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Preface

The International League Against Epilepsy (ILAE) celebrates its centenary on 30 August 2009. To reach this landmark is a remarkable achievement for any voluntary organisation, and the League is the oldest such international subspecialist organisation in the field of neurology, and one of the oldest in medicine. To mark the occasion, the ILAE Executive decided to document its history in a scholarly manner, and this book is the result. Similar attempts had been contemplated in the past, not least at the time of the 50th anniversary, but did not come to fruition. A key step in preserving the historical record was the establishment of the ILAE archive. The need for an archive was first raised by Harry Meinardi who had been given, in his roles as ILAE president and secretary-general, what papers there were still in existence from previous administrations. He and his assistant collected these documents together, and indexed and collated them and these became the kernel of the current ILAE archive. Further material was slowly added in subsequent years, but this collection remained vulnerable as it moved around Europe with each changing ILAE administration.

In 2003, the ILAE executive decided to establish a permanent archive and, after exploratory talks with several different organisations, contract with the Swiss Epilepsy Centre in Zurich to house the collection on a secure basis. The existing material was moved there in 2005. When it arrived, the archive was in a sorry state – consisting of boxes of papers, some dilapidated and damaged by water, time and lack of care. The ILAE then commissioned Giselle Weiss, from Basel, to organise and index the materials, using Meinardi's work as a basis. This task was completed in 2006 and the material is now secure, arranged in a comprehensive modern fashion and the archive is open for use by any scholar. Weiss' index is placed on the ILAE website at http://www.ilae-epilepsy.org/Visitors/ILAE_Archive/index.cfm.

However, the material surviving in the archive is very incomplete. No original documents prior to 1960 are included, and many documents from subsequent years are missing. The pages of *Epilepsia*, especially in the first and second series (i.e. prior to 1950) provide useful source material from these earlier years, and Meinardi produced a short history of the ILAE in 1999 based on these existing sources, which is an invaluable summary.

In 2007, in preparation for its centenary, the ILAE decided to embark on a more comprehensive history and to gather together material from the archive, and from as many other sources as could be identified. The purpose was to document as completely as possible ILAE matters and to place these in their historical context. This book was therefore proposed and the responsibility for producing it handed to me. A plan was drawn up and Giselle Weiss again commissioned to act as research assistant and co-author, a task she took on with immense enthusiasm and expertise. Her work on behalf of the ILAE has been outstanding, and many hitherto unrecognised sources have been discovered through her researches and inquiry, not least a series of taped interviews with major figures in the ILAE which she has collected. The book has been a formidable and arduous task, and at times seemed beyond our reach. The ILAE executive initially decided to include, along with the ILAE history, an outline survey of the progress in epilepsy during the same period. However, as the project proceeded, it became clear that the book was growing too large, and deadlines were being missed in the epilepsy section. For these reasons, in mid-2008 a decision was made to divide the history – with this book focusing on the ILAE history, and the historical epilepsy survey to be published in a less complete fashion separately as a supplement of *Epilepsia* (this appeared in

March 2009; Volume 50:Supplement 3). This solution allowed a detailed ILAE history to be published, and also provided a larger readership for the less comprehensive historical epilepsy survey.

The aim of the book, in this its final form, is to document the course of the ILAE in its first 100 years, to interpret this within its historical context and to bring together as much source material as possible. The use of footnotes has been deliberately chosen to separate the narrative from commentary, source documents and detail. The authors hope that this formulation will best prove an adequate recognition of the quality of this remarkable organisation as it enters its second century.

Writing such a history has several functions. First, history is memory, and an organisation needs a memory to operate effectively and wisely. History provides identity, context and provenance, essential ingredients for the success of any organisation such as the ILAE. History is also didactic. However, its course is never linear and indeed is often frustratingly circular – the story of the ILAE testifies to both points. The lessons of history are seldom learned, but if they were, perhaps the future might avoid at least some of the problems of the past. It is in this spirit and for these reasons that all the authors have devoted time and effort to this book.

The text relies on both the written record and also on the memories and experience of the authors and from interviews, some taped, with many others who answered queries and provided access to unpublished material. In such original historical research, the authors have tried to maintain accuracy and objectivity, but errors of interpretation or fact are inevitably made. All have worked in good faith, and the understanding and forbearance of our

readers is sought for any misinterpretation and I would be pleased if these were brought to the authors' attention.

