided to pursue its own website independently of the ILAE. Problems then arose in relations with Chase over personal and professional issues. Eventually, the ILAE dissociated itself from WebSciences, and the task of

<sup>56</sup> By 1998, many organisations were producing websites. The World Wide Web was created in 1989 by Sir Tim Berners-Lee, working at the European Organization for Nuclear Research (CERN), and launched globally only in 1992. By 1998, it had expanded to an extraordinary extent, and it became clear that an organisation such as the ILAE needed a website (by 2001, there were said to be 550 billion documents on the Web, and by 2008 100 million websites and 60 billion pages).

producing the website was handed over to Association Resources, under the editorship of the information officer and with the assistance of a newly constituted Website Task Force. This was a painful series of events, but the website (with its URL epilepsy.org) was unveiled in time for the ILAE Congress in Prague, where it was extensively promoted.

The website progressed well over the following few years, and in two stages: first, the accession of ILAE information, and second, more extensive professional information about epilepsy. The Executive Committee decided not to accept pharmaceutical sponsorship for the project despite several approaches from the industry. By 2005, the information officer reported in *Epigraph* that the first stage was complete. The website included information about the League's mission and strategic plan, constitution and bylaws, officers and Executive Committee, chapters, regions, commissions, task forces, annual reports, publications and conferences, with separate pages for each chapter and also for each region and an archive section. Work was now concentrated on adding information about more general information on epilepsy for professionals. By 2005, there was an interactive discussion group for ILAE members, an index of the materials held by the Epilepsy Information Centre (EIC, see below), digitised versions of some video and documentary material from



The inaugural issue of *Epigraph*, the first newsletter of the ILAE.

the EIC holdings, a bibliography of books about epilepsy (1945–present), a list of drug names, formulations and preparations in each country, the editor’s selection of current articles from scientific journals, a ‘hot-topic’ section, ILAE reports, and a section devoted to the Global Campaign and the Classification and Terminology Task Force. Updating these sections was an ongoing task and debate continues about the relative merits of different models of doing this. In 2007, the ILAE appointed a new information officer, Ed Bertram, who became by virtue of this post the new editor of the website.

Engel had one further idea for enhancing communication, and this was to establish an International Epilepsy Resource Centre (IERC). The information officer was asked to develop plans to create this centre, and after a series of meetings, it was agreed to site it at the Swiss Epilepsy Centre in Zurich. The initiative was a joint effort of the ILAE and IBE and was overseen by a small committee chaired by the information officer. The IERC opened in 1999, led by Sibylle Ried, a neurologist, and Ian Mothersill, a neurophysiologist. Both were based at the centre. The function of the IERC was to collect, evaluate and archive all ILAE and other resource material on epilepsy from around the world, eventually to become a truly compre-

hensive and complete collection of information resources, and ‘a tribute to the International Epilepsy Movement’ (Shorvon 1999). The collection included fact sheets, pamphlets, booklets, books, guidelines, posters, material relating to audit or standards of practice, details of regular courses and videos. A computerised database and index were created by Ian Mothersill and by 2001 contained over 800 items. The driving force behind the establishment of the Zurich centre was Ried, who was an extraordinary person with a huge sense of vocation and dedication. Driven by her vision and energy, the centre began to flourish. Unfortunately, Ried died suddenly of a pulmonary embolus on 14 June 2000, and the IERC lost its major advocate. The main problem with the centre was its lack of accessibility. Despite the posting of the computerised database on the ILAE website, there were few enquiries from members, and after Ried’s death it proved very difficult to increase accessions to the centre. In 2003, it was decided to convert the centre into an archive for ILAE documents, thereafter named the Epilepsy Information Centre (EIC) (Mothersill 2003).