We are more grateful than we can say to the many librarians across Europe and the United States who graciously indulged our repeated requests for archival materials, in particular Wiebe Boumans, Utrecht University Library; André Bouwman, Leiden University Library; Nathalie Briffod and Iris Ritzmann, Institute and Museum for the History of Medicine Zurich; Jack Eckert and Jessica B. Murphy, Francis A. Countway Library of Medicine, Harvard University; Christopher Hoolihan, Edward G. Miner Library, University of Rochester Medical Center; Donald Jerne, Royal Library, Copenhagen; Marjorie Winslow Kehoe, Alan Mason Chesney Medical Archives, Johns Hopkins Medical Institutions; László A. Magyar, Semmelweis Museum, Budapest; Martha Riley, Becker Medical Library, Washington University; Lily Szczygiel, Osler Library of the History of Medicine, McGill University, Montreal; and Dorothea Trottenberg, University of Basel. Together, they helped us to flesh out the origins of the League and of *Epilepsia* far beyond anything we dreamed possible.

Our publishers, Blackwell (now Wiley-Blackwell), have provided superb and expert assistance, and particular thanks go to Rebecca Huxley, the editor, and project manager Alice Nelson for their sterling work on this project. Thanks are also due to all the members of the ILAE who have helped with this project and whose unstinting work has assisted innumerable persons with epilepsy over the past 100 years.

Simon Shorvon
London 2009

Introduction

The early 20th century was a restless period. In the field of medicine, there were many international endeavours, large international congresses were held and international professional bodies were formed. It was in this milieu that the idea of an international organisation to assist in the promotion of better care for patients with epilepsy was conceived, and after several years achieved concrete form as the International League Against Epilepsy (ILAE). The inaugural meeting of the League, in Budapest on (almost certainly) 30 August 1909, was a small affair but the League has, from this modest beginning, grown to become the undisputed leader amongst international organisations in the field of epilepsy. As was recently observed, the ILAE itself was clearly modelled on the more ambitious International Institute for the Study of the Causes and Prevention of Insanity. Contemporaneously, that institute was in a planning phase involving kings and governments and much fanfare, but was actually never launched, largely for reasons of international politics and nationalism. The less ambitious ILAE successfully negotiated these hurdles and furthermore endured despite the cataclysms of European history in the next 40 years. Within days of its inauguration, it planned its first scientific conference and also adopted as its 'official organ' the scientific journal *Epilepsia*, itself formed only a few months earlier. These two functions – the holding of scientific congresses and the publication of *Epilepsia* – remained its core activities throughout its history. History, however, is never an unbroken upward curve of progress, and the ILAE ship of state has in its first hundred years taken a meandering course, becalmed at times and making good headway at others. As the League journeys into its second century, it does so generally in good shape and with a record of achievement of which it can be, in the main, justly proud.

One striking feature of the ILAE today is its global reach. At its foundation, internationalism and trans-continental brotherhood were guiding principles, and are again, although for long periods the ILAE was an essentially European and/or American organisation. The leadership initially was in Central Europe as were most of its members (in 1911, of the 106 members, 55 were from central Europe, 43 from Britain and Western Europe, 5 from the United States and 3 from Brazil). The collapse of the Austro-Hungarian empire in the wake of the First World War ended activity in Europe and the League went into temporary hibernation. When reawakened in 1935, an American president was chosen (as it was said, because an American was 'uninvolved with the politics of Europe, which had proved so disastrous'). Three national ILAE chapters were formed, in Great Britain, the United States and Scandinavia, and of the 248 members in 1936, 86 were in America, 102 in Britain and 31 from Scandinavia. The first international congress of the reformed organisation was held in 1939 in Copenhagen, but this tragically was on the eve of the invasion of Poland and the start of the Second World War. Again, all ILAE business was halted in Europe but the League's light was kept (dimly) burning through the efforts of the American Chapter, under the guardianship of Lennox. National meetings began again in 1945 in the United States and in Britain, and in 1949, the first post-war meeting of the international organisation was held in Paris with nine official national chapters. Since then the ILAE has continued to function without interruption to the present time. In the early post-war period, the chapters were exclusively from Europe, North and South America, with Japan (joined 1953) the sole Asian country until 1981; all *Epilepsia* editors were European or American, and all congresses were held in Western Europe or the United States.

In the last 25 years, however, the organisation has voyaged on a more global scale. The number of chapters has increased (30 in 1987, 63 in 1997 and 98 in 2007) and chapters in Asia, Africa and the Middle East have been formed. An ILAE commitment to the developing world was stated at least since the 1950s, but no substantial steps were actually taken until the 1980s. This has culminated in the establishment of the Global Campaign Against Epilepsy, in partnership with the World Health Organization (WHO), which had its first launch in 1997. In 1993, the ILAE set up its first regional commission, in Europe, and others soon followed. This new structural tier was in essence a response to the need to keep the rapidly enlarging League together and, in 2005, the constitution was amended to ensure greater regional representation on the Executive Committee.