### ILAE archive and history

The questions of how best to archive ILAE documents and to document the history of the League have been long-standing issues and never resolved. As mentioned earlier, documents and resources tended to be held by the incumbent secretary-general, and when there was a change in personnel, the archives were at risk. Indeed, B. Ch. Ledebøer seems to have destroyed the pre-1960 archive altogether (see Chapter 2), and equally little remains of the archives, libraries and letters of Lennox and Gastaut.<sup>57</sup> The Executive Committee minutes from the 1972 meeting in Venice mention that ‘the survey of the history of the League and *Epilepsia* [was] discussed. It [was] decided that Magnus proceed with the project.’ But so far as we know, nothing survives of that effort. Magnus asked Margaret Lennox-Buchthal to be on the



Sibylle Ried, the driving force behind the International Epilepsy Resource Centre in Zurich. (Courtesy Swiss Epilepsy Centre, Zurich)

<sup>57</sup> History was not lost on Gastaut per se. In a letter to P. Bergmans of Elsevier dated 20 March 1958 concerning the revival of *Epilepsia*, Gastaut revealed his eagerness to bring out the first issue in January 1959 to be able to have a tie-in to the League’s 50th jubilee. The League does have intact (thanks to Lorentz de Haas and Magnus) a small but rich sampling of documents relating to Gastaut’s classification schemes.

survey committee, but on 23 February 1972 she wrote him to decline and referred him to the 'NIH group', which she said had drawn up a list of ILAE officers since 1946. In 1987, Harry Meinardi approached Fritz Dreifuss regarding the League's upcoming 80th anniversary, and Dreifuss suggested that a special addendum to *Epilepsia* take note of the 'historic occasion'. Lennox-Buchthal was asked to edit the issue, but declined (ILAE EC Minutes, May 1989).

In the early 1990s, Meinardi began researching ILAE documents and by November 1994 had circulated a list specifying when chapters had joined the League. He then suggested that a short written history of the ILAE should be produced, and a grant was awarded to a student from Georgia to produce it, based largely on back issues of *Epilepsia*. This history was printed in 1999 and is also available on the ILAE website (Meinardi 1999). Engel persuaded the publisher Kraus Reprint (a division of Kraus-Thomson Organisation from Nendeln) to publish facsimile copies of the 1st–3rd series of *Epilepsia*, and these were beautifully produced. For the ILAE's meeting in Prague in 1999, which constituted its 90th anniversary, Meinardi also created a historical videotape and took on the task of collecting, listed and storing ILAE documents, including committee meetings. He was awarded a grant of \$2,000 for a preliminary screening and filtering of 230 document files held in Heemstede. A year later, in

1996, he received a further 5,000 Dutch florins to cover the work, travelling expenses and small materials to finish the job.

These archives were transferred from Heemstede to Bethel in the late 1990s. In 2002, after Peter Wolf had left Bethel, the Executive Committee were concerned that the archive would not be securely cared for in Bielefeld, and Peter Berry and Delphine Sartiaux travelled to Bielefeld to take the ILAE records back to the headquarters in Brussels. The question of a permanent site for the archive was a difficult one. The ILAE wanted a secure and permanent base for the archive and one that would be accessible for scholars and researchers. Ted Reynolds had approached the institute in London about housing an ILAE museum which would include the archive, and although the institute was interested, the proposal never progressed.<sup>58</sup> In 2005, therefore, the ILAE decided to move the archive to the Swiss Epilepsy Centre, where the IEC was based. The centre offered a dedicated room, and a contract was drawn up with the ILAE for its maintenance and for access. The archives were duly transported and are now housed in a series of boxes at the Swiss Centre.

With the 2009 centenary of the ILAE looming, Simon Shorvon made a series of proposals to the Executive Committee regarding the ILAE history and archive. First, it was suggested that the archive should be properly indexed, and it was agreed to hire Giselle Weiss, a friend and researcher from Basel, to index and order the documents. This was achieved and the index was uploaded onto the ILAE website in 2007. For the first time in its history, the ILAE archive is now accessible for scholarly research. Another proposal made was that, for the centenary, a collection of audio recordings with senior ILAE figures should be collected and deposited into the archive. At the time of writing, approximately 60 interviews have been collected. A further proposal, also accepted, was that this book should be written, and after a tendering process, Blackwell was taken



Announcing the ILAE's new website in a 1999 issue of *Epigraph*.

<sup>58</sup> The Wellcome Institute was quite interested and would house the museum free of charge, but they would want to catalogue it themselves, which could take several years (ILAE EC Minutes, 3rd Draft, December 1999). In April 2000, the executive concluded that as the archives up to 1993 were 'presently under expert care' in Bielefeld, there was no compelling reason to transfer them to the Wellcome Institute, although the option should be periodically scrutinised from the point of view of accessibility. The institute was again approached in 2002 by Simon Shorvon and in 2006 by Giselle Weiss, but by then the archive did not have high enough priority for the Institute.



Solomon (Nico) Moshé, elected president of the ILAE in 2009, as the organisation enters its second decade. (Courtesy Nico Moshé)

on as the publisher in 2008<sup>59</sup>. Finally, the proposal to set up a centenary committee was accepted to orchestrate the celebrations at the 28th IEC in Budapest in 2009.<sup>60</sup>

### Classification of the epilepsies

As discussed in Chapter 2, the ILAE owes much of its validity as the representative of international epileptology to its work on classification. The first attempts at deriving an ILAE classification were made by Henri Gastaut and colleagues at his famous Marseilles colloquia. In 1997, one of the first acts of the new executive was to approve

<sup>59</sup> Initially, the book was intended to cover both the history of the ILAE and also of epilepsy over the 100-year period. As the project proceeded, however, it became clear that it was growing too large. Moreover, deadlines were being missed in the epilepsy section. For these reasons, in mid-2008 a decision was made to divide the history into two parts. The book (this volume) would focus on a comprehensive history of the ILAE, and a supplement of *Epilepsia* (2009; volume 50, supplement 3) would be produced which dealt with aspects of the history of epilepsy. The supplement was published on the journal's 100th anniversary in March 2009, and the book is to be launched at the ILAE centenary conference in Budapest in June 2009.

a proposal by President Pete Engel to appoint a new Task Force on Classification and Terminology to review the current schemes. The task force was divided into four working groups concerned with descriptive terminology for ictal events (headed by Warren Blume); seizures (headed by Peter Williamson); syndromes and diseases (headed by Natalio Fejerman); and impairment (headed by Harry Meinardi). The task proved more difficult than anticipated. A diagnostic scheme was proposed, not to replace the classifications, but as an adjunct to the classifications for individual patients. In its 2001 and 2006 reports, the task force also updated the list of accepted epileptic seizure types and epilepsy syndromes, with the intention that the next step should be to organise these into cohesive classifications. A discussion on classification was part of the scientific programme at the European Epilepsy Congress in Madrid in 2002 and at the AES meeting that same year. In 2005, Peter Wolf re-established a Commission on Classification chaired by Anne Berg, and this commission has now taken up the charge of building on the work of the task force to suggest appropriate changes in the organisation of these seizure types and syndromes into more appropriate classification systems.<sup>61</sup> The commission met in Paris in 2008 and made considerable progress. At the time of writing, a new classification is close to completion and will update what is essentially a continually moving target.

The importance of classification should not be underestimated. It is a topic that has remained at the centre of the ILAE's activities, and the globally accepted schemes which the ILAE has formulated have, since 1969, been one of the League's most visible and valuable achievements.

<sup>60</sup> The committee was chaired by Simon Shorvon and comprised Giselle Weiss, Soazig Daniel from the IDM office, Howard Goodkin (who had recently prepared a history of the AES), Péter Halász, who was co-chairman of the Budapest meeting, and Judit Jerney, also from Budapest. Jerney had many contacts in Budapest as well as excellent ideas about locations and events.

<sup>61</sup> The commission has written that it is undertaking activity to: (1) update and revise terminology; (2) explore and develop objective methods, criteria, and standards for identifying and validating new syndromes or diagnostic entities; (3) revise the organisational scheme for syndromes and epilepsies into a flexible multidimensional system that more accurately reflects what we do (and do not) know about different forms of epilepsy; (4) develop a diagnostic manual to standardize definitions and provide examples for clinicians who are not necessarily experts in epilepsy (<http://www.ilae-epilepsy.org/Visitors/Centre/ctf/ctfoverview.cfm>).

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