A notable feature of the League throughout its history has been its 'volunteer' culture. None of the officers or members of its task forces or commissions, or the editors of its journal are paid. Their time is given freely, and this confers a moral authority on the organisation. As the League has grown larger, the amount of work has also increased, creating tensions in this regard. As a sign of this pressure, in 1993 the ILAE began to pay for secretarial support in the offices of its president and secretary-general, and in 2000 for the first time in its history paid for professional administration. From 1999, the ILAE has employed its own in-house conference organising company to arrange the international and regional congresses. The fiscal genie was out of the bottle, and the cost of administration has spiralled in the last decade. The creation of a professional centralised administration has undeniably altered the nature of the League, made it more professional and more process-driven. These administrative changes and the constitutional changes to increase regionalised representation are major forces of change, and the nature of the League is now being undeniably altered. Only history will judge whether these changes will turn out to be to the League's advantage, but the values of volunteerism must be preserved, for these have fundamentally underpinned the League in its first hundred years.

A core function of the ILAE has been, since its inception, the holding of international congresses. In the period before the First World War, annual meetings took place (in Berlin, Zurich and London), and since 1949 a continuous series of international congresses has been held, initially every 4 years and then biennially. These were, until

1978, appendages of the larger international neurological and neurophysiological organisations, but since then the ILAE meetings have been sufficiently financially and scientifically robust to be held independently. The original meetings were short (one day until 1973) with modest programmes, but in the last 20 years have greatly expanded to the current pattern of 5-day meetings with five or six plenary themes, parallel sessions, breakfast sessions and workshops, and with satellites from the mid-1980s. At its initial meetings less than 50 persons attended, but now routinely the number of registrations exceeds 4,000. A programme of regional meetings, held every other year, was started in 1994 in Europe, 1996 in Asia and 2000 in Latin America. In 2008, the American Epilepsy Society meeting was adopted as the first North American regional meeting. National meetings were also inaugurated in member countries in the mid-1930s, and since 1945 have occurred annually in many member countries. Meetings have many functions. They convey information, allow colleagues to meet, inspire the young and provide respite from the grind of daily practice. There is a tendency to think of these as a new phenomenon, but that this is not so is clear from the descriptions of massive conferences in the first years of the 20th century.

What though is new is the shift of the burden of the costs from the individual to corporations, and now a huge investment is made by the pharmaceutical industry in sponsoring meetings and participants. This form of sponsorship started in the 1970s and by the end of the 1980s had reached levels that some consider to have compromised integrity. Non-ILAE epilepsy conferences were being organised, for instance, in fashionable destinations (the Caribbean was a favourite) for delegates and their wives, with weak scientific programmes but lavish entertainment and massive honoraria for speakers – sponsored entirely from marketing budgets. The ILAE set up guidelines for its own financial dealings with the pharmaceutical industry, but it too has made large profits from sponsorship of its conferences and advertising in its journal. This money can be put to good purpose, and the key is to ensure that the sponsorship does not influence scientific quality, scientific programmes or editorial independence. To avoid sinking in the Charybdis of pharmaceutical cash and being consumed by the Scylla of commercial bias, and to steer a course that maintains integrity and independence, continues to test the bridge.

The second core activity is the publication of its scientific journal, *Epilepsia*. This has a complex history, being

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published in four series: series I, 1909–1914/15; series II, 1937–1950; series III, 1952–1956; and series IV, 1959/60 to the present day. It is now the premiere scientific journal in the specialty of epilepsy, covering clinical and basic science, but this was not always the case. The first series was primarily a scientific enterprise, and therein were interesting and important papers. There were also reports of ILAE activities and critical abstracts of epilepsy publications elsewhere. This first series was a distinguished publication and its premature discontinuation, on the advent of the First World War, was a lost opportunity for epilepsy.

When the second series was launched, the ILAE decided that the publication of scientific papers should not be the main focus, but that instead *Epilepsia* should abstract the scientific literature from elsewhere and act as a record of ILAE activity. H.I. Schou, the first editor of the second series, wrote that ‘The first aim of the reorganised League must be the social care of epileptics and not so much scientific research into epilepsy. The new edition of *Epilepsia* must follow these lines. It must be the organ for our league.’ The journal became what was essentially a house journal of the ILAE. Its initial issues contained chapter reports, programmes of annual meetings and also summaries of statistics of epilepsy from different countries, as well as abstracts and bibliographies. During the Second World War, publication was moved to America and during Lennox’s de facto editorship mainly provided a bibliography of abstracts, occasional papers and reports of the American chapter.

When the third series was launched, the ILAE executive was split on the question of *Epilepsia*, but it was eventually agreed that the journal should be published under the auspices of the publishing committee of the American Branch of the ILAE. The ILAE secretary-general wrote that he preferred the journal not to publish original articles – as there were many journals already doing this – but should contain reports from the ILAE branches. The publishing committee clearly did not agree. It decided not to publish abstracts or original articles but to concentrate on critical reviews, but within a few years the journal actually comprised reviews and original articles and the occasional ILAE report. Some good papers were published, but the hybrid nature of the journal was not a success, and in 1955 the ILAE again abandoned publication for a few years to consider its position.

A fourth series was decided upon and launched with Sir Francis Walshe in 1959 chosen as the new editor.

Walshe was previously editor of *Brain*, the leading scientific journal in neurology, and had a clear vision of the journal as an organ for ‘informed, original and critical studies’ covering all fields of epilepsy research. So was the current model of the journal launched and the series continues to this day as the leading scientific journal in its field, publishing original basic and clinical research.

As a secondary role, in recognition of the need for a journal of record, there is again limited space given to ILAE activities (in the ‘Gray Matters’ section). *Epilepsia* for many years required the financial support of the ILAE, and at times the cost threatened to bring down the organisation. During the Second World War it had to be bailed out by the American Epilepsy League, and the withdrawal of this funding in 1949 was probably a major reason for the termination of the second series. In 1989, for the first time the income from the journal exceeded its costs and since then it has become increasingly profitable. It currently contributes about \$1million dollars to ILAE coffers annually, and is the largest single source of income for the League. From a quarterly journal of 500 pages in 1961, it has grown to a monthly publication with approximately 2,500 pages annually. By 1969, the number of subscriptions had risen above 1,500 for the first time, and in 1997 exceeded 4,000. It initiated electronic publishing in 1990, and now about one million full-text articles are downloaded each year. The journal was published in full colour for the first time in 2007, and in that year digital copies of the entire print run from 1909 became available online. Medical publishing is no longer the quiet academic backwater it once was. Rapid changes are occurring with the advent of electronic communication, the rapid growth in numbers of competitive journals, the demand for free access to research information, the large potential for advertising income and the reconfiguration of publishing houses. The publishing landscape is being totally transformed, and in what form *Epilepsia* will emerge remains to be seen – this is a major challenge for the ILAE as it enters the rough waters of 21st-century scholarly publication.

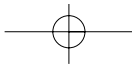
In addition to its congresses and journal, the ILAE also carried out its work through a series of ‘commissions’ and ‘task forces’. The first of these, and possibly the most successful, was the Commission on Classification and Terminology, created in 1963. This commission created the 1969/1970 ILAE Classification of Seizure Type, which rapidly became universally adopted worldwide and was

one of the most influential of all ILAE productions. The commission was led by Henri Gastaut, then ILAE president, and its success was no doubt in large part due to his enthusiasm and energy. The tagging of the classification with the ILAE name was a publicity coup for the league and, by virtue of the classification scheme, the ILAE became synonymous with professional authority in epilepsy. This single activity probably did more than any other to catapult the ILAE into the top position in the world of epilepsy. The second ILAE commission, in 1969, was the Commission on Antiepileptic Drugs, and this too exerted major influence with the Food and Drug Administration (FDA), the National Institutes of Health (NIH) and with industry, and was responsible in part for producing the guidelines for clinical trials. In the 1980s, other commissions were being established, and by 2005 there were 15 commissions and task forces in place, each assigned specific aspects of ILAE work. All were staffed by ILAE members, on a volunteer basis, and the commissions have also had the important effect of broadening participation and inclusiveness.

The achievements of the organisation have been due almost entirely to the relatively small number of members involved in its leadership and its commissions and task forces. Some have been quite exceptional individuals, deeply committed to advancing epilepsy internationally, and the world of epilepsy owes a great debt to their work, given freely. The disadvantage of this model, heavily reliant on individuals, is that perhaps inevitably personality and personal politics have always played a significant part. As Edward Luce wrote, academia is a cauldron of identity grievances, and conflict has its origins usually in power wielded by dysfunctional personalities, both bad and mad (I have seen both in my own experiences in clinical and academic institutes). This is generally the case for all such organisations, and although usually a minor problem in the League, personal enmity and personal attacks have exploded on a number of occasions, and at times have rendered good governance impossible. Gastaut, Lennox-Buchthal, Ledebøer, Magnus, Walshe, Muskens and Schou were all entangled in bitter personal arguments, and similar rows have occurred right up to current times. Possibly as a result, it has not always been easy for the ILAE, *sub specie aeternitatis*, to maintain its focus on its mission or a logical strategy, and too often in its history short-term issues have elbowed out more important long-term strategy.

Perhaps the largest strategic failure of the ILAE was the misguided attempt to merge completely with its sister organisation, the International Bureau Against Epilepsy (IBE). From its inception, the ILAE has been keen to represent the interests of patients. Between 1961 and 1965, an international lay organisation was formed, the International Bureau for Epilepsy (IBE), and the ILAE quickly formed close links with this group. Merger was proposed in 1977, and an umbrella organisation called Epilepsy International was formed as a prelude. Epilepsy International collapsed in 1981 and in 1985 was dismantled. The failure of the merger reflected the essentially different perspectives of both organisations, but despite the disruption this caused, joint congresses have continued and the organisations have grown close again. Although distinct in membership and culture, both organisations share certain goals, and representations made by both jointly are powerful lobbies.

Financially, the ILAE is currently in shipshape condition, but this has not always been the case. Nothing is known about the financial situation before 1937, but it seems likely that all monies before this were spent on producing the journal. In 1937, the assets of the ILAE amounted to £64,110.00 (About US\$4,443 at today's value). During the Second World War, the ILAE limped on with activity only in the United States and with financial sponsorship from the American Epilepsy League. The first postwar international congress was held in Paris in 1949 and at this stage the ILAE had assets of 10,808 Dutch florins (about \$27,500 at today's prices). By 1978 this had grown to SKr 158,368 (\$88,239 in 2009 dollars) and the then treasurer Karl-Axel Melin called the financial situation of the ILAE 'rather healthy'. The income from *Epilepsia* only began to cover its costs after 1989. In 1990, the ILAE had assets of only \$138,323 and was still only a rather small organisation. It had only 40 chapters, its international meetings attracted only about 1,000 people, and the organisation had no formal administrative support and no regional groupings. Over the next 15 years, there was considerable growth, fuelled by sponsorship money from the pharmaceutical industry, and during this time the ILAE consolidated its position as the leading global organisation in the field. By the beginning of 2009, there were nearly 100 chapters, its assets amounted to about \$10 million, its congresses were attracting 4,000 participants, it had a system of commissions and task forces, a fully developed regional structure and a professional outsourced administration.



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Concurrently, in the past 20 years, the ILAE constitution has been fairly continuously tinkered with and amended – partly to accommodate the needs of the larger organisation and its increasingly global stretch and regional structure (although sadly also politics) with the biggest changes proposed in 2009. Whether these changes will alter the fundamental nature of the organisation from that of a charity run by the enthusiasm of volunteers to a more bureaucratic and political global NGO remains to be seen.

The purpose of the history laid out in this book is threefold. First, it is to document the course of the ILAE so that this can be available for posterity; a story-telling function. The second is to corral together as many sources as possible for scholars to use for further study; an archiving function. Finally, we have tried to place this history within its cultural context, and to interpret its meaning, a historicist function. This latter point needs further comment. History should be an argument about the past and not simply a description or reflection of it, and historians analysts as well as annalists. History is also memory, and any organisation entering its second century should retain a collective memory of the first. Interpreting memory is no easy task (ask any psychoanalyst) and a simple reductionist or materialistic explanation is certain to fail. Walter Benjamin wrote: ‘Memory is not an instrument for exploring the past but its theatre. It is the medium of past experience, as the ground is the medium in which dead cities lie interred’, and this is an essential point. In this book, we have tried to interpret the course of the

ILAE in a way that brings out central themes from the insider perspective – but we recognise the powerful limitations of such a navigational method.

Crucial is the question of the future. The lessons of history are basically retrospective; history is the lantern on the stern. No sensible person would use history to predict the future (indeed, wise authorities, the Talmud for instance, expressly prohibit it) and this is certainly not the purpose of this book. Nevertheless, a detailed apprehension of previous ILAE history should at least inform its future action, prevent the reiteration of some mistakes of the past, and lead to a more cultivated and refined policy than would otherwise be the case.

The practice of medicine is changing, and we are caught up in a world which is more managed, more controlled and more political, and with greater patient and public expectations. The voice and influence of the professional clinical and academic doctor can get lost in this vortex. Organisations like the ILAE are vital in providing a vehicle and a mechanism for proclaiming this professional view and for ensuring it is heard above the chatter. This is a lobby that is in the vital interests of the patient and the academic aspects of epilepsy. The ILAE has endured for a century essentially because this is a useful and worthwhile function, and as the League enters its second century, this role is even more important than before.

Simon Shorvon
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